UNDERSTANDING RESPONSIVENESS OF HEALTH SERVICES THROUGH SOCIAL EXPERIENCES OF TUBERCULOSIS

AN EXPLORATORY STUDY

Dissertation submitted to the Jawaharlal Nehru University in partial fulfilment of the requirements for the award of the degree of

MASTER OF PHILOSOPHY

SANGEETA SINGH

CENTRE FOR SOCIAL MEDICINE AND COMMUNITY HEALTH
SCHOOL OF SOCIAL SCIENCES
JAWAHARLAL NEHRU UNIVERSITY
NEW DELHI - 110067
INDIA

JULY 2005

CENTRE OF SOCIAL MEDICINE & COMMUNITY HEALTH
SCHOOL OF SOCIAL SCIENCES
JAWAHARLAL NEHRU UNIVERSITY
New Delhi - 110 067

28 July 2005

CERTIFICATE

This is to certify that the dissertation entitled **'Understanding Responsiveness of Health Services through Social Experiences of Tuberculosis: An Exploratory Study'** submitted in partial fulfillment for the degree of **Master of Philosophy** of this university has not been previously submitted for any other degree of this university, or any other university and is my original work.

Sangeeta Singh

Sangeeta Singh

We recommend that this dissertation be placed before the examiners for evaluation.

Ritu Priya

Dr. Ritu Priya
(CHAIRPERSON)

Chairperson
Centre of Social Medicine & Community Health, SSS
Jawaharlal Nehru University
New Delhi-110067

Dr. Sanghmitra S. Acharya
(CO- SUPERVISOR)

Rama V. Baru

Dr. RamaV. Baru
(SUPERVISOR)

Tel.: (011) 26704420, 26717676, 26717557 Gram: JAYENU Fax: 91(011) 26717586, 26704420

CONTENTS

Acknowledgement

This research is the result of support from many 'helping hands' and 'thoughtful minds'. The time has come to express my heartfelt gratitude to everyone who made this work possible.

To begin with, I would like to express my sincere gratitude to my supervisor, Dr. Rama V. Baru who took the pain of 'thinking with me' and her valuable guidance that gave me confidence to take up the task of this study. I thank Dr. Sanghamitra S. Acharya, my co-supervisor for her useful inputs.

I deeply acknowledge Prof. Imrana Qadeer, Dr. Ritu Priya and Dr. Rajib Dasgupta for helping me gain a perspective on tuberculosis. I extend my gratitude to Prof. Nirja Gopal Jayal who helped me in formulating the concepts at the initial stages of the research.

Dr. Ghanshyam and his team at Gulabi Bagh Chest Clinic owe special thanks for their kind co-operation in the pilot study that went a long way in refining my tools of inquiry.

I wish to extend my thanks to Neelima Khetan, Bhatiji, Vidyaji, Podi Chechi and Charu who created a home away home for me at Udaipur that made an otherwise arduous field work, a pleasant memory. I am thankful to Seva Mandir for providing me with logistical support at Udaipur. Dr. Sanjana, Ratan and Manoj Paliwal shared their experiences that helped in understanding about tuberculosis in context to Udaipur. I want to thank Rama Bhenji and Yakubji for their zeal in searching for patients' addresses in the by lanes of Udaipur.

My special thanks to DTC, Udaipur, especially to Dr. B.L. Meghwal, Dr. Dinesh Kothari, Dr, K.M. Sharma, Sajanji Anup and Pritam for their support, cooperation and participation in the study. I extend my gratitude to Dr. S.K. Luhadia who spared his valuable time for my questions in spite of my unscheduled visit, and to Dr. Renu Vohra and Dr. Sharad Iyengar for their valuable inputs about the RNTCP in Udaipur.

I acknowledge the support from Mrs. Rastogi and Dinesh in helping out with references and Mrs. Bhatia, Dharamraji, and Brahma Prakash for their timely co-operations and thoughtful advices that made demanding tasks, simpler.

I deeply thank my friends who even while remaining silent to my unneeded excitement made me feel intelligent and displayed only their joys. No amount of thanks can suffice to my family who has remained as a pillar of strength in this entire endeavour. My special thanks to Dhrub for his valuable inputs and meticulous editing and to Natasha for helping me out with the daunting task of referencing.

I express my deep gratitude and respect to the patients and their families for providing unconditional co-operation to this research without which this endeavour was simply not possible.

Finally, my thanks to Ravindra who has been my worst critic and my strongest support, and for being a companion in sharing the roller coaster ride of highs and lows of this research and life. I thank him for reading each and every word of this dissertation and telling me honestly about my limitations.

I would request to be excused if I have missed anyone. I am grateful to all those who contributed towards the completion of this dissertation. The shortcomings in this work, however, are entirely mine.

Sangeeta Singh

ABBREVIATIONS

AFB	Acid fast bacilli	MO	Medical Officer
AIR	Annual Rate of Infection	MOTC	Medical Officer Tuberculosis In-charge
ANM	Auxiliary Nurse Midwife	NGOs	Non-Government Organisations
CME	Continuing Medical Education	NSS	National Sample Survey
CP	Continuation Phase	NTI	National Tuberculosis Institute
DM	District Magistrate	NTP	National Tuberculosis Programme
DMC	Designated Microscopy Centres	OPD	Out Patient Department
DOTS	Directly Observed Treatment Short Course Chemotherapy	OR	Operation Research
DRS	Drug Resistance Surveillance	PHC	Primary Health Centre
DTC	District Tuberculosis Centre	PHI	Peripheral Health Institutions
DTO	District Tuberculosis Officer	RNTCP	Revised National Tuberculosis Control Programme
DTP	District Tuberculosis Programme	SCC	Short Course Chemotherapy
EP	Extra Pulmonary	SPHC	Sub- Primary Health Centre
GoI	Government of India	SR	Standard Regimen
ICDS	Integrated Child Development Scheme	STLS	Senior Tuberculosis Lab Supervisor
IEC	Information Education and Communication	STS	Senior Tuberculosis Supervisor
IP	Intensive Phase	TU	TB Unit
MCH	Maternal and Child Health	VIP	Very Important Person
MDR-TB	Multiple Drug Resistant Tuberculosis	WHO	World Health Organisation

I. INTRODUCTION

The defining goal of any health system is 'better health' of the population it is intended to serve. "Better health is of course the *raison d'être* of a health system, and unquestionably its primary or defining goal: if health systems did nothing to protect or improve health there would be no reason for them."[1] It is well accepted within the public health perspective that medical care and health services are just one of the inputs for improving health status of the population; nevertheless it plays an important role in the curative and preventive aspects of public health. Recognising this quite early, the government of India immediately after independence in 1947 took the responsibility of widening the scope of health measures through public services. Since then, health planning in India has been an integral part of the national socio-economic planning and public health services the most important tool for delivering preventive and curative services. Although the public health services in India have expanded manifold over the last five decades, their performance with respect to utilisation and effectiveness has remained somewhat limited.

The National Health Policy - 2002 noted, "...there is no gainsaying the fact that the morbidity and mortality levels in the country are still unacceptably high. These unsatisfactory health indices are, in turn, an indication of the limited success of the public health system in meeting the preventive and curative requirements of the general population."[2] Reasoning this limited success, the National Health Policy - 2002 further adds, "... the existing public health infrastructure is far from satisfactory... funding is generally insufficient; the presence of medical and para-medical personnel is much less than that required by prescribed norms; the availability of consumables is frequently negligible; the equipment in many public hospitals is often obsolescent and unusable; and, the buildings are in dilapidated

[1] *World Health Report – 2000*, World Health Organisation, 2000, p. 23.

[2] *National Health Policy 2002*, Ministry of Health and Family Welfare, Government of India, 2002, para. 1.4.

state... the availability of essential drugs is minimal; the capacity of the facilities is grossly inadequate, which leads to over crowding, and consequently to a steep deterioration in the quality of services. As a result of such inadequate public health facilities, it has been estimated that less than 20 percent of the population, which seek OPD services, and less than 45 percent of that which seek indoor treatment, avail of such services in public hospitals. This is despite the fact that most of these patients do not have the means to make out-of-pocket payments for private health services except at the cost of other essential expenditure for items such as basic nutrition."[3]

While tangibles like physical infrastructure, funding, equipments and personnel are important factors in functioning of the public health services, there are other interpersonal processes, often intangible and beyond these techno-managerial factors, that determine utilisation and effectiveness of the services. Since health services are an important input for alleviating sufferings caused by disease, it is necessary to ensure that services are responsive to the felt needs of different sections of the population. After all, one of the tools with which the health system strives to achieve its objectives is the health services through a myriad of hospitals, dispensaries and health care providers that address the health care needs of the people seeking help.[4] "In any system, people have expectations which society regards as legitimate, so as to how they should be treated, both physically and psychologically."[5] The human interactions and transactions that take place when a patient seeks public health services and the quality of care received vis-à-vis the patient's expectations, although often neglected, are important factors in determining the utilisation of public health services. In other words, the responsiveness of the public health services towards

[3] *Ibid.*, para. 2.4.1.

[4] While a health system includes all actors, institutions, and resources that undertake action with primary intent of improving health (e.g. policy makers, planner, hospitals and other health care centres, health education and research institutions, resource mobilisation and budgeting, etc.), health services are the preventive and curative care services available to the population at the point of health service delivery like hospitals, dispensaries, and other health centres.

[5] *World Health Report – 2000*, World Health Organisation, 2000, p. 23.

patient's needs of care and the experiences of patients while interacting with the services reflect upon the utilisation and effectiveness of the public health services.

The current research is an attempt to examine the elements that constitute "responsiveness" of public health services through the lens of patients' experiences of a disease control programme. In doing so, it focuses on three questions:

- what are the motivations for seeking help from the health services and what are the patients' expectations[6];
- what happens when the health services and the person it serves interact; and
- what is the experience of this interaction for the patient

Public Health Services in India

The Bhore Committee[7] report in 1946 noted, "The existing state of public health in the country is so unsatisfactory that any attempt to improve the present position must necessarily involve administrative measures of such magnitude as may well seem to be out of all proportion to what has been conceived and accomplished in the past. This seems to us inevitable, especially because health administration has so far received from governments but a fraction of attention that it deserves in comparison with other branches of government activity."[8] The report put forward comprehensive proposals for the development of a national programme for health services on the principles of equal access irrespective of ability to pay, rural areas as focus of services and provision of comprehensive preventive and curative services. The national government, immediately after independence in 1947 created the

[6] Patients' expectation here implies not just to the sick person but also the attendant / family members seeking help for the patient.

[7] Health Survey and Development Committee (better known as the Bhore Committee) headed by Sir Joseph Bhore was appointed to survey the then existing position regarding the health conditions and health organisations in the country and to make recommendations for future development.

[8] *Report of the Health Survey and Development Committee*, Government of India, 1946.

Ministry of Health to operationalize and expand the public health services nationwide. During the first two decades after independence, the general health services witnessed manifold expansion. The government of India has, from time to time, appointed various committees to review the existing situation and the health services and recommend measures for future action and national health planning.[9]

Although the public health services have gradually expanded over the last fifty years, their performance and effectiveness have remained far from expected. The issues of utilisation, performance and effectiveness of public health services have received considerable attention over the last two decades. The discussions have often been centred on the comparison of the publicly and privately provided health services with the latter being described as providing better quality services and more responsive to patient needs and hence better utilised and more effective vis-à-vis the former. Whereas private services come in all hues – from private clinics of the local quacks to modern corporate hospitals – comparison between the services of profit-seeking urban private hospitals with public hospitals has been used to further the neo-liberal agenda of privatisation of health care. The last two decades have witnessed many debates centred on the role of market and state in health services. Those countering the neo-liberal ideologies site from different countries evidences of 'market failure' in health services and thus a need to re-examine the role of the state. Also, the comparison of private hospitals driven by the goal of profit maximisation with public care based on principles of universal access and providing health care at a nominal cost is fraught with methodological problem of comparing two systems with

[9] The Health Survey and Planning Committee (Mudaliar committee) in 1959 to survey the progress made since submission of the Bhore Committee's report; Chadah Committee in 1963 to study the arrangements necessary for the maintenance phase of the National Malaria Eradication Programme; Mukerji Committee in 1965-66 for reorganisation of family planning services administration and basic health services; Jungalwalla Committee on integration of health services in 1967; Kartar Singh Committee on multipurpose workers under health and family planning in 1973; Shrivastav Committee in 1974 on medical education and support manpower and in 1980 the working group on health for all by 2000 are some of the important committees constituted by the government of India on public health.

divergent goals.[10] Health care needs are largely unforeseen and unpredictable, and the patient while shopping for health services is not an 'informed' customer in a competitive market. Due to asymmetry of information the purchaser, here the patient is unable to make 'rational' choices from a range of drugs, technologies as also the practitioner. People, upon falling sick, do make choices of the provider and thus in a way 'shop' from choices available. Yet these choices wither out as the information asymmetry grows between the provider and the patient. Health care costs in many cases run huge and are likely to add to the inabilities that may already be affecting the patient. The most powerful argument in favour of public health services is from the social justice vantage point, that nobody should be denied treatment due to inability to pay, as besides disabilities, illness also makes the patient vulnerable that threats the very human dignity. Treatment selection on the basis of ability to pay (and not on the severity of illness) is dangerous also from public health point of view, especially in case of communicable disease. Besides the violation of equity and universality principles, with withering public services comprehensiveness is also lost since it is irrational for the profit seeking entities to invest in preventive health measures. Ironically, the shortcomings of public funded health services have led to arguments favouring the private sector in health services turning a blind eye to all the intrinsic properties of the private sector that will defeats the purpose of public health itself.

While the middle and high income groups in the urban centres who are 'able and willing to pay' for the health services might be moving out of the public health services to private sector, a large section of the population in the country depends on the public services. In cities where organised private hospitals are not developed, the middle and high income group also resort to the public hospitals. The poorer sections that constitute the largest proportion of the population are faced with difficult choice

[10] Rama V. Baru and C. M. Kurian, 2002, 'Towards an Expanded Conceptualisation of Quality in Public Health Services', Dialogues on Strategies for AIDS control in India, Workshop on Societal Concerns and Strategies for AIDS Control in India, New Delhi, CSDS and CSMCH, JNU.

between the public and private services. The public services, though less expensive, entail opportunity costs, are often not easily accessible, unresponsive and lack accountability even as the private sector is expensive, exploitative as also lacks accountability[11]. Most studies assessing the public health services have pointed to inadequacies in funding, infrastructure, drug supply, technology and equipments as important reasons for poor performance.

There is a need to understand the causes of decline of public services rather than pointing their inadequacies. The real challenge for public health research lies in re-examining and resurrecting the role of public institutions in providing welfare services.[12] Recently the questions of quality of care and patient satisfaction have attracted some interest. Here also, most often than not, the studies have defined quality as applied to medical care and laid major emphasis on the technical domain. Bias towards a search for quick fix technical solutions has often neglected the patient's perspective and experiences of interaction with the public health services – an important aspect in service utilisation. The significance of health services arises due to its response to the sufferings of the patient by dealing with the disease in the form of treatment and by reducing the pool of infections at the population level for maintenance of health of the community. In other words, due to the role envisaged for the public health services in dealing with the burden of disease and well being, it is of paramount importance that it should function in an appropriate manner. Equity, universality and comprehensiveness form the principles on which the public health services should function for accessibility by those who need it. Responsiveness, similarly, forms the means for the sustainability of this access. A public health service, no matter how equitable or universal, is likely to remain unutilised if it fails to respond to the needs (felt as well as actual need of treatment) of people. Therefore responsiveness should figure as one of the principles of health services. These

[11] Rama V. Baru, 2004, 'Abdicating Responsibility', *Seminar*, No. 537 (May), pp. 46-49.

[12] *Ibid.*

interpersonal aspects of health care have not received enough significance in public health research.

The current research is an exploratory effort to reduce this gap by studying patients' experiences of interaction with public health services and understanding responsiveness of the services towards their health needs. The Revised National Tuberculosis Control Programme (RNTCP) is used as a case in point to understand responsiveness of the public health services. The study is based on primary research in Udaipur city in Rajasthan, where the RNTCP is officially claimed to be successful.

Tuberculosis: A Case for Understanding Responsiveness

The World Health Organisation (WHO) in 1996 noted;

> "In 1995, more people died of TB than in any other year in history. At least thirty million people will die from the in the next ten years if current trends continue. Millions more will watch helplessly as friends and family members waste away racked with coughing and sweating with fever. They wish that medical sciences could cure this terrible disease. The truth is, medical science can. Since 1952, the world has had effective and powerful drugs that could make every single TB patient well again."[13]

Although tuberculosis is inextricably tied to poverty and inequality, experience shows that modest interventions have affected dramatic changes in the outcomes.[14] The national tuberculosis control programme make an ideal case for understanding responsiveness of the public health services. First, even though it is easily diagnosed and curable, tuberculosis kills more people in India than HIV/ AIDS, STDs, malaria and other communicable disease combined. India also has the largest number of tuberculosis patients in the world, contributing 30 percent to the global burden of tuberculosis, which is double the Chinese burden of 15 percent. Until recently less than half of patients with tuberculosis received an accurate diagnosis and

[13] WHO cited in P. Farmer, 1999, *Inequalities and Infections: The Modern Plagues*, California: University of California Press, p. 184.

[14] *Ibid.*, p. 207

less than half of those received effective treatment.[15] In India each day more than 20,000 people get infected with the tubercle bacillus, out of which 5,000 people develop tuberculosis and more than 1,000 die every day. It kills approximately half a million people each year in the country. More than three lakh children leave school on account of parental tuberculosis and more than one lakh women are rejected by their families due to the disease.[16] There has been a national programme for tuberculosis control for over four decades, but the country is far from reining the disease. Over two million new cases are identified each year. Second, tuberculosis shows that it is not only the mere existence of technology and health services that would conquer a communicable disease. Disease control depends highly on the operation of the control programme. The effective operation would depend upon efficiency with which it identifies issues and addresses these in the light of social, operational and epidemiological constraints that the disease might pose; in other words, the way the programme responds to these concerns and issues. Third, the RNTCP attracts high attention and monitoring from the national government as well as international health organisations.[17] Studying responsiveness of such a programme has two aspects; one, it reflects how responsive are the services which are not afflicted by other problems like poor monitoring or financial crunch, i.e. how well the 'better scenario' services are responding to the patient's needs and two, it does away with the preconceived biases against the public health services. Last, but not the least, tuberculosis treatment requires a long and frequent interaction with the health services (six to eight months of treatment under RNTCP); therefore patient's experiences of the interactions with the services and responsiveness become crucial determinant in utilisation.

---

[15] G. R. Khatri and Thomas R. Frieden, 2002, 'Controlling Tuberculosis in India', *The New England Journal of Medicine*, Vol. 347, No. 18, October 31, p. 1420-25.

[16] 'Coalition of Health Advocates', *Tuberculosis Control Report Card*, 24 March 2005 (issued on the occasion of World Tuberculosis Day), http//:www.infochangeindia.org (Accessed on 03 July 2005).

[17] One of the five principles of the programme is political commitment. RNTCP is a vertical programme implemented and monitored at the national level. Major source of funding the programme are the WHO, the World Bank and the Global Fund to Fight AIDS, Tuberculosis and Malaria. The WHO directly monitors the programme implementation.

Chapter Scheme

The Introduction delineates the relevance, nature and scope of the study, broadly outlining some of the concerns afflicting the public health services in India. It also sets out the key questions that will be examined in the course of this dissertation.

Chapter II, 'The Context of Responsiveness' proposes two sections. The first section reviews and critically analyses the available literature on responsiveness in health services in order to understand the context and meaning of responsiveness. Since the study takes tuberculosis and its national control programme as a case, it becomes necessary to first discuss the disease tuberculosis, evolution of the national control programme to tackle it and its scope to understand the responsiveness of the services. This is done as the second section after the literature review on responsiveness in the same chapter.

Chapter III is on methodology of the research and sets out with defining the scope of responsiveness for the purpose of the study. Along with describing the research method and the tools used for the primary research, the chapter also draws a landscape of the public health services in Udaipur to give a background of the study area.

Chapter IV, 'The Patient and the Service Provider' gives insight into patients' experiences of sufferings caused due to the disease and their efforts to alleviate it by seeking help from the health services. The chapter also provides a glimpse of the second actor of this interaction, i.e. the service providers. This part deals with their understanding of the patients' condition and their own role, as care providers, in relieving the patients of the disease. It also reflects upon the record keeping aspect of the service provider, on which programme monitoring depends heavily.

Chapter V, 'Understanding Responsiveness', also the concluding chapter, discusses and establishes the elements of responsiveness drawn from the patients' experiences, which also should form important inputs for health services to achieve the goal of 'better health'. It also raises some concerns for further probe.

II. THE CONTEXT OF RESPONSIVENESS

A review of available literature on responsiveness of public health services reveals that the interest on the issue is of very recent origin. The discussion started around mid 1990s with initiatives to promote patients' participation and feedback to improve the quality of health care in the UK and USA.[18] The WHO in the World Health Report – 2000 articulated "responsiveness to people's expectations in regard to non-health matters" to be one of the three goals of any health system.[19] The World Health Report–2000 published for the first time, a ranking of national health systems' performance of 191 member states based on estimates for the year 1997. The report defines three fundamental objectives of the health services; one, improving the health of the population they serve; two, responding to people's expectations and three, providing financial protection against the costs of ill-health. The WHO's health system performance index is based on five parameters; overall level of health (25 percent weight), distribution of health in the population (25 percent weight), overall level of responsiveness (12.5 percent weight), the distribution of responsiveness (12.5 percent weight) and distribution of financial contribution (25 percent weight). While the first two indicators measure achievements on the objective of improving health of the population (measured by probability of dying before age five years or between ages 15 and 59 years, life expectancy at birth, mortality by cause and sex, the burden of disease, i.e., DALY or the numbers of disability-adjusted life years lost and DALE

[18] With recognition of the need to improve the quality of health care from service users' perspective, the British National Health Services established procedures for patients' involvement and consultations for decision making in the Primary Care Groups and Primary Care Trusts (PCGs/PCTs). Surveys of recent service users have become increasingly popular to elicit patients' feedback for quality improvement. In the US the National Commission for Quality Assurance uses data from such surveys in its evaluation and accreditation of health plans. However, responsiveness of health services as a concept was not articulated. For a detailed discussion on the subject, refer to Department of Health, *The New NHS: Modern, Dependable*, London, 1997; V. A. Entwistle, *et al.*, 2003, 'Public Opinion on Systems for Feeding Back Views to the National Health Services', *Quality and Safety in Health Care*, London, Vol. 12, No. 6, pp. 435-42; S. Pickard, 2003, 'User Responsiveness in Health Care', *Quality and Safety in Health Care*, London, Vol. 12, No. 6, pp. 403-4.

[19] The other two goals are better health and fairness in financial contribution. *World Health Report – 2000*, World Health Organisation, 2000, p. 22.

or disability-adjusted life expectancy), the next two measure the responsiveness to people's expectations and the last one assesses the financial protection against costs of ill-health.

The WHO looks at the three goals of the health system in a disjointed manner and uses independent quantitative indices to measure them. "Raising the achievement of any goal or combination of goals, without lowering the attainment of another, represents an improvement...The three goals are separable..."[20] In context of fairness, responsiveness denotes how equally the health system responds to everyone without discrimination based on socio-economic status or other factors. Therefore the distribution of responsiveness is as important as the distribution of health. But primarily, the concept of responsiveness is seen as operating in the 'non-health domain' of the health system. "Responsiveness is not a measure of how the system responds to the health needs, which show up in health outcomes, but how the system performs relative to non-health aspects, meeting or not meeting a population's expectations of how it should be treated by providers of prevention, care and non-personal services."[21] The domains used to assess responsiveness are divided into two parts – respect for persons and client orientation. Respect for persons includes three elements; one, respect for dignity of the person (not humiliating or demeaning patients); two, confidentiality (the right to determine who has access to one's personal health information); and three, autonomy to participate in choices about one's own health (including help to choose what treatment to receive or not to receive). The second set, i.e. client orientation constitutes of four elements; one, prompt attention (immediate attention in emergencies and reasonable waiting times for non-emergencies); two, quality of basic amenities (cleanliness, hospital food etc. should be of decent quality); three, access to social support networks – family and friends – for

[20] *Ibid.*, p. 24.

[21] *Ibid.*, p. 31.

people receiving care; and four, choice of provider (freedom to select which individual or organisation delivers one's care).

According to Amala de Silva responsiveness in the context of health system can be defined as the outcome that can be achieved when institutions and institutional relationships are designed in such a way that they are cognisant and respond appropriately to the universally legitimate expectations of individuals.[22] 'Legitimate' is defined as confirming to the recognised principles or accepted rules and standards.[23] Greater responsiveness to the expectations of individuals' regarding non-health enhancing aspects of care is viewed to enhance the level of welfare achieved, irrespective of its impact on health. The concept of responsiveness is conceptualised to encompass the non-health enhancing, non-financial aspects of the health system. This demarcation between 'medical and non-medical' aspects is justified by de Silva, for preventing double counting in the measurement of outcomes.[24] It is also pointed out that these domains will vary in their significance with socio cultural milieu and the legitimate expectations will vary changing these domains. For example inadequate infrastructure; sleeping on the floors is generally acceptable in tropical countries but not in developed or cold countries. Similarly, waiting periods can be differently legitimate in different countries and even within countries these expectations will vary across income groups. de Silva also draws distinctions between quality of care, patient satisfaction and responsiveness. Patient satisfaction focuses on clinical aspects in specific health care whereas responsiveness evaluates health systems as a whole and focuses on the non-health aspects. Patient satisfaction represents a complex mixture of perceived needs that are individually determined expectations and experiences of care, whereas, responsiveness evaluates the individual's perceptions of the health

[22] A. de Silva, 2000, 'A Framework for Measuring Responsiveness', GPE Discussion Paper Series No. 32, Geneva: WHO, p. 2.

[23] *Ibid.*, p. 4.

[24] *Ibid.*, p. 1.

systems against 'legitimate' universal expectations.[25] Interestingly, de Silva is silent on the dichotomy raised by this very approach. Although responsiveness is considered to evaluate individual's perceptions of health services, it is expected to be divorced from the individual's expectations and experiences of care. de Silva, however, does not explain how 'legitimate' universal expectations are formed in a society.

Darby *et al* put responsiveness in the realm of basic human rights and define the goal of health system as to enhance responsiveness to meet the legitimate expectations of the population for non health enhancing dimensions of their interactions with the health system.[26] In this point of view, it is assumed that if a health system is responsive it is possible that interactions of people with the health system will lead to improvement of their well-being irrespective of actual improvements in their health status. Darby *et al* also put forth that the three goals of the health systems i.e. improving the health of the population they serve, responding to people's expectations and providing financial protection against the costs of ill-health are partially independent from each other, at least in the short run. These goals are partial to an extent that they can be enhanced without significant change in the other, but they are interrelated as ultimately, changes in one will lead to changes in the other, for e.g. better responsiveness of the health systems will lead to better health as utilisation will increase. But this will happen after a point. There are also instances where people have been dissatisfied with the health systems even though the health indicators are satisfactory. Interestingly, improvements in responsiveness can happen without major investments in the health system due to its 'partial' independence from remaining two objectives of the health system.[27] Although long term improvements in responsiveness will require a backing from changes in areas of better health and fair

[25] *Ibid.*, p.3.

[26] C. Darby, *et al.*, 2000, 'World Health Organisation (WHO): Strategy on Measuring Responsiveness', GPE Discussion Paper Series No. 23, EIP/GPE/FAR, Geneva: WHO. p. 3.

[27] *Ibid.*

financing goals, however improvements in responsiveness will not necessarily lead to improvements in the other two goals of health systems.

Gostin *et al* included another domain into responsiveness, that of clarity of communication (to the patients) and approached responsiveness from human rights view and draws synergy, accountability and cohesion between the provisions of human rights and the domains of responsiveness. [28] Responsiveness therefore through ensuring treatment of people in ways that corresponds to their needs leads to empowering them to lead healthier lives. However, the needs were restricted to the non-health domain.

Clearly, all the above studies have tried to reinforce responsiveness in the non-health domain, divorced from the health service's goal of betterment of health. There is an empirical bias towards quantifying responsiveness for inter-system comparisons. There are also methodological issues in the WHO's measure of responsiveness. To evaluate health system performance on responsiveness in 191 countries a web survey was done of over 1,000 respondents in different countries to begin studying the importance attached to the different elements of responsiveness. The responsiveness scores are constructed based on a survey of 1,791 key informants (people identified on the basis of their being knowledgeable about the health system in their respective countries) in 35 selected countries. The scores on each component were combined into a composite score for responsiveness based on weights arrived from the preceding internet survey. No informant was interviewed on this measure in 156 countries included in these ratings. Thus based on the results of the internet survey of these key informants from 35 countries, the responsiveness of the remaining 156 countries was estimated by applying the statistical estimation techniques.[29] Blendon *et al* brought out well the conceptual as well as methodological problem while

[28] L. Gostin, *et al.*, 2003, 'The Domains of Health Responsiveness: A Human Rights Analysis', EIP Discussion Paper No. 53, Geneva: WHO. p. 3.

[29] Nicole B. Valentine, *et al.*, 2000 'Estimating Responsiveness Level and Distribution for 191 Countries: Methods and Results', GPE Discussion Paper Series No. 22, Geneva: WHO. pp. 3-4.

comparing the WHO scores with people's satisfaction with their health system in 17 industrialised countries.[30] The citizen's satisfaction with their respective health system shows a weak correlation with the WHO findings on responsiveness. For example, the WHO rates United States' health system the most responsive among the 17 selected countries, however, citizen's satisfaction shows US at the fourteenth place (with only 40 percent citizens satisfied with the system). Similarly, Finland with 81 percent citizens satisfied with the health system, is at eleventh place in responsiveness ranking. Incidentally, the WHO expert panel's rating of the industrialised nations reflects that those with higher responsiveness of the health system are also the nations with the higher per capita health expenditures. While more spending may lead to higher rating on this measure, it does not however, necessarily produce more satisfied citizens. The WHO's measure of responsiveness, which are based on expert's views, are not capturing other concerns people may have.[31] Blendon *et al* maintain that many of the families have some direct experience with the health systems while others are aware of the system through other means such as media, other's experience narration, and contacts with the health professionals. Based upon these they have an informed opinion, especially on the hindrances to care and financial difficulties, shortages of services and lack of humanness of the system to name a few. Thus citizens are in an equally (although differently) competent position as fellow citizen experts to hold a valid view on the responsiveness of the health system of their respective country.[32]

The Scope of Responsiveness

The above mentioned studies make vital points in building up the concept of responsiveness and give intrinsic value to its understanding. However, they are

[30]R. J. Blendon, *et al.*, 2001, 'The Public versus the World Health Organisation on Health System Performance', *Health Affairs*, Vol. 20, No. 3, pp. 10-20.

[31] *Ibid.*, p. 17

[32] *Ibid.*, WHO clarifies for taking only expert view and not people's for assessing the health systems of their countries on the grounds that it is too complex for the common people to understand its performance and requires basic knowledge and understanding of Public Health issues. Besides, patients' perceptions are too narrow to gauge the complexities of the health systems as a whole.

restricted either to assessing theoretically the appropriateness of the seven elements of responsiveness, all in the non-health domain, as conceptualised by the WHO, or methodological questions of measuring responsiveness. The segregation of health, non-health and financial aspects of a health system might have been helpful in designing independent parameters for measurement and comparison of the performance of health systems across countries on a composite index. However, a question arises as to whether the variables of health, non-health and financial aspects are independent and separable. How does such segregation help a health system to deliver its prime and unquestionable objective of 'better health' of people it serves through its health services?

Assessment of responsiveness disjointed from the health aspects of services may be convenient. But this conceptualisation of responsiveness is divorced from some very important dimensions imperative to the understanding and utility of health care, and the relationship of the people with the health services. When people seek health services, their foremost expectation is to be relieved from their sufferings caused due to illness that disrupts their normal life. The patient doesn't distinguish between various health and non-health aspects. Fundamentally, responsiveness of health services for the patient cannot be divided as 'feeling good' and 'free from disease'. These are not exclusive to each other. The scope of responsiveness therefore should include both health and non health aspects as they both work together in alleviating patients' sufferings. WHO's approach of understanding and measuring responsiveness is therefore reductionist. This conceptualisation of responsiveness divorced from the health aspects fails to provide a systemic perspective.[33]

[33] "A fundamental principle of the systems paradigm is that, when viewed structurally, a problem or a set of problems may indeed be divisible into sub problems; but that same problem or set of problems is necessarily an indivisible whole when viewed functionally, because its essence as a system is lost when it is broken down into parts." J. W. Ratcliff and A. G. del Valle, 1988, 'Rigour in Health-Related Research: Towards an Expanded Conceptualisation', *International Journal of Health Services*, Vol. 18, No. 3, p.363.

Since the studies are limited to ranking of the member countries and the conceptualisation of responsiveness is rooted in "non-health" aspects, they do not provide any notion of adequacy of responsiveness of the health system to act according to the health status of that community/ nation of which many (like India) may have unacceptably high prevalence of curable disease. Their assessment with 'legitimate' expectation fails to provide an objective and realistic ground for the health system to strive for. de Silva gives the basis of 'legitimate' expectations as 'normative' expectations that are based on 'what should or ought to happen'.[34] But if the responsiveness domains change with milieu[35] the objectivity of what should and ought to happen fails. There are high chances are that the 'unformed' expectations[36] that refer to when individuals are unable or unwilling to articulate their expectations for various reasons, may arise. Yet the recognition of the domains mentioned under responsiveness is of value for health care and thus are equally important in the conceptualisation, but fail to give meaning to responsiveness by itself divorced from the 'health' elements.

Second set of shortcoming arises due to methodology employed by WHO framework and others that does not take into account the patients' experiences.[37] Assessing responsiveness on the view of health experts or even a 'set of people' that may not have used the services in the recent past as shown by general public survey may not give the real picture. Patients are the ultimate benefactors of the health systems (through interaction with the health services). The patients' notions of responsiveness arising out their experiences of interactions at the level of health services and therefore their view is pertinent for responsiveness assessment and

---

[34] de Silva, 'A Framework for Measuring Responsiveness', p. 4.

[35] *ibid.*

[36] *Ibid.* When individuals are unable or unwilling for various reasons to articulate their expectations, which may either be because they do not have expectations, have difficulty expressing their expectations or do not wish to reveal their expectations due to fear, anxiety or confirming to social norms.

[37] Patient or the family bearing the impact and cost (monetary and non monetary) of the illness.

should be applied, as Pickard points out, "... the focus should be shifted much further down to the level where patients interact with the healthcare professionals".[38]

Tuberculosis: The Disease and its Control in India

Tuberculosis brought misery to humans in many ancient civilisations and finds mention in Chinese, Buddhist and Greek texts, as associated with a lung disease of consumption and loss of young lives swiftly. In England, the mortality from pulmonary diseases seems to have been very high around 1650, then to have decreased slowly for many decades before climbing to a new peak before the middle of the nineteenth century.[39] Improvements in standards of living and rise in sanitary measure brought about a steady decline in many infectious diseases, including tuberculosis even before the identification of the cause of the disease, i.e. the *tubercle bacilli* by Robert Koch in 1882 and further advent of the its cure through modern medicine. Citing January 1891 issue of *Lancet*, Dubos and Dubos write that the mortality due to tuberculosis (phthisis) in England decreased from 300 per 100,000 population in 1850 to 250 in 1860 and 220 in 1875. This decline, according to them, was due to improvement in the hygienic conditions, dietary improvements among the poor classes and control over the sale of flesh of diseased animals.[40]

The disease affected both the rich as well as the poor, but favoured the impoverished. The varying distribution of disease according to social class possibly gave rise of the much associated stigma attached to it. Tuberculosis has been referred as the barometer of well being of a society, because it has emerged and checked with the rise and fall of the larger socio economic factors impacting the living conditions and nutritional intake. During the Great Depression and post World War-II period,

---

[38] S. Pickard, 2003, 'User Responsiveness in Health Care', *Quality and Safety in Health Care*, London, Vol. 12, No. 6, pp. 403-4.

[39] R. Dubos and J. Dubos, *White Plague: Tuberculosis, Man and Society*, first published 1952, 2nd edn.; New Brunswick, NJ: Rutgers University Press, p.185.

[40] *Ibid.*, p. 262.

tuberculosis emerged as a dreaded epidemic and depleted as soon as living condition began improving.

There were some perceptions attached to the disease such as it being hereditary and also caused by impure air; drunkenness and want among poor; indulgence in weakening luxuries among the rich; and ignorance towards the contemporary laws of health in nineteenth century.[41] It was also regarded as an urban disease arising out of the 'artificialities of city life'.[42] However, it was later established to be an outcome of the 'social tragedies'[43] or 'disruptions'[44] caused by the industrial revolution. In the industrial cities the migrant population had to face long and arduous working hours and had to work and live in crowded and unsanitary surroundings. These had all the required ingredients for spread of the disease. Similar trends of rapid industrialisation and outbreaks of infectious diseases in epidemic proportions are evident in Latin America and Asian countries in the recent times.[45]

Robert Koch identified the pathogen, the disease causing bacilli, in 1882 and this marked the era of ending speculation about the disease being hereditary. The bacteriological science proved that the *tubercle bacilli* can be transmitted from one human to another and it is capable of destruction. Robert Koch remarked, "One has been accustomed until now to regard tuberculosis as an outcome of social misery, and the hope by relief of distress to diminish the disease. But in the future struggle against

[41] S. A. K. Straham cited in Dubos and Dubos, *White Plague*, p.197.

[42] Dubos and Dubos, *White Plague*, p.198.

[43] *Ibid.*, p. 199.

[44] The failure of the urban administration to keep up with the growing demand of health care like hospitals and sanitary measures coupled with crowding and poor incomes in the newly migrated classes. S. Szreter, 1999, 'Rapid Economic Growth and "the Four D's of Disruption, Deprivation, Disease and Death": Public Health Lessons from Nineteenth Century Britain for Twenty First Century China?', *Tropical Medicine and International Health*, Vol. 4, No.2, Feb., pp. 146-52.

[45] Dubos and Dubos, *White Plague*, pp. 202-03.

this dreadful plague of the human race one will no longer have to contend with an indefinite something but an actual parasite."[46]

In spite of the discovery of the bacilli, focus of controlling the disease remained mostly in the realm of larger changes rather than shifting completely into the scientific domain. "By 1900, furthermore, it had become obvious that tuberculosis was most prevalent and most destructive in the poorest elements of the population and that healthy living could mitigate its harmful effects. Reformers could attack the disease from two directions, by improving the individual's life of man and by correcting the social evils."[47]

The pressure to act for tackling the disease began mounting and soon anti tuberculosis campaigns gained momentum and involvement in these campaigns became a status symbol for the rich. Press gave wide publicity about the disease. The most significant part of these campaigns was participation of people from all walks of life including sociologists, philanthropists, businessmen and the layman.[48] Public opinion about the disease became very vibrant by the end of the nineteenth century. An evidence of this is that a pamphlet, *"Tuberculosis as a disease of the Masses and How to Combat It"*, published in 1901 was translated in 27 different languages and had a very wide circulation, beaten only by the Bible.[49] The development of effective drugs by the end of the 1940s and by wide spread preventive measures, soon by the 1970s the disease ceased to be a public health problem in the industrialised countries and also ceased to attract their public attention. Murray states in 1991, "The neglect of tuberculosis as a major public health priority over the past two decades is simply extraordinary. Perhaps the most important contributor to this state of ignorance was

---

[46] G. D. Feldburg cited in Farmer, *Inequalities and Infections*, p. 202.

[47] Dubos and Dubos, *White Plague*, p. 210.

[48] *Ibid.*, p. 211.

[49] A. S. Knopf, author of the pamphlet, states that to combat tuberculosis successfully, it "requires the combined action of a wise government, well trained physicians, and an intelligent people". Cited in Dubos and Dubos, *White Plague*, p. 214.

the greatly reduced clinical and epidemiological importance of tuberculosis in the wealthy nations."[50] But the disease continued in marginalised populations only to pose as a global threat in recent years due to the emergence of co-infection with HIV/AIDS.[51]

Biology and Clinical Aspects of Tuberculosis

Today tuberculosis is a well understood disease with definite cures. It is caused by a micro-organism, Mycobacterium Tuberculosis (also known as Koch bacillus). It usually affects the lungs and is also most likely to spread through persons having the active disease and shed bacilli in their sputum.[52] The disease is found in males and females both, but biologically prefers males over females and aged over children or young. As stated earlier, environmental factors increase the risk of the disease such as poor nutritional intake and overcrowding. Approximately one third of the world's population is infected with the tuberculosis bacillus, but only eight million per year develop the active disease, the rest have latent tuberculosis.[53] The problem is acute and exists in tremendous proportions in the developing countries.

There are basically two tests for detection of active tuberculosis. First, the sputum smear microscopy developed by Robert Koch. If the sputum sample of the patient test positive by microscopy, it means the patient has active tuberculosis. However the test is incapable of diagnosis in 20 percent of the patients who have extra pulmonary tuberculosis. This becomes further insufficient in case of children because children usually are not able to cough up sufficient sample required for finding bacilli. It is estimated that smear microscopy can at best detect around 45-60

---

[50] C. Murray cited in Farmer, *Inequalities and Infections*, pp. 47-48.

[51] Katherine Ott rightly puts this resurgence and return of attention to tuberculosis as, "the story ends up as 'Tuberculosis is back' rather than more appropriately Tuberculosis is back in news". Cited in Farmer, *Inequalities and Infections*, p. 49.

[52] Gothi, 1978, 'Natural History of TB', *Supplement to the Indian Journal of Tuberculosis*, Vol. 25, No. 2, p.1.

[53] Medecins Sáns Frontiers (MSF), *'Running Out of Breath: TB Care in the 21st Century'*, available at http://www.msf.org, accessed 18th June 2005, p. 4.

percent of people having active TB.[54] The second test also developed by Robert Koch is tuberculin used for screening latent tuberculosis. But this is unreliable as results are affected by BCG vaccination and in patients co-infected with tuberculosis and AIDS it gives negative results.[55]

BCG[56] first used in 1921 has been widely used among children but has limited protection for adults. The vaccine aims to induce a benign artificial primary infection that will stimulate resistance to the possibility of subsequent infections from virulent *tubercle bacilli*. During the decades from 1940's to 1970's the most potent drugs were discovered for tuberculosis treatment that continue till date and form the basis of treating the disease.[57] In countries where HIV prevalence is low and have a functioning health infrastructure, these drugs give excellent results with cure rates as high as 95 percent to drug sensitive tuberculosis. However, these rates are subject to accuracy of diagnosis and compliance to six to eight months of treatment.[58]

In countries with high burden of tuberculosis, in other words having a large pool of infection, treatment of tuberculosis cases will lead to reduction in this pool that causes new infections. But reduction of the incidence (new cases) will take a long time to occur, because new cases will come from previous infections as old as fifteen-twenty years. Therefore sustained interventions are required and should be taken for long periods of time.[59]

---

[54] *Ibid.*, p.4.

[55] *Ibid.*

[56] Medically known as bacilli Camette Guerin named after two French scientists, Calmette and Guerin

[57] Streptomycin developed in 1944 followed by the discovery of PAS in 1952 and Isoniazid in 1952 and Cycloserine in 1955, Rifampacin in 1965 and Ethambutol in 1968 and Pyrazinamide in 1970. PAS and Cycloserine were fast abandoned due to their toxicity. MSF, *'Running Out of Breath*, pp. 4-5.

[58] *Ibid.*, p. 5.

[59] I. Qadeer, 1994, 'New Strategy for TB Control: Some Issues', Paper presented at a workshop on TB programme, CSMCH, JNU, p. 10.

Tuberculosis Control in India

Over the last four decades India has operationalised two national programmes to control tuberculosis – the National Tuberculosis Control Programme (NTP) and the recently adopted RNTCP. A brief look at the evolution of the programme, their principles, achievement and limitations are listed in this section. The National Sample Survey (NSS) conducted in 1955-58, followed by other studies from the National Tuberculosis Institute (NTI), and small scale surveys by Gothi, Raj Narain, Banerji and Anderson confirmed that there was high burden of tuberculosis; 1.5 % of the population was suffering from radiologically active tuberculosis and it was almost equally present in rural and urban areas.[60]

The first programme, NTP was initiated in 1962 to control the disease with the objective of early case detection and treatment and was based upon an operation research (OR) study conducted by D. Banerji and Stig Anderson. The study established that people with symptoms seek help. Therefore NTP was based on passive case finding, as people with symptoms act by seeking help at the general health services and this marked the beginning of treatment.[61] Through this strategy, it was possible to cover the largest number of affected population with the limited resources. This strategy also required least effort from the peripheral institutions.[62] People seeking help with symptoms of the active disease (e.g. three weeks of cough) would be tested for tuberculosis by radiology and sputum microscopy and provided free domiciliary treatment through primary health care services. Treatment of active cases would result into reducing the pool of infection and breaking the chain of infection. The programme was integrated with the District Tuberculosis Centre (DTC) and the primary level health care, and was envisaged to grow with the expansion of

---

[60] K. Park, 1997, *Preventive and Social Medicine*, 15th edition, Banarasidas Bhanot Publishers, Jabalpur, pp. 139-40.

[61] D. Banerji and S. Anderson, 1963, 'A Sociological Study of Awareness of Symptoms among Persons with Pulmonary Tuberculosis', *Bulletin WHO*, Vol. 29, pp. 665-683

[62] I. Qadeer, 'New Strategy for TB Control: Some Issues'.

general health services. Extension of coverage under Short Course Chemotherapy (SCC) was also a part of NTP. However the treatment consisting of Standard Regimen (SR) and SCC was unsupervised. This approach underlined several advantages of passive case detection and integration with the general health services that would save on costs and thus wider coverage could be achieved.[63]

However by 1993, after three decades of implementation of the NTP, a nation wide review revealed that the programme had fallen short of its purpose, i.e. to control tuberculosis in the population.[64] Some of the main failures on the treatment and diagnosis were low treatment completion rates (30 percent); undue emphasis on x-ray and poor quality of sputum smear microscopy; more emphasis on case detection than on cure and shortage and irregularity of drug supply. This was furthered by inadequate budgetary outlay, poor organisational set up and support for tuberculosis, multiplicity of treatment regimens and poor integration of NTP principles into the general health services.

It was widely accepted that the programme had failed in its objective primarily due to constraints in programme implementation. Some of the main findings are enlisted by a study conducted in 1996 by the Foundation for Research in Community Health (FRCH), Pune.[65] Firstly, there was poor information among the population regarding tuberculosis. There were gaps in the information, especially in what people should know about tuberculosis for availing the health services. The stigma towards the disease was found to be high. Private practitioners of the neighbourhood were found to be the favourite provider due to less waiting time and convenience of timings of the facilities. All kinds of private practitioners attended to the tuberculosis patients. They lacked rational drug regimens and follow up. Instances of incomplete treatment

---

[63] M. Uplekar and S. Rangan, 1996, *'Tackling TB: The Search for Solutions'*, Foundation for Research in Community Health, Pune, pp. 2-3.

[64] Review conducted by SIDA and WHO. Cited in J. Kishore, 2001, *National Health Programmes of India*, 3rd edition New Delhi: Century Publication, p. 48.

[65] Uplekar *et al*, Tackling TB.

were high. They were also found to be inadequately trained and under-qualified. Their record keeping was poor. They did not pay any attention to patient education. They were also heavily influenced by the promotion of the pharmaceutical companies. In total they had a very casual approach towards public health dimension of the disease. People experiencing frank symptoms of the disease delayed reporting to the provider. Most of them were not tested for sputum as x-ray was relied upon more. The most important finding of the study is that peripheral health institutions (PHI) failed to function as proposed by the NTP that had envisaged all services for tuberculosis treatment to be delivered at the PHI level. On the contrary, the patients had to take a circular route from the PHI to the DTC and back to the PHI. The other problem cited by the study is non adherence to treatment. Two reasons were cited for this; first, there was a high cost of care,[66] furthered by non availability of all the services under one roof. Patients had to go from one place to another. Secondly, patients experienced symptomatic relief from partial treatment and thus discontinued treatment. The health provider including paramedics and laboratory technicians didn't undertake activities within their ambit of functioning due to low priority and lack of accountability related to tuberculosis activities. There was a trickle down effect in terms of assigning the blame of failure of treatment, falling from one functionary to another and finally on the poor understanding of the 'illiterate patient' who was 'ignorant' and simply 'didn't understand'. Overall, the study points to the lack of priority to NTP reflected in allocation of the required resources for proper functioning of the grass root level workers upon whom the programme was actually erected. The private sector also worsened this failure by acting as an important but irresponsible and largely ignorant actor. The public as well as the private doctors viewed the disease from a purely clinical dimension. Their lack of social, epidemiological and public health perspective of the disease further hindered accessibility of patients.

[66] One third of the patients incurred debts for seeking treatment.

RNTCP was initiated in 1997 with very specific agenda of having 70% detection rates and 85% cure rate to break the chain of transmission and thus reduce the pool of infection.[67] The programme witnessed an increase in the budgetary outlay[68] and in organisational aspects by creation of peripheral level supervision and sub district supervisory units. Unsupervised SCC of NTP was replaced with Directly Observed Treatment SCC (DOTS). The diagnosis is based on sputum microscopy rather that x-rays during NTP (RNTCP requires three sputum smears).[69] Huge emphasis lies on compliance of treatment (the responsibility of which is on the health services and not on the patient) and on uninterrupted drug supply. RNTCP acquires from DOTS a public health based management strategy as it is aimed at controlling tuberculosis by focusing on the most infectious (smear positive) patients. Since its inception the programme has expanded manifold and covered 67.2 percent of the total population of the country in 2003.[70]

The five key principles of DOTS are;[71]

- Government commitment to sustained tuberculosis control activities.
- Case detection by sputum smear microscopy among symptomatic patients self reporting to health services.
- Standardised treatment regimen of six-eight months for at least all sputum positive cases, with Directly Observed Therapy (DOT) for at least the first two months.

---

[67] India needs to put at least 3500 (70%) of these new TB patients on DOTS each day and cure 2975 out of those (85%) in order to reduce the death rate by half by year 2010.

[68] India spends around US$ 35.6 million annually for RNTCP, of which US$ 30.4 million comes from external sources such as the World Bank and Bi-lateral aid. 'Tuberculosis Control Report Card 2004'

[69] One sputum positive case was a case in NTP, but in RNTCP two sputum smears positive for acid-fast bacilli (AFB+) is also considered a definite case.

[70] In 1997, DOTS covered only 2.3 percent of the population of India. WHO Report 2005, Global Tuberculosis Control – Surveillance, Planning, Financing, 2005.

[71] DOTS approach assumes based on evidence that detecting 70% of smear positive that is the most infectious patients and curing 85% of these could reduce the TB incidence by 6% annually effectively halving TB in 10 years.

- A standardised recording and reporting system that allows assessment of treatment results for each patient and the TB control programme overall.

DOTS defines a 'case of tuberculosis' as one which has been bacteriologically confirmed, or has been diagnosed by a clinician. 'Smear-positive pulmonary case' is defined as at least two initial sputum smear examinations (direct smear microscopy) AFB+; or one sputum examination AFB+ and radiographic abnormalities consistent with active pulmonary tuberculosis as determined by a clinician; or one sputum specimen AFB+ and culture positive for *M. tuberculosis*. 'Smear-negative pulmonary case' is defined as pulmonary tuberculosis not meeting the above criteria for smear positive disease. However, diagnostic criteria should include at least three sputum smear examinations negative for AFB and radiographic abnormalities consistent with active pulmonary tuberculosis and decision by a clinician to treat with a full course of anti-tuberculosis therapy. 'Extra-pulmonary case' are patients with tuberculosis of organs other than the lungs e.g. pleura, lymph nodes, abdomen, genitourinary tract, skin, joints and bones, meninges. Diagnosis should be based on one culture-positive specimen, or histological or strong clinical evidence consistent with active extra-pulmonary disease.[72]

A 'new case' under the DOTS is defined as patient who has never had treatment for tuberculosis, or who has taken anti-tuberculosis drugs for less than one month. Patient previously declared cured but with a new episode of bacteriologically positive (sputum smear or culture) tuberculosis is defined as a 'relapse case'. Patient previously treated for tuberculosis, undergoing treatment for a new episode of bacteriologically positive tuberculosis is a 're-treatment case'.[73]

Initially smear-positive patient who was smear-negative in the last month of treatment, and on at least one previous occasion is declared as 'cured'. A patient who

[72] *WHO Report 2005, Global Tuberculosis Control – Surveillance, Planning, Financing*, p. 14.

[73] *Ibid.*

completed treatment but did not meet the criteria for cure or failure is a 'treatment completed' case. Treatment is termed as 'failed' if a smear-positive patient remained smear-positive at five months or later during treatment. Patient whose treatment was interrupted for two consecutive months or more is a 'default case'.[74]

RNTCP puts patients under three categories for treatment.[75] New cases who are sputum-positive, or seriously ill patients with smear-negative or extra-pulmonary disease are put under Category-I. For these patients the treatment is in two phases – intensive phase (IP) and continuation phase (CP). The first two months are IP in which treatment is under direct observation thrice weekly on alternate days. At the end of IP if the patient is sputum-negative, CP starts, but in case of sputum-positive the IP is extended for another month. CP consists of four months during which the medicines are to be taken thrice weekly on alternate days, the first dose each week being directly observed. In CP follow-up sputum test is done after two months. At the end of the treatment one more sputum test is done.

Category-II patients are re-treatment cases including patients with relapse, failure and those who return to treatment after default. The IP for this category is for three months, followed by CP of five months. If the patient is sputum –positive even after three months of IP, the IP is extended for one more month before the start of CP.

Category-III cases are patients who are sputum-negative or who have extra-pulmonary tuberculosis and are not seriously ill. There treatment consists of two months of IP followed by four months of CP. If the patient is sputum-positive after two months of treatment, the patient is considered a treatment failure and begun afresh on Category-II treatment.

---

[74] *Ibid.*

[75] *RNTCP at a Glance*, Central TB Division, New Delhi.

Scope of responsiveness in RNTCP

The NTP was designed to be a part of the general health services and its failure was, to a large extent, actually described as the weakness and lack of responsiveness of the general health services. The RNTCP is a vertical programme and puts pressure on the existing health services to respond to the programme's 'needs', which is to achieve high levels of coverage and compliance. How does this affect responsiveness of the programme towards the medical and non medical needs of the patients of tuberculosis? What role do the health services play in alleviating the sufferings of the patients caused due to the disease? The study elicits the clinical and human dimensions of responsiveness from the patients' experiences of interaction with the health services.

III. RESEARCH METHODOLOGY

The methodology of the study is geared towards understanding responsiveness of health services through the patients' experiences of seeking health care. Since the clinical and human dimensions work together in responding to alleviate suffering of the patients, the study defines responsiveness as the 'manner in which the health services respond to alleviate the suffering of the patients caused due to illness.' Treatment of patient from the 'disease' is not exclusive from the humane aspects. It essentially incorporates both the health (clinical) and human (non-clinical) aspects of care through the health services. It makes two departures from the WHO perspective. Firstly, 'health' and 'non health' cannot be segregated, but operate as a whole and therefore should be seen in a holistic way. Any division would diminish the scope of responsiveness because it forms an integral factor in coping with the disease both at the individual and population levels. Secondly, the elements of responsiveness are understood from patients' experiences of seeking help, unlike from the experts as approached by the WHO.

The study is exploratory and employs a systemic[76] approach to locate responsiveness of RNTCP towards patients in alleviation of their suffering. The study examines from the patient's experiences the following elements as constituting responsiveness:

1. The health services address the suffering of the patients by treating the disease and in case of a curable disease cures. This derives from the primary objective of the health services, i.e. 'better health' of the people it serves. Thus adequacy of response is important output of health services. At the individual

[76] The health, non-health and financial aspects of the health services are indivisible when viewed functionally and can not be not broken down into separable parts, because the essence of the health services is lost when it is broken down into parts.

patient's level, this would include proper diagnosis and treatment. A person should not be denied treatment for lack of money, address proof, etc.

2. The seven elements of responsiveness as listed by the WHO, i.e. one, respect for dignity of the person (not humiliating or demeaning patients); two, confidentiality (the right to determine who has access to one's personal health information); and three, autonomy to participate in choices about one's own health (including help to choose what treatment to receive or not to receive); four, prompt attention (immediate attention in emergencies and reasonable waiting times for non-emergencies); five, quality of basic amenities (cleanliness, hospital food etc. should be of decent quality); six, access to social support networks – family and friends – for people receiving care; and seven, choice of provider (freedom to select which individual or organisation delivers one's care). However they may not be separable from the health aspects as conceptualised by the WHO.

3. The health services share proper (and correct) information with the patient/family regarding the cause and treatment of the disease, including the possible side effects and precautions to be observed during treatment. The known possibility of recovery from a disease condition etc. is shared with the patient/family.

Primary research is done in Udaipur city of Rajasthan, which represents a typical town of India. The tools used for the research are in-depth case studies of the patients, detailed interview of the service providers, and the researcher's observation of the services at the District Tuberculosis Centre (DTC) and the records of patients being maintained at the DTC.

Patients' experiences are gauged through in-depth case studies in the form of biographical narratives of the disease, their suffering and coping. Detailed open interviews are conducted for the case studies (See Annex for method of interview and

case study). The objective of this method is to get in-detail experiences of the patients on aspects of responsiveness as mentioned above and understanding the impact it may cause to utility of services for a particular disease. The group of patients consists of ten relapsed patients[77] of tuberculosis coming to the DOTS centre for treatment. Relapsed patients are taken for the study for two reasons. First, they have been declared 'cured' by the health services once but the disease has reoccurred and are undergoing their second round of treatment. These patients have adhered to treatment at least once (so they were declared cured) and have reverted back to the same health services for treatment even though they have been 'failed' by the health services once. They have relapsed with the disease and the health services have to 're-respond' to their needs, which is a bigger challenge in terms of communication and motivation and above all faith in the health services. Second, these patients have better insight regarding taking treatment and longer experience with the services. Hence, they provide better opportunity to understand responsiveness of the health services.

The focus areas of probe in these interviews are as follows:

- A brief background to understand the occupation, family size, levels of education, income caste and religion for a socio-economic context;

- The initial symptoms of illness, duration and description of the symptoms and the timing for seeking help. This includes the choice of kind of help sought and the time, reasons for postponing seeking help if any and the prime factors of decision making (like who decides to seek help etc.);

- A detail description of seeking help: What happened upon reaching, initial response, tests, and the time taken for diagnosis; shifts from one place to another, medication, direct costs, indirect costs, availability of doctor, staff, medicines and other facilities? Besides this the human dimensions of the

[77] A 'Relapse patient' is patient who has been cured of tuberculosis once, but the disease has reoccurred.

behaviour of the doctor and staff, in terms of manner of speaking, rent seeking, and freedom of communication.

- Impact of the health seeking for the rest of the family in terms of loss of income, expenditure pressures through borrowing, accompanying the patient, etc.;

- Working of the programme like time taken for initiation of DOTS, steps followed as laid down in the DOTS protocol (like home visits, contact person, confirmation of address and so on), convenience for the patient due to DOTS, number of medicines given, nature of instructions given for taking the medicines, side effects and precautions, follow up tests, instructions on duration of the treatment and communication of the importance of compliance;

- Sequence of becoming ill in terms of suffering, recovery and revival through help seeking in terms of getting well and carrying out every day lives and roles. The reasoning for getting ill by the patients and their families, not once but twice;

- How much explanation is given by the health service providers? What kind of understanding goes into answering 'why me' and its role in coping with the disease;

- Relapse of the disease: The feeling and reasoning for the reoccurrence by the patient and the family.[78] Any effort to reason the relapse by asking the doctors or any other staff of the health services, the explanations given with or without questioning. Reasons of questioning or not questioning the health service providers by the care seekers is looked into for understanding the latter's

[78] This doesn't strictly denote immediate of biological family, it any include neighbours and other acquaintances.

expectations from them that reflects the accessibility of the care providers in the perception of the patient and family;

- Understanding the kind of torment the disease brings into the lives due to the stigma attached to it. What are the initial reactions and how does one cope socially through social relationships of immediate neighbourhood and kinship. Does the patient or the family reveal this to others? What are the motivations in hiding or revealing the status? How is this reflected in the health services through the sensitivity programme staff? How does DOTS help or hinder this; and,

- Grading of the response that the patient got through the health services. There are five grades of which one can be assigned and they are; 'very good', 'good', 'fair', 'poor', and 'very poor'. Very good being for best and very poor being the worst. These are not discrete but continuous so this can be collapsed into 'good to fair' or 'fair to poor' according to the grading articulated by the respondent. This grading is done by the patient along with the family members wherever possible for re-checking the views and to get a more definite opinion. The patient and the family grade and also reason their choices for the grade they assign.

The objective of interviewing service providers as a set other than the patient is to get the remaining part of the two way interaction at the health services. Since health services are a human service organisation, wherein a large area of the functioning depends on the values, culture and aspirations that the society puts in them, both, from within the organisation, their clientele and the population at large and the same is reflected by the system.

The main areas of probe in these interviews are in light of the RNTCP, a high priority driven programme to attain high and difficult levels of achievement in view of 'controlling the disease'. What happens to the individual patients that these

personnel have to deal with? How do they balance the requirement of alleviating suffering of the patient which is the motivation of the patient to come to them with the requirement of conquering the disease at the population level? Where does it mismatch and how do these service providers deal with them? What do they understand of responsiveness from the point of view of the patient? Where do they grade the services of which they are a part of in meeting these aspects of responsiveness for their clientele? When are the times they step out of their roles to do something more and what motivation?

The interviews endeavour to provide insights into the level and nature of responsibilities the service provider is supposed to carry out. It seeks to understand their job, and the ways in which they carry out these responsibilities. How does the system prepare them to meet or develop skills for their assigned tasks in form of training, meeting, and informal discussions etc.? What are their challenges and hurdles? How much of this is due to the amendable endogenous systemic reasons and how much of it for exogenous reasons and how do they cope? What is their expectation from their leadership? What value addition they see in their work?

The descriptions by service providers are not only of one time interviews, which forms the main content, but consist of several interactions throughout the work of data and observation of the service that spanned over two weeks. It therefore consists of formal as well as informal interactions. This is more applicable to the non medical staff with whom more time is spent.

Further, the researcher has observed the functioning of the DTC for two weeks and also has collected and analysed the patients' records maintained at the DTC to collate personal observations and patients experiences with the official performance of RNTCP.

Udaipur: The Study Setting

Udaipur district is situated in the southern Rajasthan adjoining Gujarat and encircled by the Aravali range from north to south. The entire district is charecterised by an undulating topography and degraded natural resource base. Total population of Udaipur is 2.6 million with a sex ration of 972 female per 1000 male population. The Census 2001 put the literacy rate of the district as 59.26 percent, with 43.71 percent female literacy against 74.47 percent male literacy. Udaipur is a tribal district. 36.8 percent of the district population is schedule tribe. Another 8.3 percent population is schedule caste. Though subsistence agriculture is the primary occupation of majority of the population, a mere 17.58 percent of the land in the district is under cultivation. The rural areas are marred with poverty and deprivation. Recurrent droughts have further eroded the livelihood base and coping capacity of the rural population.

Administratively, the district is divided into four sub-divisions, ten tehsils and eleven blocks. The public health facilities of Udaipur are given in the following table.

Table-1: Public health facilities in Udaipur in 2003-04 (source: www.udaipur.nic.in)

S.No.	Facility	No.
1	Allopathic Hospitals	20
2	Beds in Allopathic Hospitals	2,656
3	Ayurvedic & Unani Hospitals	190
4	Beds in Ayurvedic & Unani Hospitals	221
5	Primary Health Centre	76
6	Dispensaries	11
7	Sub Health Centre	538
8	MCW/Dais Centre	11
9	Private Hospitals	60

RNTCP started in Udaipur in 2000 and by 2001 the entire district was covered. For implementation of RNTCP in Udaipur nine Tuberculosis Units (TUs) have been established to cover the whole district. Out of these, three TUs are in non-

tribal areas and six are in tribal areas. In the non-tribal area, TUs have been set-up at a population of 500,000, whereas in the tribal areas it is at 250,000 population. Each TU is supported by five designated microscopy centres (DMC). In the non-traibal areas there is a DMC for every 100,000 population, whereas in the tribal areas it is at 50,000 population. The DTC is head quarters for all tuberculosis related activities in the district like reporting and training. It also has the DTO's office and the office of the WHO consultant.[79] The DTC is open for OPD from 8:00 am in the morning to 2:00pm on weekdays and 9:00 am till 11:00 am o Sundays.

A hospital called the *Badi Hospital* that was established as a TB sanatorium during the NTP is located about 12 kms. away from the city in a village called *Badi* and hence its name. This hospital is dedicated to TB and chest diseases, and provides in-patient care. It affiliated to the Rabindranath Tagore Medical College, Udaipur[80].

[79] WHO consultant has made Udaipur DTC as a regional headquarter and looks after 9 districts.

[80] Attached to the district general hospital.

IV. THE PATIENT AND THE SERVICE PROVIDER

The Patients

Ten patients suffering from a confirmed and relapse case of tuberculosis form the sample for this research. Six male and four female patients have been interviewed. All the patients reside in Udaipur city and belong to Udaipur. They are all from a similar economic class, i.e. the lower middle or lower class.[81] The average income of the household varies from Rs. 2,000 to Rs. 9,000. There are, however, social differences in religion, caste, occupation, educational levels and family size. Out of the ten patients studied, two are *Muslim* by religion, two are schedule tribe, one schedule caste, two other backward castes and three belong to general by caste category. Their occupation range from daily wage labourers, self employed auto driver to housewives and student. Educationally the patients range from non-literates to matriculate. In the following case studies of the patients, their testimonials are written in italics text.

Sitaram

Sitaram, a fragile 66 years old man has only one indulgence in life today – smoking *bidi*, a bundle everyday. He has been advised to quit smoking because of his sickness – a relapse of tuberculosis. His four children, two sons and two daughters are all married and have their own children now. Sitaram owns a small and dingy two-story house in the congested market area of Surajpole in Udaipur, where he lives with his wife, the eldest son and daughter-in-law and their three children Sitaram is 'Kumawat' by caste. For most part of his working life, Sitaram pulled cycle rickshaw for livelihood, and later bought an auto-rickshaw. Now that he is old, he spends most of his time at his son's small auto repair shop and supervises his new house being built a few kilometres away from the city on the only small piece of ancestral land he inherited. He intends to put the new house for rent after completion to supplement the

[81] Not taken deliberately but due to the very nature of the disease, they belong to a similar class.

family income. His average monthly household income is Rs. 2,500-3,000. Sitaram had dropped out of school after the 2nd standard and his wife is non literate. The eldest son Kishanlal is a matriculate. His grandchildren attend a government school and he hopes that they would surpass their father in education.

First episode

It was during the winters of 2002 that Sitaram started coughing. For the next three months he had cough, high fever with chills and night sweats. Soon he was bed ridden, lost his appetite and could not get up even for nature's call. He felt the fever rising from the sole of the feet and remembers it to be very 'heavy' (insufferable). It was under this unbearable discomfort that his son decided to seek medical help.

Medical help

His son decided to take him to a familiar doctor at the district hospital about 3-4 kilometres away from his home. It is here that medical help required is taken by the family when it is not possible to defer any more. His son Kishanlal had visited the doctor earlier and his auto driver friends had recommended him this particular doctor as being popular. Kishanlal had faith in him, since this doctor behaves well with the patients.

The doctor examined Sitaram's stomach and chest, and recommended a number of tests. The tests were done at the hospital for which fee was charged. But even before the doctor reviewed the test reports, his recommendation was for immediate hospitalisation. However, the lower staffs at the hospital (probably the male nurse or ward boy) were reluctant in admitting him. Kishanlal sought the doctor's help again. The doctor came in for Sitaram's help himself and got Sitaram admitted. But the annoyed ward staff refused Sitaram medicines and injections from the hospital store. He was forced to buy medicines from the market. Sitaram remained hospitalised for six days. Meanwhile, his test results came and the doctor declared him suffering from tuberculosis. He was told that since he deferred seeking medical

help for over two months, his treatment had been delayed and his condition was critical. At the same time, the doctor also 'guaranteed' him complete cure from the disease and promised that he would be absolutely fine. When hospitalised, the nurse asked Kishanlal to first get a thermometer from the chemist shop, so that Sitaram's fever could be monitored. The hospital blanket was inadequate to comfort him from the chills associated with his fever, so Kishanlal got a thicker blanket from his home. Initially, the prescribed injections had to be bought from the market, but then on request of Kishanlal to the doctor, it was provided from the hospital itself. The entire cost of medicines and expenditures like purchasing of a thermometer was approximately to Rs. 500. Sitaram was discharged from the hospital after six days.

DOTS

After discharge from the hospital, Sitaram was referred to a dispensary close to his house to continue treatment for tuberculosis. He was advised to collect the medicines regularly from the dispensary. He was also told that the entire course cost Rs. 1,500 – 2,000 which he was getting for free. He discovered at the dispensary that his name was written on a box of medicine earmarked just for him. He started collecting the medicines every alternate day, but took them at home. However, he didn't understand in what way so many tablets would help him, neither had the nerve to ask the doctor as this might have 'annoyed' him. He was not given any instructions regarding how the medicine should be taken. The initial effects of the medicines came in form of vomiting, nausea and loss of appetite. He didn't have the courage to report these to the doctor or the DOTS provider. Sitaram only knows that the medicines, a total of 7, should be taken in front of the DOTS provider, but he assumes that since he had built a decent amount of trust with the provider that he was allowed to take these medicines at home. He explains, "*They (DOTS provider and the doctors) were confident that I was taking the medicines and not throwing them, or worse selling it in the market. Because they could see me every alternate day, they could make out the difference due to improvement.*"

He insists that he took the medicines regularly. Gradually his condition also improved. There were no tests carried out in the course of this treatment. After seven months of medication he was told that his course was complete. Without any further diagnostic tests at the end he was declared to be cured.

Tuberculosis again

A fortnight had passed after the Diwali (a prominent festival in late October or early November) of 2004, when Sitaram started having high fever and night sweats. His condition deteriorated and within a month he was completely bedridden. Kishanlal felt it was time he sought medical help for his father. At the district hospital he didn't find the doctor who treated Sitaram earlier, as it was not his turn of duty. The doctor at the OPD said Sitaram needed immediate hospitalisation and prescribed for x-ray and medicines for 8 days. Kishanlal bought the medicines from outside for Rs 200, but waited for the x-ray which he could eventually get done from the hospital.

The doctor informed Sitaram that his tuberculosis was back. He said injections were necessary to kill the remaining organisms. The doctor also informed Sitaram that since during the previous treatment his tests were not done properly, some remaining infection couldn't be detected and the disease has reoccurred. Sitaram or Kishanlal never knew what these tests were, neither their necessity. Kishanlal says, *"If I knew that these are so important, I would have insisted in some manner for these tests to happen. Now that I know, I will be cautious"*. They don't feel any grudge against the previous treatment incompletion as they expect the government services to work in this fashion. *"If one wants better attention and expects the doctor to explain the treatment, side-effects, and other details, or to question the doctors, one can see them in the evenings at their residence where most of the government doctors carry out their private practice"*, says Kishanlal. Interestingly he also tries to reasons why the doctor did not explain the details of treatment and the significance of the tests, *"they* (doctors) *don't have so much time to interact... they have to see so many patients, if they start talking and explaining to everyone, then when will they see patients?.....this*

is the way they deal with all the patients. It should be sufficient to make the patients understand because others are getting well by the same treatment. There must've been some mistake from our side... " Kishanlal however admits that if there was any further requirement which could have been fulfilled in the first episode and could prevent the relapse, it would have saved a lot of inconvenience and suffering.

DOTS again

After six days at the hospital, sputum testing and x-ray, Sitaram was discharged. During hospitalisation he was given 5-6 injections. He had to purchase medicines and injections again costing Rs. 450. At the time of release from the hospital, he was referred to the DTC. There he was put under 'Category-II' tuberculosis patient. As part of his treatment this time, he got injections also. To relieve him of the sufferings, he was prescribed two bottles of cough syrup and two tins of protein supplements, which needed to be bought from the chemist shop outside the DTC. These cost him Rs. 300.

This time also Sitaram could strike an arrangement with the DOTS provider to allow him to take his medicines at home. Unlike the previous time when he himself had to visit the dispensary to get the medicines, this time his grandson or anyone else from the house goes with his dairy and empty foils and gets the medicine. He has completed the intensive phase of treatment wherein he was given seven tablets every alternate day and now is in the continuation phase of five tablets every alternate day. Sitaram has evolved his own way of taking medicines. Rather than taking all the tablets together every alternate day, he divides the medicines into two sets and takes them in two days. *"This way I don not have to swallow down so many medicines together every alternate day and I also have some medicines to take every day"*, he explains candidly his innovation. However, he sees to it that the first 'set' of medicines is over before he takes the next set of dose. He doesn't know whether this method of taking medicines is correct or not, but it is definitely convenient for him. Kishanlal disagrees with his father's method of dividing the dose and says it must be

less effective this way, but doesn't stop him. Sitaram again emphasises very strongly that he is taking medicines regularly and that is why his condition has improved.

Services

Sitaram was prescribed 2 cough syrups bottles and 2 tins of protein supplement to have it with milk. His son bought them from the medicines shops outside the DTC and spent about Rs. 300. *'Initially, the nurse (DOTS provider) shouted on me loudly to sit at a distance and cover my mouth with a piece of cloth'*, Sitaram remembers. She has never asked him about his condition and well-being, on the contrary, she tells him at times when he goes to the DTC himself that he is getting better. *'What is there to ask? Nobody there is bothered about my health. It's their job to give me medicines which they are doing. Rest is all extra, so there is no binding for them to do so. It is only now that you are asking about my disease in such details. You are the first person to visit my home regarding the programme'*, Sitaram says to the researcher. But he also promptly adds that the nurse providing DOTS is 'nice' and 'cultured'. Sitaram was asked to attend a 'function' organised by the DTC on World Tuberculosis Day on the 24th March 2005. *"They told me to bring my diary, come with the empty foils and tell the officials about my treatment done there. They told I would get Rs. 25 and lavish snacks along with tea, but I simply forgot the day and didn't attend the function"*, he explains.

Grading the treatment

Sitaram graded the response he got from the health services in the form of treatment by choosing a category from the five categories.[82] He chose 'fair'. The reason he opted for this choice is that treatment is not excellent or good because it took a lot of time for him to get well. His condition has improved but is not as good as earlier. The disease reoccurred inspite of the 'guarantee' given by the doctor of getting absolutely fine, due to incomplete treatment and finally the costs that his son had to bear for the treatment. He doesn't put it in the 'bad' or 'very bad' category

[82] Mentioned earlier in p. 33.

either since his condition has improved and the validity of this marking according to him is that he is still taking his medicines regularly. Had the impact of the medicines been poor, he would have stopped. Thus he qualifies the 'ok' grade.

However for Kishanlal, the response was 'very good', as his father was admitted promptly and most of all, he could organise medication including injections from within the hospital after sometime, if not immediately. As a result of the treatment his father's condition improved, so the treatment did work. Although, his version doesn't include the alleviation of discomfort from the disease or revival of the former life before the disease had struck, as is reflected in Sitaram's grading.

Life has changed

Sitaram admits that, "*I haven't revealed my disease to my relatives or neighbours.*" During he interview, he and Kishanlal scarcely use the term 'TB' and whenever doing so lower their voices as the interview is conducted at the auto repair garage of Kishanlal. "*My daughters also don't know of this because they will start worrying....more about their vulnerability of contracting the disease.*" Sitaram's neighbours are not aware of it because he has sighted some generic disease for his illness and repeated visits to the hospitals or the DTC (District Tuberculosis Centre). His initial reaction upon knowing about his disease was not of shock. Since he belongs to a generation that has seen a high death rate and taken it as a dreaded disease, but the reason of his calmness was a past experience of tuberculosis of his wife 18-20 years ago. She was completely cured of the disease and is now healthy and active even in her old age. Sitaram also sights some other persons in the neighbourhood having a visible incidence of tuberculosis. Despite this self assurance he has decided not to disclose his disease, even to his daughters in fear of a probable bias. There is no mention of any assurance given by the programme staff, except for the guarantee of complete recovery by the doctor in the initial episode, which proved false.

"I try to endure the pain and discomfort as much as I can. It costs money even to go to the government services. I don't want to burden my family further. If there is no money one just has to die... Every one in the family gets affected if a person in the family falls ill. After treatment I am now able to undertake certain responsibilities like supervising the construction of the new house, social events like laying the foundation and treating my community people. I can ride a bicycle to some furlongs. It is not just money. When I was ill, my son was busy in looking after me and everything had halted", Sitaram says in despair about his life with the disease, and adds, *"I have started living like a saint. I don't go near my wife. My capacity has diminished"*. Sitaram draws suggestive analogy to describe his sexual life that has undergone a change as he keeps away from his wife. But he doesn't sight any reasons given by his wife for this. In his daily functioning, Sitaram feels worthy by discharging his self assigned duties, being independent and not a financial burden for his family.

Hemlata

Hemlata, a 16 years old girl, would have been a high school graduate this year if her schooling was not interrupted by tuberculosis, not just once but twice. She lives with her paternal grandfather, parents and three brothers of whom one is younger to her, in a family owned small three-room house in Bekni Pulia suburb of Udaipur city - a lower middle class neighbourhood near the university. She belongs to Meghwal community, a schedule caste of Rajasthan that was traditionally engaged in leather works. Her father Bhagwatilal is a matriculate, and has a small photo framing shop which generates on average Rs.2,000-3,000 monthly income. The family owns 2-3 acres of land, which was cultivated by Bhagwatilal himself till a few years ago, but now is rented out for share-cropping. Hemlata's mother is non-literate and elder brothers are pursuing higher education after schooling. However, despite of strong persuasion and support of their father who values education highly, they would soon drop out to generate more income for the household. Hemlata's youngest brother studies in 8th standard.

First contact with tuberculosis

Hemlata had gone to her maternal uncle's house 9-10 kilometres away for his wedding during the summer vacations of 2003. After the wedding, she started having fever with chills. *"The reason of this was sleeping in the cooler and drinking cold water from the refrigerator due to which a lot of cold entered my body"*, she explains. When her temperature would not come down after a few days of home remedies, her uncle took her to a private practitioner. The doctor[83] checked her chest with stethoscope, asked her for how long she had the fever and gave some injections and pills. The fever came down for a couple of days. But on the 3rd day her temperature and shivering were back and she started feeling extremely weak.

Medical Help

Bhagwatilal explains the decision of Hemlata's uncle to take her to a private hospital and not to the district hospital or government dispensary, *"the waiting time at the private clinic is very little as compared to the government hospital. Besides, the government hospital or dispensary timings are very limited. Many a times, one has to return unattended if you do not reach early or if it is too crowded"*. They usually go to this doctor who gives the medicines including injections for Rs.25-30. Hemlata was taken to another private practitioner since her fever did not go. He, like the earlier one charged a similar amount to check her chest with stethoscope and gave her injections, syrup and some pills. She had instant relief, but it didn't last for long. He had also suggested seeking his advised if there was no relief in the fever. Hemlata's uncle took her to this doctor again, who gave her similar looking pills and syrup again. None of the two private practitioners, however, advised and diagnostic tests and did not inform Hemlata the cause of her fever. It is uncertain whether they were able to ascertain the cause of illness, but both of them prescribed injections and medicines. The prescriptions did give instant but ephemeral relief to Hemlata. However, her condition

[83] It is not confirmed whether the private practitioner was a qualified doctor or not. However, he was considered a doctor by people as well as the patient in question; hence the term doctor is used for the private practitioner.

deteriorated and within a weeks time her it worsened rapidly. By now she was running incessant high temperature and coughed heavily. She could not even breathe as much as she coughed. Hemlata's uncle called Bhagwatilal who immediately rushed his daughter to the emergency section of the general district hospital at 9:00 pm.

At the district general hospital, she was admitted immediately and prescribed tablets and injections that had to be bought from the market and cost roughly Rs. 200-250. By the next morning her fever was brought under control. Bhagwatilal does not know which doctor was treating her, *"everyday there would be some new doctor according to duty turn. We don't know their names"*. After her condition stabilised, Hemlata was brought home. Bhagwatilal still didn't know the reason of her daughter's illness, "*I didn't ask, neither would they tell*", he adds, "*Until they are sure of the disease after conducting all the required tests, how could they make a judgement of cause of the illness?*"

Within two days of discharge from the hospital her fever was back again. Along with persistent coughing she was growing weak and had no appetite. Her mother took her to a nearby PHC. Although private practitioners are a preferred choice with Bhagwatilal's family as well and going to this nearby government dispensary is not the regular choice, but in minor illnesses they do resort to it. The doctor here prescribed an X-ray of the chest, which was done at a private diagnostic centre costing Rs. 150. After examining the X-ray image he recommended immediate hospitalisation for Hemlata at the general hospital. *"The reason for this advice was that when the doctor examined the x-ray he found water in Hemlata's lungs"*, explains her mother. Hemlata returned to the general district hospital where she remained in admission for 7 days. During this period, she was given medicines and injection, twice daily, each costing Rs. 75 that had to be bought from the pharmacist, besides the antibiotics and other vitamins. The cost of medicines purchased during this admission and treatment amounted to Rs. 2,000. It was only now that the doctor

reasoned the cause of her illness as tuberculosis. This was based on x-ray examination. Sputum couldn't be tested as she didn't get any sputum.

After her release from the hospital, she stayed at home for two days. Bhagwatilal sought to consult a reputed chest specialist of Udaipur heading the TB hospital at Badi, which was earlier a tuberculosis sanatorium. While Hemlata was hospitalised at the district hospital, the ward staff there also had suggested Bhagwatilal to take her to the TB hospital. He had brushed aside this advice then. Bhagwatilal sought to meet the chest specialist at his residence in the evening when he practices privately. The chest specialist prescribed Hemlata a medicine to induce sputum and referred her to the TB hospital. The inducing medicine was bought from the market. Her sputum then was tested at the TB hospital to reveal that she was acutely infected by tuberculosis and was 'highly positive'[84].

DOTS

She was immediately put on for six months treatment under DOTS. Hemlata was explained that she had to take certain medicines every alternate day for killing the organism completely that caused her illness. Her card was made and was she asked to get her medicines after a few days from the nearest DOTS centre from her residence, the government dispensary. They were told that this much time is taken for medicines to reach the DOTS centre from DTC. After 2-3 days when the medicines didn't reach the stated centre, Bhagwatilal had to go to the DTC requesting them to send the medicines at the dispensary DOTS centre. Two days later, a box labelled with the name of Hemlata came from which she started her course.

Initially, Hemlata was instructed by the DOTS provider to bring her own bottle of water and to swallow the dosage in front of her. The reason was, "*suppose I missed even one dose the organisms of that day would remain inside and increase*"

[84] The classification of this is done in four categories to know the strength of the infection. These are scant, 1+, 2+ and 3+. The last one is the highest positive of these and the first is lowest.

explains Hemlata. She was also instructed to take the medicines on full stomach. Taking the seven tablets was necessary and these were the only medicine for the disease. Therefore if she wanted to get well, she should take the medicines without fail every alternate day as told. She was not informed about any side effects that these medicines might have caused.

Bhagwatilal assured the DOTS provider that his daughter would take her medicines regularly and that they would keep full vigilance and take extra care to ensure that she takes her treatment in the prescribed manner, and requested to provide the dosage to him to give to Hemlata at home. He made this request initially in the name of her weakness, as visiting the centre frequently was very troublesome and later in the name of protecting her identity, as she would have to bear social stigma if people come to know about her disease. Under this arrangement, someone from the family would fetch the medicines for her once a week in return of the empty foils of the previous dose as witness of compliance. However, the DOTS provider also explained to Bhagwatilal that this arrangement was an exception to the rule and a very stringent rule was being softened to accommodate his request. Therefore he and his family members should observe strict confidentiality and it should not be disclosed to anyone else. Hemlata's treatment thus progressed upon this '*agreement*'.[85]

Hemlata completed her treatment duly by the end of 2003. She also had her stipulated three sputum tests during the entire course. She had to go to the DTC about 4-5 kilometres form their house for these tests. Her weight was taken initially at the time of registration and along with these tests. She had gradually gained weight and this was confirming to her parents that the treatment was effective and she was getting well. Her end sputum test showed that she was 'cured' of the disease.

[85] There is no mention of any kind of tip asked or given by Bhagwatilal, but the probability cannot be ruled completely out.

Tuberculosis is back

The time from 2003 winters to 2004 summers passed rather quickly for Hemlata. She was looking forward to going back to school and getting enrolled in the new session. Around the same time she started getting ill again with similar symptoms as the previous year. She had high fever with violent coughing. Worried Bhagwatilal took her to the DTC again, because this was the place he had visited during the entire course of Hemlata's treatment last year. He hoped she would get help there. X-ray was prescribed which was again done for Rs. 140 at a private radiologist. No sputum testing was done. She was again examined through the stethoscope and was prescribed certain medicines. Bhagwatilal had to purchase them from the chemist shop lining outside the DTC. They were advised to report back to the DTC after 2-3 days of taking the medication. Bhagwatilal and his daughter had no clue of the reason of the illness. Drawing from the previous experience, Bhagwatilal thought of seeking help at the TB hospital at Badi. Although it was about 18 kilometres from his house, without any proper transport facility, the motivation for going there was that a proper diagnosis would locate the cause of his daughter's suffering.

There, Hemlata was diagnosed as having fluid in the lung lining that required to be extracted. However, during extraction procedure, no fluid was found. The doctor then advised her to get admitted for a couple of days to do her complete check up. Subsequently she got hospitalised, but the couple of days converted into a full of week and gradually to nearly a month, without any clue to the cause of Hemlata's suffering. During this period she had undergone all kinds of blood and urine tests, some were even repeated. Her blood test showed malaria. According to Hemlata, they decided to treat malaria first and then think of tuberculosis. The pills given for malaria gave her nausea. According to Bhagwatilal, the doctors decided to keep her for a few more days and probe further into reasons of her illness. They couldn't determine whether she had tuberculosis, nor could explain the fever. Finally, after an ultrasound imaging the doctor declared tuberculosis to be the cause of her suffering.

Bhagwatilal was keen to knowing why the disease had reoccurred? When Hemlata asked the doctor about the same, he said that even he was puzzled. The doctor then put the blame on Bhagwatilal for, *"there must've been some lapse in taking the medicines during the previous treatment"*. Bhagwatilal pleaded innocent, and defended himself on the ground that if she hadn't taken her medicines properly she wouldn't have recovered, her suffering would have continued and moreover there was no reason why she would default. The doctor then displayed his puzzlement, "*it shouldn't have been this way if there was no default in taking medicines.*" Bhagwatilal recalls the doctor's reply to the question. The doctors declared that, if Bhagwatilal was believed, they had come across first ever case of relapse in case of a patient who had finished the entire course duly. They repeatedly blamed Hemlata for having missed her dosage sometime for getting the disease back. She was also threatened if she repeats her 'mistake' she would develop cancer about which they could not help.

DOTS again

The hospital staff told Bhagwatilal that Hemlata would require treatment for tuberculosis, but it would be difficult to get her the free government course as it is only for the first time patients. But they assured him that they would still 'try'. Fearing that her daughter's treatment might be left undone, Bhagwatilal pleaded to the doctor for her treatment and that he could not afford it from a private source. The doctor 'mercifully' allowed him to fill up the forms. He then had to visit the DTC for putting her case on their records and subsequent visits, as the previous time, requesting dispatch of her medicines to the nearest DOTS centre to his residence. This time although the previous arrangement couldn't work as she had to get injections for two months every alternate day along with the tablets. She had the same discomforts as in her first episode - nausea, breathlessness, uneasiness and loss of appetite. She was not able to carry on her daily routine independently. In fact with the start of the course, her situation worsened due to these side effects that emerged immediately after starting the treatment. Hemlata communicated this to the doctor at the dispensary

who explained that the tablets would give her some discomfort in the beginning, but then she would grow used to it, which she gradually did. Her sputum tests were done in between but this time her weight was not taken. There were no supplements prescribed to Hemlata, but she already had a number of bottles of cough syrups till now, all from the market. These did give her relief and a soothing effect. She was asked to have some precautions during taking of the course, like not having chilled drinks or food, not to be exposed too much to cold and not to have sour or spicy food.

Services

"*When someone dear to you is ill, you don't want to find out whether the doctor is taking advantage of you, fooling you to make some more pennies, the equipments there are working or that you're just being tricked into getting the tests done outside. You don't think about all these. Your sole concern at that moment is to get the person well, to relief her from the suffering by getting her the right treatment. I know that many a times the doctors at the DTC did try to make me run needlessly for some bucks. But one has to do it because it is the question of your dear one's well being or even life. In my case, my daughter might have just died if I didn't do what I did. In those moments, the doctors are Gods and we are puppets. We have to dance to their tunes. And possibly, literally dance if they want us to*", Bhagwatilal discloses his vulnerability as from the patient's side vis-à-vis the doctor due to the high stakes of the patient (and the family) and the powerful position that a doctor enjoys.

Bhagwatilal clearly chose the TB hospital inspite of its far off location because he trusted the skills of the doctors there over the ones at the DTC. The preference of this is simple, as the TB hospital gave a diagnosis, a definite line of therapy and better treatment in terms of human aspects of listening to the requests and explaining his daughter's condition. Although, he had to purchase lot of medicines from the market, most of the tests were done in house at government rates, which provided convenience more than the economy. *"I had more faith on doctors at Badi hospital"* repeats the father several times. This information of the 'good doctor' was provided

not by any referral, but through informal channels of the lower level hospital staff who showed some concern for the plight of the patient and family and also from the auto drivers lined outside the general hospital and the DTC. '*The auto drivers have a good awareness as to who is the best doctor of the city for a particular kind of disease*', says Bhagwatilal. The chest specialist gave a good 15-20 minutes time to the patient, spoke gently, examined her with lot of care and patience. Although this doctor prescribed some initial tests that were conducted from outside, but were not exorbitant. "*Since the doctor is very kind and wise one, he didn't prescribe unnecessary tests. Anyway, it saved a lot of time than the mindless running around at the district general hospital, which anyways would have been probably costlier for me in terms of loss of precious time for the patient and my business also.*" The indirect expenses of running around would have taken away the 'free' part of the tests at the district general hospital. The chest specialist then referred them to the Badi TB hospital for further treatment. Bhagwatilal explains the motivation of going to the chest specialist on a private basis, "*it took us some more time to reach this doctor because she remained hospitalised for long time. But I wanted to consult him as the knack of this doctor is good. And anyways going far off to the TB hospital for the same doctor doesn't guarantee that he only would see the patient. It depends on the duty turns among the doctors. Since I wanted this particular doctor's verdict only, I chose to see him on a private basis in the evening at his residence, which is nearer also.*"

RNTCP protocol calls for home visit, verification of address, identifying a contact person and most importantly, directly observing the therapy. None of this was met in the case of Hemlata. Ironically, none of these affected her treatment also; rather much of it was to her benefit. Her identity was protected, the inconvenience of walking a distance of a kilometre was saved and she was still in a better situation to communicate her side effects, unlike many other patients, and her tests were more or less duly done. In all during DOTS it was a good deal for Hemlata, only if it had

saved her from the relapse. Bhagwatilal now plans to visit TB hospital at Badi very soon for Hemlata's thorough check-up, to be sure that she is completely cured and to put right if any requisite has to be fulfilled.

Grading of treatment

According to Bhagwatilal, the treatment was 'very good' because, Hemlata got free treatment from the government. The doctors were very kind and supportive as they had got the free treatment available for Hemlata "*out of way, even though it was probably my daughter's fault that the disease reoccurred*", assumes Bhagwatilal in gratitude. Hemlata herself however says that the guarantee of complete cure from tuberculosis that the programme advertises so much everywhere had failed in her case, because the disease relapsed. Hemlata put a lower score for her treatment as she had to undergo a long ordeal for dealing with her disease. "*The tablets of the first time were probably not effective*" she says as reasoning out the relapse and adds "*I keep on blaming myself for the relapse and for so much trouble to my father and the entire family. Well let me have it again this time and see if I get completely cured.*" She lists down her expectations from a health service system in very articulate manner as, providing good treatment, proper attention, sufficient time by the doctor, correct diagnosis and complete treatment alleviating all suffering due to the disease.

The father listed his expectation as getting from the system what the government has provisioned for the people like free treatment or diagnosis etc. He adds that the diagnostic tests that can be conducted in the hospital should be done there only. Often, due to lack of time, when the doctor asks to get a particular test done immediately and his timings are about to close, the patients have to rush outside to get the same tests done which could have been very well done inside. But there is so much crowd and load on them that one prefers of getting done from outside than waiting and also loosing that particular doctor's turn, for which one may have to wait a few days or even a week. In that case you need to reschedule your activity accordingly. He later in the discussion wherein his wife and son join him candidly

accepts that there was some lapse in his daughter's treatment. "*You can say that about 20-30% less of what the treatment should have been in her case.*" But maintains that the doctors at the TB hospital spared no efforts to find out his child's disease, even though all the investigation were done from the hospital without benefiting any doctor as is the case in private practitioners. He also praises the doctors of the hospital on account of their behaviour to be gentle, not only of few, but even the trainee doctors. "*It is the culture of that place because of few good doctors. I cannot say what will happen when they retire or leave the place. But there is some sense of duty in them compared to other places.*" Why didn't he ask for more information regarding his daughter's illness if he wanted to? "*We don't ask. There is no scope of questioning. It is their discretion, their domain. If we ask question they may think that we don't trust them enough which may affect treatment. You see it not for no reason that doctor is attributed as God. Upper class educated people can ask them, they won't mind. But in our case, they feel irritated.*"

Life has changed

Young and vibrant Hemlata chose not to share the nature of her illness with her friends because of the strict instruction from her father. Bhagwatilal insists that the decision of not sending her back to school in times when her condition improved was to save other children and people at school from spreading the infection, but it clearly appears that the measure was taken to contain spreading of the news of her disease. "*They would not have even water from our house. They are ignorant people. They don't know that now there are better modern facilities available for treatment of this disease. They still remember the old times where they saw people having medicines for the rest of their lives and several others who would still die inspite of everything.*" Disclosure regarding tuberculosis would not only create a stigma against the family, but may also malign the reputation of girl for whom groom searching can add to the hardship when the time comes in just a few years, explains her father.

For Bhagwatilal and for the rest of the family it has been unprecedented hardships in terms of loss of income. Since Bhagwatilal was occupied for nearly two years for varying periods in looking after her daughter, running around for treatment and hospitalisation, his business suffered as his reputation for delivering finished product on time among buyers fell. He is still coping with the losses in business. He had to borrow from acquaintances and take a loan from a bank to make his business move and to maintain an earning for the family and for meeting the extra expenditures necessary for Hemlata's after care and recovery. Today a sizeable portion of household income goes towards repayment of loans.

Hemlata's mother still spends most of her time indoors in household chores, looking after her daughter and sometimes escorting her to the dispensary for tests. She prays to all her revered God for her daughter's life and speedy recovery. In doing this she gained strength for dealing with the situation as she cannot reason out the 'why' and 'how' like 'Hemlata's father, *"because of my ill literacy"* she says. She restricts her interactions with acquaintances and relatives that were prominent activities in her schedule, otherwise it would lead to 'unnecessary' question by visitors and relatives and could reveal what they want to 'conceal'.

Hemlata restricts her activities within the four walls of her house. Her uncle, who had sought initial medical help for her, also doesn't know that she is suffering from tuberculosis, for obvious reasons.

On the day of this interview, she took the last dose of her second round of treatment. But there is no sense of joy or relief for her, as the last tablet last time may not be the 'last one'. Tuberculosis came back, for reasons she fails to understand, and the fear that it still may, remains very real with Hemlata.

Nandram Gameti

Nandram Gameti is aware of his illness, but not with its name as no one ever told him that he is suffering from tuberculosis. He lives in an erstwhile peripheral

village in Udaipur that has become a part of the expanding city, but the ways of lives have changed little for this tribal family. Nandram has two daughters and a son. All of them are married and are moving on with their lives. He lives with his wife, Ramli separated from their children as the Gameti families usually separate the married son to start and raise his family on his own. Nandram and his wife are non-literate. His grandchildren are the first generation school goers. Nandram's house is owned by him and after him by his son. The house is airy and has three rooms for living divided by a courtyard in the middle and is located a stones throw away from the village PHC overlooking the Fatehsagar lake. Nandram works as a gardener at the Udaipur town hall and gets Rs. 5,000 as monthly compensation. Ramli suffers from arthritis which limits her movements and she doesn't go out for work. Their son works as a carpenter and daughters as factory workers, but this have no impact on his and his wife's financial being.

First Episode

In mid 2003, Nandram developed persistent coughing and was gradually weakened. "*I couldn't lift this stone*", he describes pointing to a pebble. It increasingly began difficult reaching home after work since his house is over a hillock to where he has to either cycle or walk. There is no other transport within 2 kms of his home. Soon he started having fevers and shivering that would not go with ginger tea and his herbal trials, which he knew were usually effective in minor coughs and cold. Running to the doctor is usually avoided by him and his likes as it means undue high expenditure and inconvenience. In about two week's time, night sweats and coughing left him with no strength to attend to his work. His wife, Ramli started getting worried and decided to seek help. She found out from acquaintances that a known chest specialist[86] who is also in-charge of the hospital in Badi[87] is good in treating and providing relief from such condition. Although the hospital is far away (12 kms.), the

[86] Referred in other interviews in similar manner.

[87] A Tuberculosis hospital set up as a sanatorium during NTP which is in a peripheral area, lying about 10 km. away from the main city.

doctor sees patients on a private basis in the evenings at his residence that is about 2-3 km. from their house, a distance that they could comfortably walk.

Medical help

Ramli took Nandram to the chest specialist who asked them about the problem in a soft manner, examined him and asked them to come to Badi hospital next morning. Nandram's daughter lives near the hospital, therefore undertaking the journey became a little simpler. At the Badi hospital, Nandram's chest x-ray and sputum sample were taken without any fees. He was given some medicine for fever and a few injections and was admitted in the hospital ward for two days under observation. After being discharged, he stayed for two days at his daughter's place and visited the hospital again as they were advised to come for some more tests and reports. Neither Nandram nor his wife knows anything about these tests. They were told that he was sick, but would get well with medicines only if he would not default in taking them. Default would mean that he was risking his life, and in that case, neither the doctors nor even his God would be of any use. But for Nandram, the only concern was relief from his current condition.

DOTS

Nandram or Ramli do not remember the exact number of days between the diagnosis of Nandram's condition and initiation of treatment from the PHC, but it was within a week. They were asked about their address which was not verified in their knowledge, "*the dispensary is so near by that everyone knows that we live here*", says Nandram. They don't know if there was any 'contact person' to see that Nandram adheres to the treatment. "*Doctor saheb called me at the dispensary and said that I have to be responsible for these medicines. These were very expensive and if I fail to take them as advised, the free treatment from the government would stop and then I would have to get it from outside. We are poor people, how could we afford these medicines from our pockets. Saheb also told me that no small children should go near me and my utensils for eating and blankets etc. should be kept separate so that the*

illness could not spread to others", Nandram recalls the doctor's advise. He took the medicine at the PHC for the entire six months by going there every alternate day for the entire period. He didn't get a week's supply even during CP as he was scared if he lost track of his medicines, and might result in default, thus waste of the entire treatment. The threat of getting an expensive treatment was enough for him to undertake the small inconvenience of going to the PHC every alternate day. He underwent sputum test twice during the treatment after the initial (pre-treatment) one. No test was done when his medicines were stopped after six months. Soon he got absolutely fine and was back to normal life.

Illness and medicines again

During the rains of 2004, Nandram got soaked one day and fell ill. Along with fever and night sweats, he started coughing. His condition deteriorated rapidly due to weakness and within a few days he was unable to get up form the bed. "*It was strange to see him go down so fast. I knew only the doctors at Badi could help,*" says Ramli, who acting upon the previous experience took Nandram to Badi hospital again. There his condition was diagnosed and he was told that his previous illness had come back. He was asked whether he took the medicines regularly. He produced his diary that he would always take along with him for taking medicines at the PHC. The doctor found that he had received the treatment and the follow up tests were done duly, except for the last one (post treatment) that would have decided for his cure or further need of treatment. However, unaware of any such possibility, Nandram was put on treatment for relapsed tuberculosis in early September 2004. At this time of this interview, he has got two follow up sputum tests done this time as well.

DTC

It was a repeat of the first situation, with a difference that this time he had to go to the DTC, 5 kms. away from his house, before he received any medicine. For his follow up tests he had gone to the DTC earlier as well. "*The doctors anywhere didn't tell us what has happened. It is you for the first time that we have come to know the*

name of the disease", says Ramli to the researcher. In reasoning this out she further adds, "*Perhaps they don't tell us because we may get terrified needlessly. We are illiterate people, how could we know how serious or not an illness is, the educated people can understand it better. But after each test they did say that he was getting better, which was quite evident otherwise also.*" But nonetheless, Ramli asserts that it is their right to know as to what is wrong with the patient. "*We did want to know what the problem was, but didn't have the guts to ask. Doctors don't speak much. For us it is enough if they have seen us well and give us treatment. We don't expect much but, I would have appreciated if they had told us the name of the disease. I don't know exactly how that would have helped, but at least it would give us some idea for our own sake*", says Ramli.

Nandram participated in the march organised by the DTC to mark the World Tuberculosis Day on 24th March 2005, along with some 100 other people. The importance of this day is expressed better by Ramli, "*the march was to generate awareness among people that if they have cough for more than a week, they should come to the DTC and get their tests done, they would get free medicines from the government.*" But the motivation of participation by Nandram was not the same as it was a working day for him and for the march, he had to take half day leave. He said, "*I went there because I was asked to come. My only purpose of attending it was because if I didn't go, they might get annoyed and my treatment would not be done in the same way...I got free refreshments also and it was about a 2 km walk. We had banners and posters with messages written on them",* says the non-literate who was an active participant of the day. Nandram ironically himself by now was not aware of his own 'tuberculosis'.

Grading

Nandram and Ramli grade the response on the basis of the treatment given and the doctor's behaviour that they considered to be good, especially at the Badi TB hospital. They got most of the treatment free, except for some medicines for a few

days from the market, including cough syrup and a powder (protein supplement) for mixing in milk. Ramli puts this amount to be approximately Rs. 500-600 each time adding up to a total of Rs 1000-1200, apart from transport costs and other overhead expenses. The overall grading by them is 'fair', which is the second in the scale[88].

Life with TB

Although unaware of name of the disease, Nandram or Ramli didn't have to deal with the anxiety or social stigma, but suffering due to it was no less for them. His lack of awareness is also of the government's promise of 'guarantee' of cure from tuberculosis and of what protocol needs to be followed. Not that this knowledge could be put to any use by him or Ramli for questioning or betterment in the treatment, as they understand the rules of social hierarchy and their vulnerability vis-à-vis the doctor as well, and therefore would not undertake the slightest risk to evoke any annoyance to the service providers. This is clearly reflected in his participation in TB march on the World TB day.

The treatments for tuberculosis is free, but Nandram had to take long leaves of which one third were unpaid. He couldn't carry out his daily life with the same stamina and this put load on his ailing wife for his care. His dietary requirements suggested by doctors made Ramli spend more on meat and other nutritious and expensive food. However, this is not claimed to be very burdensome by them as they are fortunate than many other patients of the same social group with not so stable employment, as they are still able to fend for themselves and the salary suffices for their decent living.

Nazneen

Fourteen year old Nazneen is a quiet and composed child for her age. Nazneen has three sisters of which one is elder to her and two younger brothers. They all stay together in a small two-room house in the congested by-lanes of a crowded part of the

[88] Scale is excellent, good ok, poor/bad and very poor/very bad.

old city near the city palace of Udaipur, called Bichughati. She belongs to the Muslim community '*Mir*' that was traditionally engaged in silver craft. Nazneen's father, Aziz Mohammad is an auto driver and her mother, Farida works as domestic help since two years coinciding with Nazneen's illness, to meet the burden of her treatment. Their combined monthly household income is roughly Rs. 4,500-5,000, out of which Rs. 1,000 is contributed by Farida, which also equals the monthly rent for their accommodation.

Nazneen's father, Aziz Mohammad, is a religious man who attends at least three *namaz* (prayers) out of five of the day and has to run a large family with the meagre earnings. He understands the value of education, also for his daughters, and sends all his children to school except for his eldest daughter, Nazia. She gave up schooling after 7th standard despite lot of persuasion from her mother who alike their father is unschooled, but understands the difference education could do to everyday life. But it is a blessing in disguise, as Nazia now stays at home to look after her siblings and shares the household chores, which allows Farida to go for her work without worrying much about the home front. Nazneen and her younger sister attend a government run school only for girls. She is a bright student of her class but has been very irregular at school for the past two years. She has finished taking her annual exams for 8th standard, which she could have finished last year only if she was not ill.

First episode

In late 2003, Nazneen got a cold with fever. The home remedies could not provide much relief to her; rather her fever and coughing increased, and she soon started loosing weight. Over a month and half had passed when her parents decided to seek medical help. They took Nazneen to the district general hospital, where they usually go, especially in the case of their children, when home remedies don't help. This hospital is about 3 km from their residence, but it is the steep slope to their house that makes walking back to home an arduous task, especially for a sick person. That is why Farida could not take Nazneen to the hospital all by herself. Aziz Mohammad

had to accompany her, which meant loosing out on half a day's earning as the hospital OPD timings coincide with the time when he gets most of the passengers commuting to their offices or workplace. "*I had to see my child suffer. I knew she needed medical help, but a hospital visit is not easy for us*", says Nazneen's mother. The doctors at the general hospital treated Nazneen for the next two months. They conducted scores of diagnostic tests of blood, urine and x-ray but failed to find the cause for her illness. The anguished parents started feeling something very wrong with their daughter. An arduous way to Nazneen's treatment did await them. *'They said it was weakness and nothing else, and suggested to feed her well"*, as Aziz recollects doctor's explanation. Farida remembers a young doctor sarcastically advising her to take care of her children as her responsibility and not just giving birth to them. "*He thought as we have many children, we don't care for them. If that was the case, why would we do rounds at the hospital*", she says sadly. The tonics and cough syrup prescribed by the doctor at the general hospital would not provide much relief to Nazneen. Her father started getting worried and thought of taking her to a private doctor, although was not sure as to which doctor to visit. It was then, by pure coincidence that he was advised by a lower staff in the hospital to go to the DTC, which is located inside the hospital premises, for seeking an opinion before going anywhere else.

Treatment at the DTC

Nazneen's journey from the hospital to the DTC was not a smooth one, as she was not officially referred. Aziz had heard stories from his other driver friends that the doctors at the DTC were so snooty that they would reject patients coming even from the Badi TB hospital. Anticipating this, Nazneen's parents worked out an alternative. Farida, who had started working as a domestic help to meet Nazneen's medical bills, pleaded her employers to help for her daughter's treatment. Farida knew that her employers were respectable members of the society and their reference could be helpful. However, she did not know that her employer himself was a retired doctor. He willingly offered to examine Nazneen and advised for a chest x-ray. On examining

the x-ray he suspected a possibility of tuberculosis and suggested Farida to take her daughter to the DTC. Back to square one, Farida requested her employer to give a recommendation for her daughter's treatment at the DTC. The employer obliged her request by writing a letter to a senior Medical Officer at the DTC requesting to test Nazneen for sputum to detect tuberculosis as he understood from her symptoms and x-ray. In the letter he specifically mentioned to be kind and get her free treatment as she was poor. Armed with this letter Aziz felt confident that he could have a smooth treatment for his daughter.

At the DTC, Nazneen was tested for sputum which revealed that she had tuberculosis. It was a blow to her parents to know that their daughter was suffering from the dreaded disease. "*My heart sank hearing that my child was suffering with this kind of a disease. My head spun as to why a thing like this happened. I couldn't make any sense of happenings around me. What if my other children were also suffering and I had no idea of it*", recollects the mother of her initial feelings.

Nazneen was put on DOTS for the next six months without any address verification or identification of any contact person. She took 7 tablets in IP for two months and 5 during CP for 4 months every alternate day. She did have side effects of uneasiness and nausea, but it was not told to her before hand. She didn't have the courage to reveal to the DOTS provider about this. The nurse (also the DOTS provider), upon a meek inquiry by her mother replied that since she was weak and had to take all the tablets in one go, she felt so. "*When she would go to take her medicines, they would ask if she had her breakfast, so we assumed that the medicine should be taken on full stomach. I don't think it was ever explicitly told to us about empty or full stomach*", says Nazneen's father about the method of taking medication.

After two months again she underwent x-ray to know the improvement due to treatment.[89] Her parents were again unaware of the use of the x-ray, but got it done dutifully, similarly as they had the previous one. Her follow up tests were conducted duly and her weight increased from 30 kg to 32 kg[90] by the end of treatment, however she remembers only one instance, in the beginning of the treatment, when her weight was taken. During the course of treatment, Nazneen was prescribed cough syrup, vitamin tablets and several tins of protein supplements to be given with milk. Aziz had to buy these from the chemist shop. "*Doctors said she was very weak, so to improve her condition I took all these things or the treatment wouldn't have been effective, I felt*", says Aziz sombrely.

Nazneen got well with the treatment and her card says she was cured of the disease on 14th July 2004. The DOTS was free of cost, but for her family the direct cost came to be over Rs. 3,500. "*I have not kept an account of it, but the approximate amount that we spent was around Rs. 3,500 – 4,000 during the entire process. The expenses were mainly on the x-ray, cough syrup, vitamin tablets and the protein supplement. This did not include the transport as I took her myself. In addition to these, I lost some earning as well. But it did not matter much to me because my child was getting well. It was grace of Allah to grant our child back to us*", says Aziz in gratitude. No one remembers of the sputum test at the end of treatment as per the RNTCP requirements, neither do the records (patient diary) show this.

---

[89] From the market in spite of one, having a recent x-ray due to the advice of the doctors in her past two month's treatment, and two, in spite of a mini x-ray machine available and working at the DTC. Possibly because this is the only point in diagnosis where the doctors can send them to their specified private radiologist lined up outside the DTC. This is observed in almost all the cases coming to the DTC, apart form direct observation done by the researcher over two weeks at the DTC and patient interactions. Ironically his is also in spite of the request for 'kindness' and 'free treatment' by Farida's employer who must've indicated for being kind for these kind of untoward practices and not to squeeze the family into such undue expenses, as in the letter the employer specifically requests for treatment under RNTCP which he would also be knowing is 'free'.

[90] The average weight for an Indian girl of her age is around 46 kg.

Tuberculosis again

Unfortunately, Allah's blessing for Nazneen was short lived. Nazneen's coughing and fever came back in late September 2004. Her parents thought it to be the effect of changing weather, and it didn't occur to them that the disease could be reappearing. When even after two weeks her fever and shivering would not go and she started loosing weight rapidly, her parents thought of seeking medical help again. "*She is a very timid child and would not complain about her discomfort unless it becomes unbearable for her. In spite of being weak, she endured a lot; probably she felt it would bother us. Our anxiousness for her grew. We couldn't wait anymore, knowing that seeking help would be another gruelling exercise but it was time we acted soon*", explains Farida. Aziz took her to the DTC, the place where she got treatment last time. The doctor there immediately prescribed an x-ray for her from the private radiologist outside the DTC. Aziz was reluctant as it would be expensive. "*I knew they have all the facilities in-house and the treatment is available free to patients. I had read it on the posters put on the DTC walls and my friends had also told me. Last time I realised this after the tests were already done. I was a little meek also because we were very worried about Nazneen's condition. The doctors can make you run for anything because they know that nothing more than the patient's wellbeing is important to the family members. So no matters how poor one is, one would beg or borrow for the treatment, the doctors would fill their pockets at just about anyone's expense. It is ironical and shameful that we consider them the chosen ones of Allah, and they become shaitan (*devil*) for their petty interest playing with people's lives and their vulnerability. I could not even curse them, as it would be wrong in the eyes of the almighty, because ultimately they are the ones who would treat my daughter for her disease. But this time I mustered courage, as I was sure that time I was right*", he says in a tone mixed with frustration, helplessness and confidence at the same time. The doctor told him that since the DTC's x-ray machine was small, it would not give clear picture. Aziz requested the doctor for doing sputum test, as he remembered it was the sputum test that had led to conclusion last time. 'I

told the doctor that this is your own blessings that you have such equipments' laughs Aziz upon these words which he told bluntly to the doctor, who also had a laugh on this unexpected confrontation wrapped in subtle humour. Aziz candidly describes that the doctors invariably send all the patients to the designated private radiologist, unless they were special due to some 'approach'. "*I have taken passengers who come to the DTC to these assigned shops*", he supports his remark.

The entire process was a repeat of the first one for Nazneen. The sputum test proved that Nazneen had severe tuberculosis. She was put on treatment for relapsed tuberculosis on 15th October 2004, after three days of the test result as per the records. This time she had to take injections as well, which Nazneen remembers roughly continued for about a month and a half. By the time of the interview, she had completed six months of her treatment and appeared to be a normal, although weak, for a girl of her age.

Why relapse?

Nazneen relapsed into the disease in spite of abiding by all the RNTCP treatment requirements. According to her father the guarantee of cure from the disease if treatment is completed properly and sincerely, as claimed in the posters and professed by the doctors had failed in her case. "*I did ask the doctor the reason for her illness again, but he had no answer. The doctor asked Farida whether Nazneen missed any dose. There is no chance this could have happened. We were very cautious about it. We believed that with the treatment our daughter would recover completely from the disease and any laxity would make her revert into the same suffering. How could we be careless? It was more of our concern that she got well than the doctors who kept insisting on taking the medicines regularly*", says Aziz of his interaction with the doctor at the DTC upon her relapse of the disease. However, he did not contest the doctor's verdict any further, as he feared it could affect the nature of her care if the doctors got annoyed – a risk he simply could not afford, especially realising from the previous experience that it might not be the last time for her treatment. But

his distress remained and he started doubting the judgement of the doctor attending Nazneen. He sought solution to his distress by consulting the 'x-ray shops' and the chemists lining up outside the DTC, whether taking his daughter to the known chest specialist[91] at the Badi TB hospital be a good idea? "*I knew he is a good doctor. I get many passengers in the evenings that go to him for private consultation at his house. But they suggested not doing so, since eventually he would send us back to the DTC only, because this was the nearest point of taking treatment. Moreover, if the diagnosis confirmed tuberculosis, this would surely happen. I was also cautioned that if I did so at that point, the doctors at the DTC might get annoyed and start mistreating us. I thought why to elongate the process and delay the treatment?*" Aziz speaks about his dilemma. He resolved it himself by taking the middle path. Since he doubted the diagnosis and not the treatment, he took Nazneen to the chest specialist at his residence where he runs a private practice in the evening. Aziz confesses, "*I thought if I pay the fee he would check her more sincerely. I missed taking this step in the earlier episode and the relapse occurred, so probably going to the doctor and then too on a private basis was the answer. My sole concern at that point was that my daughter should be treated accurately this time and I should do everything possible as a father for her so that my child need not suffer again due to any lapse on my part. I couldn't take a deliberate risk this time.*"

DOTS

"*Confirming to DOTS has not been easy*", admits Aziz. Although he denies not adhering to DOTS, he collects the doses for his daughter from the DTC. The DOTS provider also admitted this. Nazneen's family had changed the residence even prior to initiation of her treatment. The DOTS provider however didn't take notice of this and in her usual way of functioning, entered the previous address assuming that it would be the same for the relapse patient. However, when the researcher failed to trace Nazneen for the interview at the address on record, the nurse, almost

[91] Referred in other interviews in the same manner.

miraculously, found the new address and provided it to the researcher. Aziz or anyone in his family doesn't remember telling anyone at the DTC of the new address. The answer lies somewhere in the lower level DTC staff that was pulled into action by the DOTS provider perceiving some kind of threat from this entire episode of jumbling up of a non negotiable requirement of DOTS, besides providing medicine to the family member and not to the patient directly. "*Nazneen has her exams that is why so*", is the ditto reply from both the father at his residence and the nurse at the DTC, to explain the temporariness of this arrangement to forgo direct observation and excuse Nazneen from coming to the DTC.

Life with tuberculosis

The treatment for Nazneen was also a painful process. She had to go to the DTC for taking her medicine, when she was miserably down with the disease, until her father worked out an arrangement with the DOTS provider for collecting medicines for her at the convenience of her home. In the second episode, she had to take painful injections. "*She would often cry with pain. The nurse said since she was underweight it was painful for her*", recalls her mother.

Nazneen realises that she is suffering from a formidable disease, not only from her own experience, but also from the anxiety in her parents and fear she has seen in the eyes of her extended family members. Nazneen while playing with her cousins felt the stigma relating to her condition; "*since my paternal uncle and his family stay down stairs, he and my cousins know about my illness*", she says. They also know because Aziz had to borrow from his brother to meet the expenses of the treatment and the loss of income on account of time spent for her treatment requirements.

Nazneen had to forgo 8-9 months of schooling during the entire length of these illnesses and also had to repeat eighth standard. But she braved her debility and tried to attend her school as much as possible. This has been supported by her father's efforts to facilitate her schooling, especially when she started getting better with

medicines. Aziz requested a letter from Nazneen's doctor describing her illness and pleading for her continuing in school which was honoured by Nazneen's school. "*I was made to sit at a distance from other students in the same class for some time when I was quite still ill after starting my treatment, both the times, so that others would not get infected from me*", says Nazneen very objectively. Her friends also did keep a distance from her, but she understands the reason. "*I knew they were afraid, but it was for a very short time. When they saw me getting well, they started being friendly with me*", says Nazneen assimilating this discrimination as a part of the disease itself.

The doctors had advised Farida to keep her bedding and utensils separate, but didn't give any timeline for it. "*Neither did I ask, nor they told us till when to do so*", says Nazneen's mother. Her father eats with her and sleeps next to her to give her company and moral support in inevitable discrimination from the rest of the family. "*She has to endure not only the pain but these kinds of things also. My heart sinks for this young soul, so I've made it a point to have my meals with her even if it means rescheduling my timings for auto driving. I want her to recover form all aspects of the illness completely*", supports Aziz who is also hit by the rising fuel prices that have further shrunk his income. Nazneen was not advised for any dietary precaution during the treatment. Her diet is supplemented with milk and eggs which was started by her parents without any doctoral advice. She, however, is uncomfortable with the fact that her other siblings are devoid of the milk and eggs. She understands that her special diet is being afforded to help her conquer her weakness.

Grading the treatment

Nazneen's parents list down their expectations while visiting a doctor that the diagnosis should be correct and treatment should be effective to make the patient better form his/ her suffering. They deem good behaviour is an intrinsic part of the entire process. They believe that speaking nicely and telling the patient about the disease and the reason of its occurrence helps the patient fighting the illness.

"*Somehow it works better that way*", says Aziz not knowing how it happens so. It takes about 20-30 minutes to meet the doctor if one has to consult the doctor, informs Aziz, but taking medicine by the DOTS provider is not so long. "*She gives me these tablets in 10 minutes*", says Nazneen. The doctor gives about 5 minutes to each patient.

Aziz grades the treatment of his daughter between 'poor' to 'fair'. The reason of this he sights is evident in his frustration of undergoing the same ordeal again. "*She had to undergo the treatment twice. There was no explanation given to us as to why the disease reoccurred. There must have been some lapse in the earlier treatment, had it been done properly the disease should not have come back, as per the claims of the programme itself. I feel treatment for a patient should be stopped only when the patient has recovered fully and not before that. In her case it had to be repeated, and I don't know whom to blame for this*", says Aziz airing his disappointment and doubt over the treatment as the reasons of relapse that were deliberately concealed from him. *"There should not be a third time"*, he says with finality.

Ida Bano

Ida Bano is not sure of her age, as many other non-literate women belonging to her generation, but she tries to estimate it from the age of her eldest child and concludes her age as 55 years. She has two sons and three daughters. All of them are married and have their own children. She lived at Gogunda, a block of Udaipur district about 30 kms from the city. She has come to Udaipur city to stay with her eldest son Asif, for her treatment. Her husband has a stomach ailment for a few years, and had stopped working. He has resumed work to meet the extra burden of Ida Bano's illness. He now works as a school bus driver and earns Rs 2,000 as monthly salary. Ida Bano now lives with her son and his family in a small two-room house, leased for a sum of Rs. 40,000 for 7 years, in a congested area of the walled city of Udaipur adjoining the city palace. The house has a small toilet blinded off by a small curtain instead of a door. Ida's son, Asif is a driver and earns Rs. 2,000 per month,

much less than enough to make the two ends meet in the city and frequently borrows for consumption and health expenses. His mother's illness has pushed him further into debt. Asif's wife, Sakeena manages the household chores and shoulders the entire family responsibility except for earning bread. Asif has attended Madrasa[92] for a few years for his education, while Sakeena is barely literate through little education provided at her home.

First episode

In 2003, Ida Bano had barely managed to console herself after the sudden demise of her son-in-law five years ago and was depressed over the future of her daughter and her children when tragedy struck again. Her younger son-in-law also met the same fate. Devastated by a series of tragedies in her life and too fragile to pick up the strings of life together she fell ill, describes Sakeena the beginning of her mother-in-law's sickness. Today Ida Bano lies on the floor on a thin soiled mattress close to the door that opens into the small house, with coughing and sighing in between the only signs of life in her. She is too frail to see even the relatives and acquaintances that come to pay social visits and enquire about her health. Sakeena's burden of responsibility of taking care of Ida is evident from her this very state.

Ida Bano got ill with tuberculosis towards the end of 2003, when she was still living at Gogunda. Incessant coughing, night sweats and later fever that left her frail and her weight dropped rapidly. A few months later, her younger son took her to the city and put her under the care of his brother for treatment. Since Asif has a busy life due to his occupation, the responsibility of Ida Bano's treatment fell on Sakeena. She took her mother-in-law to a private practitioner among the scores of that are lined up in the nearby market in the old city. Most of them do not have any legitimate basis for practice, except for the faith of their clients who for convenience and more importantly low treatment cost, keep on returning to them. *"I tried many treatments*

[92] A school attached to a mosque and run by its clergy.

by these hakims, but they would not work for long. It would relieve her temporarily of coughing which would resume after a few days", says Sakeena. She would spend Rs. 50-60 upon every visit and did about 5-6 such rounds. Around the same time, Ida Bano had severe pain in her stomach and was hospitalised at the district general hospital. She was operated there for gall bladder stones. During the investigations done there, the doctor suspected her to be suffering from tuberculosis and referred her to the DTC. It was April 2004 by now.

Treatment

At the DTC sputum testing was done to confirm the referring doctor's suspicion of tuberculosis, which came to be true and Ida Bano was put on treatment for tuberculosis. The doctors assured Sakeena that her mother-in-law would become absolutely fine with the treatment, but only if she complies by their mode of treatment. She was needed to come to the DTC for DOTS without a single fail, or else the entire effort would go waste. The doctor suggested her to think over this arduous exercise before embarking on the treatment. Sakeena did not ask if any alternative existed, which could probably have been putting Ida Bano on the conventional treatment regimen. But Sakeena anyway, agreed full heartedly to undertake the painstaking effort of getting DOTS treatment for Ida with the promise of never defaulting to treatment.

Ida Bano was put on treatment after a home visit for address verification by the staff nurse who is also the DOTS provider. Her health improved with the treatment and after the six months' course and sputum tests, she was declared cured. The medicines had severe side effects on her. The doctor didn't check Ida Bano's past records like the recent surgery, neither asked about the delay between the referral from the hospital and this visit to him at the DTC. Sakeena also didn't deem it important to speak a lot 'unnecessarily' to the highly esteemed and educated doctors. The side effects of medication of tuberculosis for Ida included severe discomfort, nausea and vomiting. During the treatment, her sputum test was done thrice according

to her records and twice according to Sakeena's remembrance. Her weight taken at the beginning of the treatment was 30 kg, this climbed to 32 kg and remained so till the end of her course in October 2004. She was still very weak, so the doctor prescribed some tonics, protein supplements and medicines to restore her appetite and treat her weakness.

Tuberculosis strikes back

Ida Bano's improved health even after the tuberculosis treatment could not tolerate the winters and her coughing, acute breathlessness and night sweats came back. Sakeena saw a repeat of the symptoms. After the deferring the treatment to the extent possible, she resorted back to the DTC for help. Sakeena explains this delay, "*she was ill for quite sometime, but I have so many other things to do as well. Since the climb back from the hospital (DTC) is difficult and one has to take a vehicle, both to and fro otherwise I could not handle her alone, putting her on DOTS treatment was very expensive for us. You could say that I delayed taking her to a doctor deliberately, but I knew if it was the same illness, I would have to put myself to her care again, besides the expenses. I secretly wished it was just a winter related sickness and nothing serious. But I was wrong. Since my husband is usually out of town, I have to do everything on my own. But I couldn't take her suffering any further, as she is like my mother after all, so I took her to the DTC when her condition became similar to the last time.*" Looking at Ida, the doctors said that they will give medicines for her relief till sputum test and are x-ray done and which should be done immediately, to look for relapse of her tuberculosis.

DOTS again

The tests revealed presence of tuberculosis and she was put under the Category-II patient for treatment. This time she would have to take injections along with tablets. She was put on DOTS fifteen days before the interview. Sakeena asked the doctor the reason of relapse to which she was given no answers, except for that probably Ida Bano's weakness was responsible for it. "*He said he doesn't know how,*

particularly when he claimed to have done such good treatment and he looked puzzled. They also said that they were amazed at such an instance and they actually praised my dutifulness as I had regularly taken her to the DTC and therefore they knew that she had taken all her course regularly", Sakeena recollects doctor's reply to her query. According to Sakeena, the doctor claimed it to be the first instance of its kind; the doctor said *"that anyone who takes his treatment and course doesn't ever come back."*

During the entire course of treatment Ida Bano was prescribed tonics, food supplements and 10-12 bottles cough syrups. All this cost about Rs. 1,500, tells Sakeena. She has not kept track of all the expenses on her mother in law's treatment of tuberculosis, but she estimates to approximately Rs. 6,000-7,000. This will escalate further by Rs. 300-350 if the previous expenditure of going to hakims is included. As mentioned earlier, taking Ida to the DTC has been a costly affair and each trip cost Rs. 50. Besides the money it was difficult getting autodriver to go to their house since getting a passenger from there was not assured and the steep climb would waste a lot fuel.

Life with tuberculosis patient

Ida Bano is too ill to give any account of the changes that the disease has brought into her life. So this aspect is also covered by Sakeena. It hasn't been easy for Sakeena to deal with a tuberculosis patient in a congested house. "*The doctor said that I should take good care of my mother-in-law and therefore it was important for me to be fine*" and she was advised to keep Ida's bedding and utensils separate from the others till completion of the treatment and also to keep children especially small ones away and to not talk very closely as precautions. Sakeena and her family thought that perhaps it was because of the untimely deaths in the family, apart from tensions of loans, which had given her the disease. But she was taken aback and felt defeated when her illness relapsed, "*I did everything possible to make her well, I don't know where I failed in my efforts*", she says in note of introspection.

Sakeena describes Ida as very active in earlier times when she was not ill, that Ida would perform all the functions that the elderly women of the household in the given cultural set up do, like running simple errands of looking after the children, helping out with kitchen chores, and so on. But due to her illness Ida is unable to even do her own basic activities. The burden of looking after her is singularly on Sakeena, "*everyone in the mohalla* (colony) *praises her hard work and the sincerity with which she looks after her mother in law. It is not easy to care for someone so ill for such a long time single handed, apart from looking after other things of the household by her own. I always support her in this as it is one's duty to look after and serve the elders in their need. Allah blesses such souls*", adds Sakeena's mother, who comes in at the end of the interview to visit her daughter and know about her well-being and her mother in law's health. She sums up a kind of social insurance mechanism of Indian families that has provided Ida Bano also with the much needed care for her to recover and resume her normal life.

The knowledge of her disease to others in the vicinity has not changed their attitude towards the patient or towards anyone in the family is Sakeena's claim. She says, on the contrary women from the neighbourhood frequently visit to see her and also sit by her so that she feels good. There are other cases of tuberculosis around; in fact two other women came in during the interview, which are also undergoing DOTS. This can be a probable explanation of no discriminatory behaviour among them due to stigma.

Grading the treatment

Sakeena is unaware of the provisions of free treatment under RNTCP so she is in full praise of the doctor, who in turn has left no opportunity to boast about his own generosity of providing as much possible for Ida Bano and has obliged her to no end. "*He is a very nice doctor. He gave all the medicines and tests free from the hospital itself, except for the x-ray which he said he could have tried from there but it doesn't come out clear with the machines. I had to buy the cough syrups and milk powder*

also from outside as these is not available in the hospital. He also instructed the nurse to give medicines properly. He never spoke loudly to me and always appreciated that I looked after my mother in law so well", describes Sakeena in full admiration of the doctor and in turn the treatment Ida Bano received. The doctor displayed his utter dismay at the relapse and assured Sakeena of even better treatment than the earlier one that will definitely make Ida Bano better this time. Interestingly the doctor after knowing the family turmoil placed the relapse on her 'tension'. Sakeena describes the doctor's assurance "*he said that it is only due to the tension that she has that the disease has come back. She should not do that or else will not get cured again. He asked me to keep her happy and not to worry for she will get fine*",

She rates the treatment given to Ida Bano as 'good to very good'. This is so as the doctor's in Sakeena's verdict did things 'out of their way' for her treatment. The relapse as understood by the family and conveyed by Sakeena's interview is not due to factors pertaining to the health services, but due peculiar to the life of the patient such as weakness and tension. The DTC staffs have been kind to them in giving the treatment and therefore the family deems it an obligation in their own understanding, rather than as a right to free treatment.

Sakeena however, claims no laxity in Ida Bano's treatment during the first episode. She didn't default and regularly undertook DOTS. She took Ida every alternate day even during CP for if she confused the dosage it would affect the entire treatment. Sakeena is unable to tell the dosage of CP and possibly did miss some doses as it is not known[93] for how long she gave CP tablets to her mother in law with this confusion. The diary for the current treatment is also not available with Sakeena as it is at the DTC in which next date for coming for the dose is entered in with other details like date of initiation of treatment, of sputum tests and results and weight.

[93] Because Sakeena realizes this as something wrong and doesn't admit to having continued CP in the laid down manner in which only one dose in a week is administered as DOTS.

Sakeena's only wish is that no matter what it takes in her efforts, Ida should get well and get rid of the disease as soon as possible.

Kheyalilal

Kheyalilal retired in 2003 as a Forest Guard after 35 years of service with the state Forest Department. A *Brahmin* by caste, Kheyalilal has settled down in his ancestral village Panerion ki Madari, 15 km from Udaipur city. He lives with his wife, son, daughter-in-law and a grandson. His three daughters, all married off, live with their own families in nearby villages. Kheyalilal inherited a small piece of land, which he sold over time to meet expenses of wedding of his three daughters, a heart surgery of one of the son-in-laws, purchase of camera and equipments for his son to start business as a marriage photographer and construct a modest two-story house. The ground floor has been rented out for Rs. 500 per month and the whole family lives in the three rooms on the first floor. Retired from government service, Kheyalilal gets a monthly pension of Rs. 4,000. His son, a poly-technic graduate, does not have a regular job and earns during the marriage season through lighting arrangement contracts and video photography jobs. On average, the monthly family income from all sources adds upto Rs. 7,000 – 9,000.

First signs of tuberculosis

Few months after his retirement Kheyalilal started coughing. Assuming winter to be the cause of his cough, Kheyalilal relied on home remedies and herbal tea prepared by his wife for relief. His cough would not go and at the same time he started loosing weight. His discomfort increased, but only after a couple of months of persistent coughing he thought of seeking medical help. "*One should not run to the doctor at the first instance, because they may give you a lot of medicines unnecessarily*", Kheyalilal explains. He visited a Community Health Centre (CHC), about two kilometres from his home. He was asked to get an x-ray of chest done from the private diagnosis centre outside the hospital. This cost him Rs. 120. Following the x-ray, his blood and sputum testing was done at the CHC. The doctor informed

Kheyalilal was suffering from tuberculosis. In January 2004 he was put on DOTS for tuberculosis.

DOTS

Kheyalilal's address was verified by a hospital staff and he was explained about the importance of compliance before starting the treatment. "*The doctor told if I miss even a single dose, the infection inside my chest would grow and I would not be able to recover, so under any circumstance I should not miss any dose. He also assured that if the treatment doesn't work, he would change the line of treatment*", shares Kheyalilal. For the first two months, he had to go to the CHC every alternate day to get his medicines. Later he would get his weekly supply of six medicines from the CHC. He had to take five tablets one day and one the next day, and similarly repeat the sequence throughout the week. The doctor also prescribed him protein supplements which he bought from the market. The treatment continued for 6 months with periodic sputum smear tests. Kheyalilal remembers four such tests, however his diary records only three – no test was done at the end of the treatment. Kheyalilal confirms that there was no test after stopping his medicines. By June 2004, when the six-month treatment ended, his coughing had disappeared, he had gained 4 kg bodyweight and felt healthy.

Tuberculosis is back

Kheyalilal's troubles did not end with the treatment. Three months after the completion of his tuberculosis treatment, in September 2004 he started coughing again. Since he had already completed his tuberculosis treatment sincerely, he thought the cough to be due to a common cold. But the symptoms would not go; rather they grew more troublesome than the previous experience. His son describes that he would often get breathless even while climbing down the stairs and would cough incessantly during the nights. Kheyalilal's wife adds, "*He concealed his real sufferings from us feeling that we would start worrying. He kept his discomfort to himself and only after it became unbearable he asked Dinesh to accompany him to the hospital. He didn't*

want to disturb Dinesh as it was the season for his business due to various functions and marriages coming up." After enduring for a month, he went back to the doctor at the CHC to seek help.

DOTS and DTC

The same procedures and diagnostic tests as the previous time were repeated again at the CHC and the doctor revealed that his tuberculosis had come back. He would have to undergo treatment again - a longer one this time which would include injections as well. Even after a month of the treatment, his discomfort remained and his condition was not improving. He informed the doctor about his sufferings. The doctor did not pay any attention to it and told him that the disease would take its own time to go. Unsatisfied with the doctor's response, Kheyalilal decided to seek another opinion. One acquaintance advised Kheyalilal's son that his father would get better treatment at the DTC. In December, his son took him to the DTC about 14 kms. away from his home. Kheyalilal showed his test and treatment details to the doctor at the DTC. The prescription he got at the DTC comprised of two bottles of cough syrup, two tins of protein supplement to be taken with milk and vitamin tablets. He needed to buy all these from the market lacing the DTC since the hospital did not supply them. *"The doctor also asked to show him the supplies after having purchased"*, recalls Kheyalilal's son. All these cost him Rs. 450. Kheyalilal was advised to continue his treatment at the CHC and in addition take the prescribed cough syrup and protein and vitamin supplements. He was asked to report his condition after a fortnight. He got relief from his cough from the syrups, "*one bottle would last for 3-4 days and I took about 10-12 of them*", tells Kheyalilal.

Kheyalilal never informed the doctors at the CHC about his visit to the DTC. *"Although the CHC got a new doctor as the earlier one was transferred, I did not inform him about my DTC visit. Had I informed the CHC doctor about my DTC visit, it might irritate him as I did not abide by his advice. But I continued both the treatments as the medicines prescribed at the DTC relieved me"*, reasons Kheyalilal

with amusement. Such is the fear of annoying a public doctor. Kheyalilal continued his undisclosed visit to the DTC. This time another doctor attended him, who alike the first one prescribed him vitamins, protein supplements and cough syrups, with the difference that this time he got a week's supply of vitamin tablets from the DTC. The rest costing Rs. 350, he purchased from a medicine shop outside the DTC.

Why relapse?

Did Kheyalilal ever tried to know the reason for relapse of his disease? Perturbed by the repeated sickness, he did ask the doctor why his disease returned. *"Discontinuation of treatment after six months caused the relapse*[94]*. It should have continued for nine months. This time it will be for nine complete months"*, the doctor explained to him. "*My medicines were stopped after six months by the compounder (DOTS provider) when it should have lasted for more. The compunder told me that my treatment was complete and I need not take any more medicine", Kheyalilal* blames the compounder.[95] He feels that although the paper of completion of his treatment was signed by the doctor, it was the compounder's judgement endorsed by the doctor in a routine manner. *"This is how any public officer functions"*, adds Kheyalilal. Interestingly, Kheyalilal doesn't sound bitter for the doctor for stopping his treatment that led to relapse of the disease and suffering that could be avoided. He didn't question the compounder as well. "*It would not help me in anyway now that I have got the disease back. Moreover, saying anything at this point may annoy the compounder and affect my treatment adversely. But I will definitely keep a check that I complete my entire treatment and is stopped only after completion*", he reasons out his silence.

[94] It should be noted that in the first episode of treatment, Kheyalilal was a 'new sputum positive patient' put under Category-I and tested negative in the subsequent follow up sputum tests during the treatment. The RNTCP protocol prescribes for a treatment of six months for such cases.

[95] A common term for male nurse.

Treatment

Kheyalilal's has completed the two-month IP of the treatment which included 14 injections this time. He is in the fifth month of the treatment. He recalls to have undergone 3 follow up sputum tests after the pre-treatment test, but his records show the first one (pre treatment) only[96]. The objective of DOTS according to Kheyalilal is to ensure that people take the medicines. *"Left to themselves, patients may throw away the tablets after sometimes"*, exclaims Kheyalilal. A good natured nurse administers DOTS to him. *"I have seen doctors shout at patients who pester them with questions or do something which irritates them. But the sister giving me medicine is very calm or else it is so difficult to give medicines to so ill patients"*, appreciated Kheyalilal. He doesn't mention any side effect of the medicines, except that it would spoil his taste and due to which his appetite decreased. He did share this with the DOTS provider and was advised not to worry about it.

Grading the treatment

Kheyalilal, like others seeking public health services, never expected wonders from the hospitals. He feels that the treatment at the CHC did not care for his disease properly. He was not fully cured the first time and the disease relapsed soon. He is also dissatisfied with the second round of treatment as it is not mitigating his sufferings. Still, Kheyalilal considers the services to be 'fair' when he compares his own sufferings with the sufferings of other TB patients. *"I was not as seriously ill as I have seen other patients. It was the discomfort due to coughing that upset me the most. I thought I should get treatment thoroughly or I'll become like them"*, he remarks.

The disease

Kheyalilal has never been the most social type of person. He had limited interaction with his peers and still goes out when he feels well. People around do not

[96] Kheyalilal might be mixing up the number of times he has given sputum for test with the number of total tests. Three samples of sputum are collected for one sputum test for higher reliability of the test

know about his illness as it would lead to unnecessary stigma. He explains, *"the younger generation today may be more aware and understanding, but people of my age have seen many deaths due to TB in their times. This was a rural place before the city started growing some 5-10 years back, but people's ways here are still the same. I have not revealed my disease to my set of acquaintances"*. After retirement, Kheyalilal used to go to the nearby market and spend some time with others of his age group. The illness has debilitated him in carrying out his daily routine and has contained him within the four walls of his house. *"It may not make sense to you today, as you're young, One should always be independent. The day one becomes dependent on others especially one's off springs, his dignity also goes away soon. I only wish to get well soon, and not to fall ill with this disease again. The body will wither one day but not like this"*, remarks a withered and frustrated Kheyalilal.

Manju

The congested by lanes in the backyard of a bustling old market of Surajpole in Udaipur lead a dingy building with an open space in front of it, which can be better described as a *chawl*[97]. Manju's family lives in one of the rooms in the building, not bigger than 10 feet by 10 feet. The room has no windows and is always dark. Manju's frail body lies on a thin bedding on the floor looking like a bundle that sighs giving proof of life. Her scalp is visible as she has almost no hair left and every bone of her body is distinctly visible. She also has blisters on the skin across her neck to the shoulder that looks like severe burns. Her son tells this patch of skin is painful for her. Manju's condition appears to be worse than the most destitute beggar one would come across on the streets. She cannot sit up or speak except for some whispers and sighs, through which she communicates with her family. However, she is alerted to someone's presence besides her family member. Her state is very unsettling at the first encounter.

[97] Referred for a crowded building where many families live and each family lives in one or maximum two rooms. All the families share a common set(s) of toilets and bathrooms. Kitchens are also cordoned off in the same single room.

Manju has two sons, Madhav and Suresh aged 14 and 16 and a daughter, Sanjana who is about 18-19 years old, married and has an 8 month old son. Manju's husband, Shankar puts up a peanut stall for a living, in front of a busy street about 2 kms away from his home. He is a matriculate, but his sons have dropped out from schooling after 8th standard to help supplement the household income by doing odd jobs of a helper at store or tea stall. Sanjana is a primary school drop out and stays nearby with her husband and in-laws. Her husband works as a *kabadiwallah*[98]. However, most of her time is spent at her parent's home looking after her mother when all the other members are away at work. When Sanjana also has something to attend at her home, like guests, then Manju is left all by her own.

The total monthly income of the family varies between Rs. 2,000-3,000, depending upon the availability of work for each of the bread winner. Out of this Rs. 750 is given towards rent for the house and another Rs. 50-200 are spent towards rent to police constables that according to Shankar are necessary *"to maintain harmony"* with them so that he is allowed to put up his stall. This amount varies according to their *"kindness"*, says, Shankar.

First episode

Manju does not remember when exactly she started coughing, but it was sometime in early 1991 when she began feeling weak and doing the household chores became challenging for her. One day after meal, she vomited with significant amount of blood. This was the not the first instance, her cough had traces of blood which Shankar came to know later, because Manju thought it was some blister inside her throat that had ruptured. Shankar, alarmed by the sight, took her to Badi hospital for Tuberculosis which is 15 kms away from his home. *"People around told me such illness are treated there* (Badi hospital) *only and the treatment is good"*, Shankar explains the decision. There, she was immediately hospitalised for 15 days and her 9

[98] A term used for people engaged in collecting and even purchasing trash from homes and selling it for further use like collecting old newspapers used for making paper bags purchased by shopkeepers.

months long treatment began. Shankar was told that his wife had tuberculosis. The patient was called in every Friday during the entire course for which Shankar took her regularly. With treatment she got well and resumed her life as usual.

Ill again

In March 2004, Manju started coughing and she would get fever by every evening. Gradually she grew very weak. Shankar took her to district general hospital where she was again admitted immediately for a week[99]. At the hospital three bottles of blood were administered to Manju and a series of tests were done. *"I got every test done as prescribed by the doctor. At the time of discharge, he said she was fine"* recollects Shankar. Manju remained fine for a few months, but sometime in late August 2004 she fell ill again and by September she was down with high fever, coughing and nausea, she could barely get up from the bed. Soon, she could not speak and would just nod her head in yes or no when asked for something. "*One day I got scared. My heart told me she would die"*, Shankar describes his panic. The very next day, he took her to the DTC because he had heard that now[100] tuberculosis patients get medicines from the (DTC). Besides it was only 2-3 kms from his place, much nearer than Badi hospital. The doctors tested Manju's sputum and determined that she is suffering from tuberculosis again.

Manju was put under Category-II for relapse patients, and her treatment under DOTS started on 25 September 2004. Just within a week of starting the treatment, the medicines gave her severe side effects and she stopped taking the medicines on 6 October 2004, and according to her treatment diary *"They* (DOTS provider) *would give her 4 tablets for a dosage. I would feed her and give her the medicines. Thereafter, I would go to my stall at around 10:00 in the morning. My children told*

[99] According to Shankar the number of days Manju's admission this time was 15 days, but her records show from 17th March to a 24th March, one week.

[100] Badi hospital specialized in chest diseases and tuberculosis patients went there for treatment.

me she would vomit everyday by 2:00 in the afternoon. This became an everyday affair", describes Shankar.

Shankar didn't seek help from the DTC when Manju started having trouble in taking her medicines. *"As such she was too weak to go to the DTC to take the medicines. I pleaded them to allow me to collect it on her behalf, with the promise that she would take the medicines without fail. The doctors would not trust me. They said that everyone promises, but then, when people fall ill again, they come back only to put the blame on them. After a lot of persuasion, they allowed me to collect Manju's dose. That way she didn't have to hurry up for taking the dose and could take it in her comfort at home. So, I didn't want to go back to them* (DTC) *because they would shout on me for discontinuing the treatment, without understanding my wife's terrible state. Moreover, if I went there I knew for sure they would make me get Rs 100-150 medicines from the market for various things like nausea, indigestion and appetite etc., blindly without wasting a minute because their commissions are fixed with these chemists and the medicine companies. They make the patient's family buy many medicines*[101] *from outside, only then they would put the patient on the government's free treatment"*, Shankar explains through his experiences and puts allegation of corrupt practices on the DTC staff. According to him, if the patient fails to purchase the medicines, it is very likely that he/ she would be denied the DOTS treatment from the DTC.

He decided to undertake the hardship of taking Manju to Badi hospital where she was treated last time. *"I took her there because when earlier she had got ill, it was the treatment from there only that she got well. Also, because treatment was free and most of the tests were done from within the hospital and most of them are also free. The doctor who heads the hospital is good and kind hearted. I knew that there, nurses and doctors would take care my wife. At the home, my children were not able*

[101] Other than those included in DOTS like cough syrups, protein supplements and so on.

to do so and I could not stop working to be with her all day for her care. Besides, now my both son's have started working", Shankar explains the motivation of pursuing treatment at the Badi hospital and not anywhere else. Manju remained hospitalised at the Badi hospital from 7 October 2004 till 18 January 2005, about three and a half months.

Ill but discharged

Manju was discharged from the hospital although she had not recovered from her sickness. Shankar's brother who worked in a stone quarry had died in an accident at the mining site. Shankar had to go to his village, 80 kms from Udaipur, to attend the last rites of his brother. There was no one else in the family who could attend to Manju's requirements at the hospital. *"My daughter went and got her discharged so that at least she could be with her mother at home. Sanjana's in-laws would not allow her to attend her mother at the far away hospital and besides, she had a very young baby then after a premature delivery. She couldn't handle everything at the same time"*, reasons Shankar for getting Manju released from the hospital. The doctor discharged Manju with medicines for one month and instructed her to continue the treatment at home. She was asked to revisit the hospital for a follow up after two weeks. *"I was given 90 injections during my stay at the hospital. They gave it daily. It was only about a week before discharge, it had stopped"*, tells Manju in feeble voice. After 15 days of taking the medicines she developed painful blisters on her neck and upper arms. *"I took her to Badi again; also it was time to get her follow up visit. They saw the blisters and said that it was not their disease because it's a skin problem and that I should see a skin doctor. I always thought that all the doctors have a basic degree in which they are taught everything and they can attend to such problems. I was quite dismayed by his reply. A doctor junior to the head at the same hospital identified the illness, but Manju was denied treatment by the head."*, Shankar says bitterly and continues, *"I thought if I go to the DTC, they would tell me to unnecessarily buy hundred things from the market."* Therefore he turned to a nearby

hospital run on charity[102]. *"The doctor there asked my occupation and said that the treatment for her skin disease was expensive"*, recollects Shankar and adds, *"I told him no matter what, I want my wife to be treated for her pain. I would beg or borrow to meet the expenditure."* Indeed it was an expensive deal. Shankar calculates the total cost for one day's medicines consisting of one capsule, 2 ointments and 2 tablets to be Rs. 118, prescribed for 10 days. The entire cost of medicines alone was over Rs. 1,100, besides Rs. 25 as doctor's fees and transportation. On the follow up visit, the doctor repeated the same capsules. The blisters became better and the pain diminished, but didn't go altogether. It is still painful but bearable with little massage over the area. Shankar assumes that these blisters (that is herpes) spread and worsened because after denial of treatment at Badi, it took him more time to seek help from some where else.

Side effects

Manju developed jaundice twice during the treatment in the second episode of illness. The chest specialist at the Badi TB hospital attending Manju during her hospitalisation told Shankar that two of the tablets included in her course of DOTS were not suitable for her because her liver was very weak. So these tablets needed to be kept out of the course of treatment. But because of the exclusion of those medicines, she would have to undergo a longer treatment, which may last for more than 2 yrs, the doctor told Shankar. *"He said that if she responds to these medicines, there is nothing to worry. But if they don't work, there is no guarantee of such patients becoming well. The patient may die any day if the medicines fail to check the disease"*, recalls Shankar the doctor's caution.

Manju's condition again deteriorated about 5 days ago (from this interview) with vomiting and acute weakness. Sanjana describes that Manju's eyes had rolled back; she had convulsions and became unconscious. Shankar then called the same

[102] This is not officially confirmed; it was set up in the British period for public welfare and is now under the local government.

doctor who treated her for herpes. He prescribed some injections for relieving her from her jaundice, which was the reason for her such condition. *'The doctor charged Rs 50 for the home visit. He wrote some medicines and injections that totalled up to Rs. 350. The doctor prescribed two injections daily for three days. But I got six injections in six days; as I couldn't afford all of them in one go or even in 3 days, I asked the compounder to give it in six days, that he said wouldn't affect the impact much. The compounder charged Rs. 15 per visit. This was much less than the amount I would spend by taking her to the dispensary"*, tells Shankar.

Why relapse?

Manju's treatment was done for nine months under the conventional regimen during her first episode of tuberculosis in 1991. Shankar was puzzled by the relapse and asked the doctor at Badi (the chest specialist) about the reason for it. He was explained by the doctor that sometimes the disease reoccurs due to many factors, such as weakness or due to default in the earlier treatment. *"It is not unfounded that the disease would not reoccur. The only measure we can take from our side as doctor and family is early and complete treatment. In a few cases, in spite of all this, the disease can still come back"*; Shankar recollects the doctor's reply to his query.

Services

Shankar reluctantly admits that the staffs at the tuberculosis hospital at Badi also expect some 'tips'. According to him, the doctors don't expect any such 'rewards', but the lower staff does. He reveals *"the staff demands it on the ground that patient has got well from a deadly disease. They claim the tip by saying that if the family could spend thousand or two thousands on treating the patient, and the patient recovers due to their efforts, the family should therefore reward them with some amount as well, as 'appreciation' of their* (staff) *work."* This 'appreciation' is actually extortion ensured by staff by not co-operating with the patient if they are not tipped. *"We cannot afford to disappoint them, as they are the ones who would help us in times of need at odd hours. Moreover, the amount asked is not much. It is only*

some tea or snacks or a ten rupee note. But if they get irritated, they would start creating problems, so it is better for us as patients to maintain harmony and make sure not to create problems. As such for the patient and the family, there are enough problems", as soon as he says this; Shankar quickly justifies it as a small amount for the 'dirty work' the staff has to do, *"they have to handle the sputum, and other dirty stuff. If one is good to them it is reciprocated in their action. If they are pleased, they could get the tests done faster, better and one could get the report without getting caught in the whirl of procedures of signing the forms, getting in the line etc..."* Shankar explains the benefits of appeasing them are saving of time and better care, *"since many a times when I was not around, I had confidence that Manju would not face any undue difficulty or harshness from the staff, since I had already obliged them."* Shankar sites another example of his efforts of pleasing the lower staff, besides tipping was by maintaining cleanliness in the ward. He would keep the space around Manju's bed clean and would ask the other patients also to do so or even shout at them if needed. Shankar describes, *"I would at times wash the ward floor myself. If I and my wife had to be there for some time, the place should be bearable. Often people don't understand the value of cleanliness. Patients might not be well enough to observe cleanliness, but their families also would not fail in adding to the filth by their own doings. If the place is not clean enough for a healthy person how would the patients get well? A healthy attendant is also likely to fall ill in that surrounding."* Shankar adopted a strategy of being good to the staff by talking to them nicely and doing small errands for them which made them co-operate with him well and he got most of the medicines etc. from the stores that is usually denied to other patients. Shankar smiles, *"After all, these staffs are also human beings and deserve respect. People like me who could not spend money could do with little humility. It does wonders. They may then even break the rules to help you out. You could think that I am a crook, but situations make people smart."*

Grading the treatment

Shankar rates Manju's treatment as 'fair'. He denies the claim of free treatment of tuberculosis by government *"Who will treat patient for a disease for free? All these are empty claims"*, he cites examples of many other medicines like cough syrups, glucose, ointments etc. that are not supplied by the government and one has to buy from the market. *"The patient is expected to go to get medicines every second day under DOTS. Has the government thought of the commutation and the cost of time that a family member will have to take out for this purpose? But I still opt for 'good', because earlier, her condition was like an injured bird that would incessantly twinge with pain. At least that has stopped for now, so I think the treatment given to her has impacted in lessening her suffering, if not completely curing her of the illness."*

What does Shankar expect from a care provider? *"Only better treatment! Today I buy only five days medicines if they prescribe for ten days, because I know rest of it is unnecessary and moreover, I don't have a pocket that big to afford such treatment, even if it is necessary"*, he says in a tone full of despair and endeavour to abide by the physician's advice as much as possible. According to Shankar, the doctors at Badi were nice to him, except for one instance when Manju was denied treatment for herpes. But his actual complain is towards the DTC doctors. *"They also speak to the patients nicely, but ask to get medicines from the market. If the patient is not intelligent enough, he/ she would be caught in the trap. When I was asked to do the same, I said hat these medicines were already at home. At another instance, I purchased the medicines and later returned them to the chemist, who in turn told me to get lost, but for that day I survived."*

Shankar's despair is evident that he wants his wife's suffering to end, but the only way out is by doctor's treatment. *"I would have given her the most expensive treatment if the doctor actually had a treatment that would make her free of tuberculosis, even if it meant selling myself in the market. If only these doctors can*

understand the patients' and their families' plight and treat them accordingly. I wonder whether some of them are actually human beings or from some other world who don't understand the value of people's health and don't feel their pain. Such doctors loom at large these days, and have brought a bad name for a noble profession whom people revered as God. I expect them not to take advantage of our situation, but feel for the patients' suffering and make it go away", Shankar describes his expectations and despair at the same time.

Living with tuberculosis

Till now Shankar has already spent about Rs.30,000 on Manju's treatment in her second episode. He doesn't remember the first episode's expenditures. To meet the expenses of Manju's treatment, Shankar has borrowed money on high interest rate of Rs. 5 per hundred per month. *"My meagre savings that we managed in earlier days by foregoing many essentials have been long exhausted. I have not been able to pay back the loan I took for my daughter's wedding and delivery, because my wife never kept well and there were always some miscellaneous expenses that became inevitable. I try to treat my wife by getting medicines on a daily basis from the market. I couldn't get the entire medicines or even for two days in one go, so I buy them just for the next day. In all this I've became a mute spectator seeing my sons quit their schooling at a tender age to work, as they realised it was getting harder for me to keep it going. I wanted them to study at least more than me, but what could I do. I couldn't afford to do even as much my illiterate father did for me. They have to suffer along with their mother, as our fortunes and misfortunes both are connected"*, Shankar says in self consolation.

The family takes turns in looking after Manju. Sanjana remains with her throughout the day, after that her brother who returns from work takes over in the evening and Sanjana leaves for her home after cooking dinner. Finally, Shankar takes over when he reaches home around 9:00 in the night.

Manju's illness has meant complete debility for herself. Earlier when Manju was in good health, she would not only do the house work, but also helped Shankar at his peanut stall, making packets and preparing them for the next day. Shankar would put sweetmeat stall on festivals and other occasions at places wherein Manju helped him out. But now she is dependent on her family members for her care and everyday living. Her daughter, Sanjana, says her life is divided in the two household, her own family at in-laws' and her parent's. At times there is tension between her husband and herself since she cannot contribute to the household chores as much at her in-laws' place like the other women in the joint family. *"I try to balance my attention but at times, things do get out of hand. I silently pray to God to take away my mother and relive her from this suffering. We can do as much as possible, but I fail to understand God's intention in making her suffer like this."* says Sanjana in desperation.

Parasram

Parasram is 45 years old according to the DTC records, but appears at least ten to fifteen years older. He belongs to the *Prajapat* (potter) community – a scheduled caste. He has seven children – five daughters and two sons. Three of his daughters are married and live with their own families. He lives with his wife, the two unmarried daughters, the sons, both of them married, daughter-in-laws and two grandchildren in a modest house with four small rooms built on a piece of inherited land in Mallatalai area of Udaipur, on the other side of Fateh Sagar lake away from the city. The locality is still underdeveloped with lower middle-class settlements. Few better houses have come up in the area built by middle class government servants who have recently bought land here as the land is still cheap. Very few houses have proper water and electricity supply. The locality also has a significant number of tuberculosis cases registered[103] with the health services.

[103] As informed to the researcher from this patient as well as neighbours who while searching for the address helped out the researcher and informed her of some other patients in the same colony getting DOTS from the near by CHC.

Parasram and his wife Kanta work as brick kiln labourers about 2 kms from their house, and their eldest son has opened a small shop in the front portion of the house. His daughter-in-laws attend to the household chores. The total family income from all sources varies between Rs. 5,000-7,000, depending on the availability of Parasram and Kanta's employment and the income from the shop. Although Parasram has attended a few years in school, he says he has forgotten to read and write. His wife is non-literate and the eldest son is 9th standard pass, but left school to run the shop as his further education, he feels, would not improve his employment opportunities.

First episode

Two years ago, in 2003 Parasram developed coughing and later accompanied with fever and sweats. He lost his appetite and within a few weeks became too weak to go for work, or even to carry on his daily routine. After about a month of this condition, he went to a private practitioner about 6 kms from his house. He had heard from others that this doctor was of repute in helping with cases like himself. The doctor asked him to get an x-ray of his chest. The doctor gave him some medicines for two weeks and asked him to revisit him after the course. This private treatment cost Parasram over Rs. 300, including x-ray, medicines and the doctor's consultation charge. But the attempt to seek help went in vain as he did not get much relief in his coughing or other symptoms. The doctor didn't tell him any reason for his condition. When he complained back to the doctor, he suggested Parasram to continue with his treatment, without telling him as till when he should expect to get relief. Unsatisfied and discouraged with this line of treatment Parasram sought help from the chest specialist heading the tuberculosis hospital at Badi, during his hours of private practice in the evening at his residence. The specialist advised him to get admitted in Badi hospital for a few days for getting the tests done. He subsequently went to Badi about 10 km from his home, where he got admission and his urine, blood, x-ray and

sputum tests were done. Of all the tests only x-ray was charged, but Parasram does not remember the amount[104]

DOTS

After examining the test results, the doctor informed him that he was severely suffering from severe tuberculosis and he should remain in the hospital for more days. Following this advice, Parasram remained hospitalised for the next two months after which he was discharged and referred to the nearest CHC to his home, also the DOTS centre, for further treatment. When he submitted the hospital discharge papers at the CHC, the DOTS provider visited his home for address verification, after which he started getting medicines immediately at the CHC under DOTS for the remaining 4-5 months treatment. In the beginning he had to go to the CHC every alternate day, situated about one and half kms from his home, to have his medicines there. Parasram explains the method of taking medicines, *"they told me to have the medicines there. In all I had to take seven tablets of which one was to be taken on empty stomach and the rest after eating. This was explained to me at Badi itself. But I used to have all the medicines there only on full stomach, because it was convenient for me that way to go there to have the medicines."* He and Kanta were explained by the DOTS provider the importance of complying with the treatment. Kanta was asked to monitor her husband's taking of medicines if had to be cured of the disease, or else the disease would come back. Kanta tells, *"the doctors said if he took the medicines regularly, without missing a single dose, he would surely get well and if not so, the disease could kill him. He shouldn't eat sour and spicy food."* After completing IP, he was put on CP after his sputum was tested for follow up. Parasram started getting a week's supply of medicine during this period. He got well with this treatment and after six months, in mid 2004 his treatment completed. He had gained weight and visibly looked healthier, says Kanta. His post treatment sputum test, however, was not done.

[104] His documents are also not maintained by the family for cross referral.

Relapse

His wife accounts that Parasram had resumed his work and started living as before. But after a few months, in late November 2004 he started feeling weak again and soon he was coughing substantive amounts of blood. He lost his appetite and weight and soon became bedridden. Kanta recollects, *"when I saw him spitting blood, I had an intuition that the very time has come to us. I took him to Badi as his condition at home didn't improve after a two-three days."* He was admitted at Badi again, where his tests were done as in the earlier case and he was diagnosed with tuberculosis relapse. He was immediately hospitalised and remained there for the next two months. This time he was given injections daily.

This time also, as in the earlier episode, he was referred to the CHC after his release from the hospital. The DOTS provider there was taken aback to see Parasram come back for treatment and told Parasram that she had never seen any patient return after duly finishing the treatment. His DOTS started again in December 2004, and by the time of this interview he had completed the IP and was put on CP. His end IP follow up sputum test has been done about which he is informed that he still has some infection left[105]. Parasram doesn't report any prominent or disturbing side effects of medicines apart from a strange taste in his mouth and little dizziness in the beginning of the treatment. Only that the colour of his urine has changed to red. The doctor told him this apparently was due to the medicines.[106]

Why relapse?

Parasram went directly to Badi upon experiencing the symptoms for the second time, as had been advised by the doctor last time. He didn't ask anyone there the reason of relapse of his disease. *"How would asking help? It is the doctor's job to*

[105] It is not clear if IP was continued for one more month. His diary shows him sputum negative at the end of IP test. Confirmation of this is difficult, as the recall of patient is not very specific regarding number of tests and its results.

[106] According to a service provider, urine discolouration caused by Rifampacin is one of the leading causes of default by patients due to medicine side effects, as they think it to be traces of blood, apart from metallic taste in the mouth.

treat, and our job to go to them for treatment and do as told by them. On the contrary, asking such questions would irritate them and they'd say that are we (patients) smarter and more educated than them. The doctors would surely turn such irritating patients away and tell them to treat themselves of their problems if they think they have better brains than the doctor. We should never make the doctors feel that we are questioning them or doubting their judgement or else they get very upset. They are God's chosen persons who have the power to heal. It is God who makes us suffer for some bad deed of ours and the same God makes doctors, to save us. How can we question such noble souls?" Parasram justifies his subservience towards doctors and attempts to dispose his questions. His only concerns are that if there was some way of insuring that the disease would not come back, it should be told to him so that there is no another relapse. *"It was my destiny that my disease came back. What could the doctor do in it? If taking the treatment well means that the disease would not reoccur, then I would do so. I don't know what wrong did I do in the previous instance, but this time I would be more careful."*

Services

Parasram did not go to the DTC as the services at the CHC are sufficient to treat him. This sputum test was also done at the CHC. Parasram tells, *"In small cough and fever, we go to the chemist who gives us something that is prevalent for that condition. This saves us all the run to the doctor as well as the fees and most of the time this works. But in serious cases only we go to the dispensary (CHC)"*. But in his case he went to a private practitioner first and not to the CHC directly. In fact, the chemist told him to see the chest specialist when he saw the first private practitioner's paper. Although, the practitioner gave the medicines also himself, Parasram took his prescription to the chemist assuming that more medicines were prescribed. According to Parasram and Kanta, many other people around go to Delhi Gate, an old market place of Udaipur to consult private practitioners who give medicines along with advice and charge Rs 50- 60. The motivation of doing so is explained by Parasram,

"there are no tests done and hence no money wasted on that. One also gets medicines free with doctor's advice."

At Badi hospital, during the second hospitalisation, Parasram was also given injections. *"The injections were for stopping the blood in his cough had to be bought from the market. He was given 10-12 such injections and each cost Rs. 30-35. The rest of the injections were provided from within the hospital without any charge. Some of the tests were charged, very nominally like Rs. 15 for a blood test, and the x-ray was also charged. Sputum test cost Rs. 5 that was taken by the lower staffs for their* chai pani (miscellaneous expenses) *but all this was much less than the amount charged by the private doctor"*, recounts Kanta.

Grading

Parasram grades his treatment as 'good'. *"My treatment was started without waiting and most of the tests were nominally charged. I have been getting medicines regularly and free of cost that is why I've got well from being so near to death. Doctors came like God for me to save my life"*, he explains. However, ironically his 'Gods' become helpless in case of relapse; he says *"what can the doctors do if my illness returns?"* His wife, although, has a different opinion about the assurance of cure from the disease, *"I would admit that it shouldn't have been the case. There was surely something improperly done, because the disease came back. I cannot say who did it, but there surely was more to be done either from our side or by the doctor. In our knowledge, there has been no slip, but God alone knows. This time I am even more careful, even though it is not within our means, we would try to ensure that all the requirements are met"*, Kanta indicates to diet and other precautions that the doctor said would be beneficial for Parasram. He feels that compliance should be maintained as the government is providing such expensive medicines, therefore one shouldn't waste it. He denies if the cost of the medicines was told to him by any service provider.

Along with the medicines Parasram also takes regularly the cough syrup prescribed by the doctors at Badi. The cough syrup has to be bought from the chemist. It appears that he has developed an addiction for it. Parasram says, *"It relives me of the pain. Whenever I feel uncomfortable due to coughing or otherwise, I take a few gulps. One bottle cost Rs. 40 and lasts for 2-3 days. I have stopped counting the number of bottles I have taken till now".*

Life with tuberculosis

Parsarams's symptoms are common amongst the labourers at the brick kiln; however, he denies tuberculosis prevalent among other labourers at his work place. The possibility of tuberculosis being an occupational hazard for him is high. He has not informed his fellow labourers about his disease. Parasram says, *"I have not told any of the labourers at the kiln, although they understood that I had TB when I was admitted at the Badi hospital for about two months each time. Only my family knows about the disease. It would not help by telling others, so why should they know?"*

His disease has brought testing times for the family, especially for Parasram and Kanta. Parasram has been out of work for 6-7 months during his illness in the last two years. Kanta has also lost about 3-4 months of work in looking after her husband. Her wage is Rs. 55 while Parasram gets Rs. 75. He is still not well enough to work. *"Lifting these heavy loads and digging are still very difficult for me. I try because we have to fill our stomach"*, he says. Even though Parasram is not on the muster rolls at the kiln any more, he still accompanies his wife. The two episodes of tuberculosis have meant a huge loan for the family. Kanta has mortgaged her silver ornaments for loan at a high interest rate of Rs. 3 per month per Rs. 100 borrowed (36% per annum), that has now reached Rs. 23,000, in order to meet expenses of treatment and nutritional diet for Parasram, when the income has shrunk. Kanta articulates the indirect impact of Parasram's illness on the family, *"I wanted to marry off one of the daughters who is now 17 years old. Our girls marry early, so now finding a groom for her is more difficult. My son has backed out of any help, as he is scared he would get*

the disease. I have single-handedly taken care of him (Parasram). *My son is educated but still did not help us out in during hospitalisation. I always went with him. When the disease came back, I felt terrible. I know, after him I would be all alone. These children are of no support."*

Udaylal

Udaylal is 45 years old and stays with his wife and 14 year old son. He is a matriculate and worked as a peon for a chartered accountant. His wife, Sita works as domestic help in nearby houses. Their son, Gopi studies in 8th standard. They all live in a small two-room self owned house in Nimachkheda, a village situated on over a hillock near Fateh Sagar Lake, which is rapidly getting assimilated in the growing Udaipur city. The house is situated at a climb, and in spite of being near to the lake has frequent water scarcity. When Udailal worked, the total household income was Rs. 4,500, but for the past one year, Udaylal is not working and the total income is what Sita earns i.e. Rs. 2,000. Udaylal is Rajput by caste and his house is built on inherited land, while all his others kith and kin sold off their lands and moved from the village for employment due to recurrent droughts in Udaipur.

First episode

In summers of May 2003, Udaylal started having cough. He thought it to be common cough and tried some home remedies consisting of ginger tea and herbs. However, gradually his coughing became more violent and he started having fever also. He rapidly lost his stamina to cycle to work 5 kms from the house, and the climb back to home became arduous for him. His weight fell, and in the words of Sita comparing his earlier health, *"He was well built and fond of wrestling and sports in his younger days, but became so frail and weak due to the cough and fever. Our relatives, who came to visit him upon hearing of his ill health, could not believe if this was the same man."*

Seeking help

A month later, i.e. by June 2003, Udaylal started having problems in attending to his work and asked his employer to help him out with seeking medical help. His employer sent him to his acquainted doctor, a private practitioner located in a busy market near his work place. The doctor examined Udaylal and gave him some tablets. This consultation came free for Udaylal, since he was sent by his employer, a friend of the doctor and thus no consultation or medicines were charged from Udaylal.

Udaylal took the medicines for a week, but they proved to be ineffective in lessening his discomfort and he went back to the doctor to report this. The doctor, suspecting a chest ailment requiring specialised attention, suggested him to go to Badi hospital. Udailal's friends and acquaintances had also been suggesting him to consult the popular chest specialist heading the Badi TB hospital. They advised that it was much easier to see the doctor at home, because he lives about 2 km from Udaylal's place whereas the hospital is 10 km far.

TB hospital

Udaylal did as advised by his well wishers. He sought advice at the residence of the chest specialist where he runs his private practice in the evenings. The doctor charged Rs. 50 for consultation, examined him and asked to get a chest x-ray. The x-ray cost Udaylal Rs. 120 and he went to the doctor's residence again the next day. Upon observing the x-ray, the doctor asked him to come to the hospital for further diagnosis and consultation. Two days later, Udaylal went to the Badi hospital where he was admitted for 4 days and a series of blood and sputum tests were done within the hospital at nominal charges. During his admission he was given some medicines free of charge from the hospital. His sputum tested negative for tuberculosis, but the x-ray showed legions in his lungs. The doctor told that he didn't have TB. *"The doctor said there are holes in my lungs due to which I have breathlessness and the medicines would comfort me. I would get well"*, Udaylal recalls the doctor's advice. However, his medical record (doctor's prescription at the Badi hospital) shows that he

had Bronchitis. He was prescribed some medicines that he had to buy from the market. The medicines cost him Rs. 250 for a month. He continued these medicines for one and a half years and went to the doctor for follow up, initially, fortnightly and then on monthly basis as suggested by the doctor. He always went to the chest specialists at his residence as it was nearer. Udaylal explains the reason of not going to Badi hospital for follow up but to the doctor's residence even if it meant paying fees, *"Doctor sahib had asked to come to the hospital, but I thought it better to go to his residence because it was nearby and I could even go with my son and did not need someone to help me go there. Also there, it is less crowded than in the hospital. To meet the doctor at the hospital it could easily take one and a half to two hours because one has to wait for him. At home one could get the appointment for evening by going and getting registered in the mornings. So, one doesn't need to wait. At home he is more relaxed and gives more time in probing."* Similarly, Udaylal preferred diagnostic test also from the private as going to the hospital for the tests, he adds, *"Even for the tests, it is very inconvenient to go so far and the wait is also long, also going just once may not suffice. It is easier if one gets admitted there, but still someone needs to be along with".*

His treatment alleviated his discomfort and he started regaining his health. *"With a month's treatment I was able to go back to work and after some more time, I could go on the cycle. My life resumed normalcy"*, says Udaylal.

Ill again

The treatment kept Udaylal in good health for 9-10 months. But in June 2004 he started coughing again. This time, his cough had blood in it. He also had fever and night sweats. *"The discomfort was back and with greater force this time. The fever and night sweats came as if it would just kill me"* says Udaylal. He went to the chest specialist again with his compliant. Like the previous time, the doctor asked him to get an x-ray and examining the x-ray advised him to come to Badi for further tests. His sputum test done at Badi hospital this time confirmed tuberculosis.

DOTS

He was referred to the DTC for registering himself by filling up the forms to initiate treatment. The forms later had to be submitted to the DOTS centre that would provide him the medicines. The onus of getting treatment started is put on the patient, like filling up of forms and even getting the box of medicine dispatched from the DTC to DOTS centre. The patient informs the DTC if medicines do not reach their designated DOTS centre on time. Udaylal was also no exception. He had to run to DTC thrice before his treatment started. At the DTC when he showed his hospital papers to the doctor, Udaylal recalls, *"The doctor said that I should take two tins of protein supplement with the treatment for my weakness and two bottles of cough syrup. Although I didn't complain of the weakness, but I thought it might be important part of the treatment so I bought it from outside. The doctor had asked me show the purchased tins to him for verification, if I had got the right one or not."*

He was put on DOTS as category 2 relapse tuberculosis patient[107]. Udaylal was asked his residence, which he doesn't know whether has been verified by the PHC staff in some manner or not. His treatment started from 10 November 2004 from the nearest DOTS centre which is a PHC less than half kilometre from his residence. Udaylal has been told that his treatment would go on for 8 months. During the intensive phase he was given seven tablets every alternate day at the PHC and injections on those very days, a total of 22 injections. He was suggested to come after the morning meal for having these medicines at the PHC. *"No one had told me about the side effects. But after starting these medicines, I used to feel dizzy and a strange taste in my mouth. I lost my appetite and didn't feel to do anything. I asked the doctor*

[107] Udaylal was not diagnosed with tuberculosis in the first episode, but with bronchitis, according to his medical history and the interview. But upon falling ill again, he was registered as relapse patient with the RNTCP. It is not clear about why so. Probably there is no cross checking of papers of patients of prior treatment. In this case the researcher didn't make a cross check with the services, as it may affect patient's treatment because of revelation of patient's identity. It is mentioned in the service providers' interview that the patient is asked clearly before the initiation of treatment about any previous history of tuberculosis treatment.

at the PHC about this who said that initially it would feel like that but later on it would go away as I grow used to them. The taste still is a problem, but since I have to get well, I take the medicines. People come from far places to see these doctors at Badi for treating tuberculosis and if this is the only way of getting better, I will have to take this discomfort. It is either this way or death for me. The doctor told me at the DTC that if I didn't abide by the method of taking these medicines and discontinue, I'll surely die of coughing up blood", he says with fear of further suffering by the disease upon defaulting to treatment.

His diary doesn't record any follow up tests, but according to him, his follow up sputum test was done for which he had to go to the DTC. *"The DTC staff said that the organism was not found in the sputum and this means that the medicines are effective and I am getting well. My medicines were reduced from seven to five"*, he says. He had to collect the test report and submit it for getting further treatment from the PHC. He was put on CP and he still goes to the PHC every alternate day for his medicines and the reason for this, in his words, *"I was asked by the compunder* (DOTS provider*) to do so."* No one asks him about his well being at the PHC. *"They may not know my name also if not written on the booklet"*, laughs Udaylal.

Why tuberculosis?

Sita says, *"It was terrible knowing that he had tuberculosis. In my childhood days I had seen people dying in the village and it was considered dreadful. I don't know whether or not it is so now, but it is a troublesome disease. I didn't know that his state was life threatening."* No one told Udaylal as to why he developed tuberculosis from a non -tuberculosis condition - Bronchitis, and what could've been done to stop it from happening. *"I felt defeated, because after doing all that the doctor asked to do my condition didn't improve for good. Rather it worsened. I don't blame the doctor for it because he was kind and always ready to help, perhaps he wouldn't have known that it could turn into TB"*, says Udaylal.

In the earlier episode he had to buy medicines from the market. He preferred going to the doctor on private basis and most of the diagnostic tests were also done from the private diagnostic centres. *"We haven't kept any accounts for it as such, but based on our estimation, Rs 700-800 every month for more than a year in the first go. It is now for the past 4-5 months that I am getting free medicines"*, tells Udaylal. Thus, total cost approximately till now comes to Rs. 10,000, excluding the loss of Udaylal's income. Sita has taken Rs 13,000 as loan from her two employers where she works as a domestic help. *"People who are kind have given and those who don't understand have asked me to do just cleaning and washing and have stopped me from doing the cooking. I have left their work as they started discriminating. I am a Rajput and people treat me with respect even though I do menial work. I am not given separate tea cups for myself as other maids usually get in houses"*, describing her experience which she has registered due to her husband's illness. Udaylal still is not able to go to work as he feels weak. For Sita, Udaylal's illness has meant, *"A constant battle for me. I have to do everything. Although Gopi helps me out but I have to go for work, look after him, even submit the electricity bill by myself. The income of the house has halved and the expenses have gone up. I haven't had a sound sleep since he has got ill. My worries have no end. I don't want my son to give up his education in all this so I have undertaken all the pressure. It is like holding a mountain of problems alone. We haven't celebrated a single festival all these times. I know of something coming only from the houses where I work. And in all this I also have to see him suffer. If he was away at some other city and doing nicely, even if I was to handle myself and Gopi by myself it would have been a lot easier"*, narrates Sita.

Grading the treatment

Udaylal says, *"My treatment was fair, because it made a difference in my condition."* He doesn't pick 'good' or 'very good' because *"there is still more treatment to go. Let us see what happens by the end of it. It can happen like before that I get better for sometime only to fall ill again."* His expectation from a doctor is

to make him get well. In his own words, *"the doctor should free me of my problem."* Aspects like 'good behaviour' and 'dignity' don't figure in his idea of seeking help, although he does list convenience, lesser cost and less waiting time as his other expectations.

Bhagwanlal Gameti

Bhagwanlal Gameti is a non-literate and works as a daily wage labourer in stone quarries growing around Udaipur city to feed into its fast growing construction industry. He lives in Nimachkheda village, now a suburb of the city, in a self made *kucha* (mud) house on a small piece of land that his father got decades ago as a benefit of a government scheme of allotment of public land to the poor tribal families. He lives with his wife Radheya, two unmarried daughters, two married sons and their wives, and three grandchildren. His has two more daughters who are married and live nearby with their own families and a son who migrated to Ahmedabad (Gujarat) two years ago in search of employment and now stays there. Bhagwanlal belongs to schedule tribe. Out of the 11 members in his present household sharing the same kitchen, four adult members work and earn a total income of Rs 7,000- 8,000 for the family, depending upon availability of work. In the rainy season since quarrying is difficult, they work at construction sites whenever they get work or even have to sit idle. His wife has stopped working after developing knee pain 4-5 years ago. No one in Bhagwanlal's family has seen the insides of a classroom, except for his 8 year old grand daughter who goes to a nearby government run primary school.

First episode and seeking help

Bhagwanlal does not has his treatment details except for the treatment diary or the DOTS 'identification card', as named officially in RNTCP, that has some obscure information about the dates of initiation of treatment and his follow up tests. According to Bhagwanlal, his illness began in late months of 2002 when he developed cough and started feeling weak. *"Lifting head loads of stone began troublesome. I had fallen ill with fever and cold, but this coughing became all limiting"*, says

Bhagwanlal. Soon this limitation grew into disability to carry on the very basics of life. *"We have to go out in the mornings for nature's call, since there are no toilets in our kind of homes. One day, I didn't reach back home. My children went out looking for me. I was so exhausted by the climb and walking that I sat down under a tree to rest for a while. I saw them searching and calling out for me but I didn't have the strength to shout back a reply. I finally made an effort to stand up, and then they located me and took me back home. After that I couldn't go out for many days together"*, narrates Bhagwanlal. He remained bedridden for few weeks and assuming the coughing would go with the winter. But till start of March 2003 his condition didn't improve and one night after dinner he vomited and fell unconscious. His wife decided not to delay taking medical help any further. She says, *"We didn't know what was wrong with him. We don't go to the doctor for problems that we can bear or that would go away in some time. But his condition was more than that. His coughing and fever had broken him completely."* His family and neighbours took him to a private polyclinic nearby with emergency service, after he vomited. Bhagwanlal was admitted here immediately and was given glucose and saline and some medicines purchased from the pharmacy in the clinic. *"He gained consciousness in the hospital and we brought him home the next afternoon. The doctor advised for blood and urine examination"*, tells Radheya. This venture cost Rs. 3,000 including medicines, consultation and hospitalisation. *"It was so expensive for daily wage earners like us. We live from hand to the mouth, which probably people like the doctor at the clinic did not think of. If his condition hadn't become so bad, we would never have gone there. How could we afford such expensive treatment? Two days later, after consulting more people around us, I thought it would be better to take him to the doctor at the government dispensary. After all the aim was to get well, and doctor of any place was a doctor. I could care better for him in my house than he would get at good clinic"*, she points out.

A few days later, when he had gained some strength, Radheya took Bhagwanlal to the PHC. There the doctor examined him and advised him to go to Badi hospital for further investigation and consultation. It took another two days for Radheya to go to Badi, which is about 10 kilometres away. *"I am not familiar from that part of Udaipur. So I thought of taking along some one who could help us out"*, says Radheya who took one of Bhagwanlal's friend for helping her to take her husband to Badi. At Badi hospital, the doctor advised him to get admitted. *"They admitted him for tests and gave him injections for stopping fever. I asked the friend to come back home and get some essential things like clothes and some utensils like glass, plate and so on, as I didn't come prepared for hospitalisation. For the next two days, we kept running around the hospital for tests"*, Radheya says sharing her experience of Badi. The tests included x-ray, blood and sputum tests. The test reports came in after 2-3 days and the doctor said the reason of Bhagwanlal's illness was tuberculosis. Radheya says, *"The doctor sahib told me to keep him in the hospital for 4-5 more days. It was almost a week by then since we had taken him. I came back home and sent my eldest son to Badi, as I wanted to rest for a day. I went again the next day. Five days later, the doctor said I could take him home and he had to go to this (nearby) PHC with the papers for further treatment"*, pointing towards the direction of the PHC. Radheya did as advised because she wanted Bhagwanlal to get well. In her words, *"What's the use of all the running around if I didn't take him to the dispensary for the treatment. I wanted him to get well. All this till now hadn't brought much change in his condition."* Bhagwanlal had stayed at the hospital for 12-13 days and was advised to be put on DOTS, available from the PHC. But before starting of the medicines, he was told to get the forms from DTC which is about 5 kms from his residence. Here he was advised to comply by the treatment, only then it would be effective. Radheya was briefed by the doctors at Badi, *"They said that the treatment has to go non stop or else it won't be effective. Till the treatment was going on his bedding and utensils should be kept separate and he should avoid food that may bring coughing like sour or oily food"*, she recalls the doctor's advice. At the

DTC, they were asked to produce their address proof, which they could not since they did not have any government document stating their address. The DTC staff asked if they would continue to stay at the given address for a long time, which Radheya affirmed. She recalls the interaction, *"They* (DTC staff) *said if we leave the place during the course of treatment we would have to inform them. If we didn't do so, the government would take money from us as fine for not following their instruction. Only then they filled up the form. It probably must be having some written words about the fine. They also said if he followed all their instructions he would surely get well."*

Finally Bhagwanlal was put on DOTS from the PHC. According to Bhagwanlal, he didn't feel any awkwardness due to medicines. Bhagwanlal reports, *"I was asked by the compounder* (DOTS provider) *to come on full stomach. The colour of the urine changed after start of the treatment from Badi where the doctor had told my wife that it was due to the medicines."* During the course of treatment he had two sputum follow up tests for which he had to go to the DTC. The onus of bringing the report and submitting at the PHC was also on him. Bhagwanlal says, *"They said at the dispensary that until the report comes, they could not give further treatment. So I went without delay as it might lead to default in my treatment."* Based upon the test reports, he was told that he was getting better. After 6 months of treatment, in July 2003, Bhagwanlal was declared cured although no tests were done after he stopped taking medicines to confirm the absence of tuberculosis in his lungs.

Ill again

Bhagwanlal resumed work even before he had finished his treatment. He remained well for the next one year. In September 2004 his illness struck him back. He narrates, *"I started feeling weak with some cough. I thought it was the summer that was draining. But one day I collapsed and my mouth filled with blood even though there was no injury. I was taken to a private hospital nearby the quarry by my co- workers. They informed my son working nearby. The doctor gave me glucose and*

an injection for stopping the bleeding and referred me to a doctor at Delhi Gate[108]*. I was brought home. We thought it was better to consult the chest specialist at Badi who had treated me last time as he knew my case"*, explains Bhagwanlal. The services at the private hospital along with medicines and glucose had already cost him Rs. 1,200.

After two days, he went to Badi hospital along with his wife, who felt more confident this time. The doctor admitted him immediately and advised him sputum tests and x-ray. He was put on medication to lower his fever and for stopping blood in his cough. When the test reports came two days later, the doctor declared that his disease had come back. Radheya recollects, *"The doctor asked me several times if he had his treatment from the PHC regularly. I always said he did because he did. They raised doubts on missing any dose. To my knowledge he never missed any dose, except for one instance when he had to go out for two days; he had taken his medicines along with him and took them also as per the routine, because he understood he shouldn't miss any single medicine. I don't know if they still trusted me"*. Bhagwanlal was hospitalised for a month this time, and was referred to the DTC at the time of discharge The DTC referred him back to the PHC, from where he was told to get medicines similarly as the first instance.

"The compounder recognised me as last time I had taken medicines from him. He wondered as to why did I have to come again as he knew I had taken my medicines as said", Bhagwanlal recalls the reaction of the DOTS provider at the PHC. He didn't ask any of the doctors about the reason of his relapse into tuberculosis. *"I am a poor and illiterate man. It did come to mind, that if the treatment ensured that my illness would go, as told to us by the doctors at DTC, why it came back? Probably something was missed by us in the treatment. I couldn't hold them responsible. If I asked any questions, they might feel as if I did not trust their medicines and would*

[108]A market place of Udaipur

have doubted my claim of taking the treatment without fail. They probably could have rejected treating me again and in that condition where else could have I resorted to. After all the treatment by the government services is free. It is only the lower staff, that too if hospitalised, takes some money for chai pani", Bhagwanlal explains the reason for his not questioning the relapse. His treatment again began in November 2004 from the PHC under category 2 patient for relapsed tuberculosis. He got medicines along with injections, both of which had already started during his hospitalisation at Badi. Bhagwanlal's follow up sputum test has been done after which he was told that he was better, but needed to take one more month of medicine. He was again tested a month later and was told he was getting better and his medicines were changed, i.e. he was switched to CP from IP. His diary doesn't record these test details, except for the first pre- treatment test. The next date is also not filled up.

He was prescribed cough syrups and protein supplements by the doctor at the DTC. He says, *"The doctor asked me if I had any weakness and cough. I said yes, but by that time I was much better due to the treatment at Badi. The doctor said that I should take them as they would help me in recovering faster."* Consequently, he bought bottles of cough syrups but just one tin of protein supplement, because he had fallen short of money. *"I told the doctor that I would get it from a shop near my home or from the same shop outside when I visit the DTC next time. So next time whenever I went, I was suggested to purchase the protein tin and cough syrup and I did so, because the doctor said that he wanted to see if I got the right one or not. He was so concerned for me because he knew I could not read or write and it would be difficult to know just from the packing. There are many fake things sold in the market these days"*. The entire treatment of both the episode together has cost Bhagwanlal approximately, Rs. 10,000–12,000 including the cost of stay for treatment at the private clinics twice and medicines prescribed by the DTC doctor. Radheya provides better view as she did most of the spending, *"Most of the medicines were provided from the hospital at Badi, but still some medicines that were not in the store had to be*

bought. Once, he developed acute breathlessness and the doctor said he needed a gas cylinder. The store keeper said there was none in the hospital and had to be arranged from outside. The store keeper only arranged it for Rs.25 for one night. Then they took some money for their chai pani from time to time. In total, that alone would be Rs. 500." Radheya describes the rent seeking behaviour of the lower level staff at the hospital. The cost does not include the loss of income due to Bhagwanlal's inability to work.

Meaning of tuberculosis

For Bhagwanlal and Radheya, tuberculosis has meant not only physical suffering and hardship but also incurring large expenses and all efforts to bridge the gap from the income. *"Poor are doubly cursed. We don't have fixed employments, and then upon falling ill, we have to run around in circles. I couldn't ask my children to help me out since it would mean loss of their wage for that day. I have borrowed Rs. 20,000 from relatives and other acquaintances because the income of the household fell and the expenses of his treatment went on increasing. I've mortgaged my jewellery and pay an interest of Rs 3-4 per Rs. 100 borrowed per month. It is good that he got treatment from the PHC or this could be more difficult for us. Even after doing all this, God does not feel happy; he gives us more illness to test our endurance"*, narrates Radheya depicting her frustration with the situation and prays for the health of her husband as that would mean some relief for her also.

Grading the treatment

Bhagwanlal grades his treatment as 'fair'. His grading is reasoned on the basis of improvement in his health. *"The medicines have made me feel better."* He doesn't give better grades as he feels that if he got well with the treatment in the first go, he would not have to suffer the second time. *"They said I would get well. Then I did, but the disease came back. I think probably they didn't understand my case well or the medicines were not effective. I know they would not do so deliberately. So I would not say the treatment was excellent, because who knows if it comes back again. I am*

taking the medicines hoping that this time things will go fine", he says cautiously. Radheya on the other hand, rates the treatment from 'poor to fair'. According to her, this rating comes from two factors. Firstly, as the disease came back in spite of the doctor's assurance and she tried her best to follow their instructions. Secondly, because the brunt of the non-physical difficulty of accessing treatment for her husband was faced by her, in terms of the lower level staff at Badi who helped her out, but at a price. *"I was not very confident since I had never gone so far on my own in my whole life. There I had no one from whom I could take help. Gradually I got familiar with the place and directions. I started taking help from the sweepers and other women staff, but then they began asking for money. My only concern was that his treatment should go on well, so I paid them. Although they didn't ask money everyday, but I didn't know for what help they would ask for money again. The second time I was more certain. I am relieved that he got treatment and is now much better. Although he still finds it difficult to walk to the PHC for his medicines, but I know he will live at least till I am alive. It is a very lonely life for a widow in our society, where children don't support as in the upper caste."*

The Service Providers

The service providers interviewed include four public sector doctors and two doctors from local non-government organisations (NGO).[109] This includes the chest specialist at Badi hospital whom most of the patients consulted at some point of treatment. The other doctors interviewed include the DTO of Udaipur, a former DTO and a state training co-ordinator. Apart from the doctors, a STS, a nurse at the DTC who is also the DOTS provider and a peon were also interviewed because they interact with the patients on a regular basis. With the change from NTP to RNTCP there was also a complete change of strategy of implementing the programme with a huge onus of achievement resting on the shoulders of the programme implementers.

[109] Qualified doctors.

Training has a big role to play in this changed orientation for achieving better responsiveness from the components of the reformed programme through these implementers. There are newer needs of training and support to the implementers especially case of those directly interacting with patients and of fulfilling their roles in accordance to the expectations of the patients as well as the programme targets, are covered in these interviews. The doctor interviewed is also a part of the 'mangers' of the programme.

While the service providers in NGOs have a greater role to play, acting not only as pressure groups but also as associates in the RNTCP. The Ministry of Health and Family Welfare has formulated and disseminated guidelines suggesting numerous schemes for NGO involvement dependent on their capacity.[110] These are schemes are:

1. Health Education and Community Outreach – involves training volunteer/health workers to disseminate information, counsel patients and families and if agreed, retrieve defaulters.

2. Provision of Directly Observed Therapy – involves training volunteers/health workers to engage in DOTS provision. The role would involve maintaining records as per RNTCP policy, ensuring the collection of sputum during treatment and retrieving defaulters if necessary.

3. In-hospital care for TB patients – The hospital would perform sputum smear tests and participate in the quality control of the District TB centre.

4. Microscopy and Treatment Centre – involves providing microscopy and TB treatment services free of charge. The NGO is responsible for ensuring the treatment or referral of all patients found to have a positive sputum smear.

[110] Central TB Division – TB India Report 2004, there are over 750 NGOs are actively involved in DOTS, of which 93 are based in Rajasthan

All service providers interviewed have a long experience of working in their respective fields. The interview with STS and peon present at DTC is a result of interaction over a period of time. Fictitious names are used to protect identities. All providers talk about a wide range of issues pertaining to responsiveness of the programme and their own role in it. The doctors speak in an overview manner about the programme, its responsiveness and limitations. The other supervisory level service providers speak out of their everyday experiences and the obstacles they face in their daily operations. The researcher has also made observations at the DTC during and post OPD hours.

The District Tuberculosis Officer (DTO)

The DTO is overall incharge of the RNTCP at the district level. He is also the ex-officio member secretary of the District Tuberculosis Society (DTS). According to him the DTS is a component of the District Health Society, a registered society in every district of which the District Magistrate is the ex-officio chairperson.

DTO's key responsibilities are supervision and monitoring of the programme at the district level and reporting the progress of the programme. For programme monitoring he tours the district frequently to cover the various TUs and DMCs. He has to report the programme's progress every quarter to four agencies – the state health department, Tuberculosis Division of central ministry of health and family welfare in Delhi, National Tuberculosis Institute at Bangalore and the WHO zonal consultant at Udaipur.

The DTO praises the current RNTCP and DOTS as a successful programme as it is an improvement over the previous NTP. The main weakness cited by him in the earlier strategy was the unsupervised therapy wherein the health provider couldn't know whether the patient has taken medication or not. The patient was suppose to visit the doctor on monthly basis and weak monitoring was the main reason for high default rates which resulted in high death rates i.e. about 15-20 percent that has

declined to 5 percent. In his view, strict observation through DOTS has helped patients comply with the treatment. The follow up measures taken as soon as the patient defaults for a dose has added value in getting the patient back on therapy. Still some patients do not comply because, according to him, most of the patients are illiterate and uneducated. To overcome this hurdle, he says that once the patient is diagnosed for tuberculosis, he should be provided 'health education' that should include the importance of compliance to treatment and the precautions one should observe during treatment to contain further spread of disease among family members. He points out that the health workers and NGOs have been trained under the Information, Education and Communication (IEC) component of the programme to educate the patients. The indicator of the importance attached to this aspect is the development of 300 IEC centres to give training and produce banners and posters to make people more aware of the disease and its symptoms.

The DTO points out the programme is dedicated towards controlling the disease at a population level and that is why treatment is available free of cost and in his words, "at the doorstep of the patient". He quickly adds that the earlier treatment was also free, but due to 'illiteracy', people could not take benefit of it. But now with massive awareness campaigns, they are getting more aware. Defending the logic of how the 'illiterate' are able to read the posters, he says that the school teacher in the villages, or school going children and other literate persons can at least read and can tell people around them about the disease. The programme has made treatment diagnosis and outreach better by switching to sputum microscopy as the main tool of diagnosis, which is highly effective in detection of sputum positive patients than the erstwhile reliance on Miniature Radiography. For increasing the availability of care, he points out that ICDS worker, school teacher, any educated persuasive village based person, ayurvedic government doctors, NGO worker, etc. can also become DOTS provider. This increases the coverage of patients and people providing DOTS are given an honorarium.

Among the difficulties he faces in implementing the programme 'default' by patient tops the list. According to him the main reason of default is migration. The district has a large migratory population due to recurrent droughts. There is a high prevalence of the disease among the migratory population, but DOTS cannot be applied to them. The next important reason is getting symptomatic relief after which many patients discontinue. But the DTO maintains that 90 percent of the patients put on DOTS complete the IP and the cure rates have gone above 80 percent and conversion rate upto 90 percent. He does not state side effects of medicines as any prominent reason for defaulting to DOTS. But he admits that all these medicines do have side effects which vary from patient to patient. Rifampacin, for example, changes the colour of the urine from yellow to amber. Some patients report this and also get scared if it is blood. They are told that this may happen while they are taking DOTS and there is no need to panic. Majority of them develop tolerance shortly after initiation of the treatment. In rare cases jaundice is also reported, and in such cases the jaundice is treated first to move on with the treatment or to change from SCC to SR on the conventional method.

The DTO deems DOTS as a convenient strategy for the patients too, simply because it is curing patients of tuberculosis. DOTS, in his view is responsive to the needs of the patient through convenient treatment. The strongest point of DOTS according to him is that the responsibility of providing treatment to the patient, once diagnosed with the disease lies with the service provider. He claims that all patients coming with three weeks of cough are tested for sputum microscopy and x-ray. According to him, since the treatment through DOTS is available to the patients on their 'doorstep' implying that no patient has to go beyond three kilometres to take DOTS and not every day but alternate day only during IP and weekly during CP, has made it 'patient friendly' therapy. [111] The relaxation of DOTS during CP from every dose to one dose in every three is to give relief to the patient from coming to the

[111] Unlike in NTP, under SR medicines had to be taken everyday for a longer duration.

DOTS centre regularly. Earlier, patients would take medicines for a month, and default after they started getting symptomatic relief. After relapse of the symptoms they would head for help again. DOTS has brought down this kind of default and, in his view, now it is negligible. In case of follow up tests, the patient does not need to travel more than 10-15 kms; there are five DMCs in each TU. There are nine TUs in which the entire district is divided into and the category of the patient can be determined there. After the test the patient needs to collect the report from the DMC and go to the TU for category determination at the beginning of the treatment. So the proximity of the services for the patient has improved. The conversion of sputum positive patients to sputum negative is an important achievement of the current programme, as it checks the spread of the disease. Sputum negative patients do not spread the disease. Thus RNTCP is reducing the pool of infection in the population.

Reflecting on patient's expectation the DTO points that there are two main expectations, one of free diagnosis and the other of free treatment, and both of these are being fulfilled by the programme. Patients get facilities near to their home and need not come to the district hospital. The DTO shares that sometimes patients feel that they are uselessly called in three times for taking sputa for smear microscopy, but when they are told that this would improve their test results, patients co-operate.

The DTO denies of any unscrupulous practices at the DTC by any service provider. He claims that his team, especially at the DTC works very hard. He also claims of full support of his seniors as and when needed. He points out to the flexibility of hiring staff on contract basis where ever needed by the WHO and by the state government, as one indicator of this support. He claims with pride that it is because of this measure, he disburses a huge sum of Rs. 50,000 only as salary to the staff "in his own discretion".

In his view the programme does suffer from few problems especially due to understaffing and multiplicity of work for the grass root worker in the villages, e.g.

the Auxiliary Nurse Midwife (ANM). She has to work on many programmes simultaneously like Malaria, MCH, etc. which are also equally demanding. His prescription for effective implementation of the very effective programme of RNTCP is through having a completely vertical programme with exclusive manpower. The ANM has to cover long distances and there are problems of implementation in the villages as people according to him in the villages don't take proper care of their treatment in terms of regularity of coming for DOTS and don't understand in spite of repeated advices. The programme is better functioning in the areas near zonal headquarters because of close monitoring.

The Chest Specialist, Badi Hospital

Badi hospital had been the hub of tuberculosis patients during the NTP era and its legacy continues. This chest specialist is based at this hospital and has witnessed programmatic changes. Almost all the patients have sought help form him and many of them on private basis. There are some qualities about him that the patients have highly regarded – accuracy of diagnosis and good behaviour, besides, convenient location and timings, lesser waiting time and lesser tests from the market are the motivating factors for the patients to seek help from him. In this interview the chest specialist gives his views on the programme and its effectiveness. Although his involvement is limited only to medical aspect of the disease and has less involvement into programme implementation he gives insights based on his over thirty years of experience with tuberculosis patients in the region and on five year old DOTS and its convenience for patients. He cites a few problems of the programme and suggests some changes for increasing effectiveness of the programme. His liaisons are with the DTO for reporting and referral purposes of the programme.

According to him, technically the RNTCP is an improvement over the NTP. Specific diagnostic tools, regular supply of medicines and good monitoring make the RNTCP a sound programme. However there are operational problems at the field level. The grass root worker like the ANMs have a heavy burden of implementing

such programmes along with other similarly target oriented programmes. On the other hand, there needs to be constant interaction between the staff and the tuberculosis patient. People's convenience may also not match with that of the health services, e.g. timings, and may lead to hamper compliance to the treatment. At times side effects may also become the reason of default as many of the medicines have side effects, but they can be managed. The health service staffs have to be very supportive to the patient and in cases of severe intolerance medical help should be assured. It sets an example for other patients in the community. One badly treated patient makes ten other patients' delay their treatment at the public health services or pushes them into private sector, many a times to unqualified doctors. So responsiveness to side effects is very important.

The chest specialist states some important causes of default. Firstly, due to symptomatic relief patients discontinue treatment as they think there is no need of further popping up pills. The health services can play a role in this by immediate home visit for follow up action. Secondly, patient can develop intolerance to medicines and due to side effects can discontinue. Neglect or inadequately response to the side effects by the health services when sought help also adds to default. Thirdly, defaults can arise out of social problems due to stigma of the disease, like in case of young girls, wherein the family hesitates in sending the girl for regular DOTS. They fear that revelation of the disease to others make their marriage difficult. He cites cases where women have been left by their husband due to the disease. Migration is another hindrance of compliance to DOTS. There are very little economic reasons vis-à-vis the earlier regimen because the drug supply is ensured once treatment begins and the patient does not need to buy any medicine due to irregularity of supply.

Reflecting on the expectations of the patient, he cites that the patient wants a good doctor who can firstly and most importantly make correct diagnosis in the given facilities. He next puts good behaviour towards the patient. Little kindness gives relaxation and comfort to the patient that no medicine can provide, because the

expectations of a patient are of getting well and therefore he wants immediate attention from the physician for treating it. The other expectations of the patient are low costs and appropriate timings of the health services. He emphasises the main reason of people resorting to seek help from the private practioner because of convenience and trust in a particular physician.

DOTS, according to the chest specialist, is not an inconvenient regimen for the patient, primarily because it is effective in treatment. So the patients do undertake the hardship of complying by DOTS, if only properly advised and informed. Interestingly, he says that the distances of seeking treatment are more in cities than in the rural areas, where people walk distances. But in the town or cities, DOTS should be available nearer in absolute distance as people seek conveyance to reach the DOTS centre and therefore it would lessen the indirect cost for the patient to comply with DOTS. He candidly disapproves of the unfair practices by some physicians in the public sector and agrees that it adds to the cost of seeking treatment for the patient for vested interest of the providers, but feels helpless on the issue. He specifically replies that protein supplements are not required in majority of cases and this need can be addressed through diet which is cost effective for the patient's family. Secondly about cough syrups, he says, may be required in some cases, especially if expectorants are required. But surely it is not required as widely they are suggested to the patient by the doctors.

Lastly, he gives two suggestions to improve the programme. His first recommendation is inclusion of Ethambutol in CP to make the treatment regimen more efficacious. According to him this measure will increase the cost of the entire treatment by merely Rs. 75 per patient, but go a long way in dealing with drug resistance. He points out that advises by practitioner like him who have a long experience with the population with the programme are not taken seriously by the policy makers. His second recommendation is to make RNTCP a completely vertical

programme which will lessen the burden of the grass root level implementer of programme the rural areas.

State Training Co-ordinator (STC)

The main functions of the state training co-ordinator, according to him, are sputum microscopy quality control, training of DTO, MOs, STLS, STS and lab technician, organise the Continuing Medical Education (CME), workshops, train the new intern and NGOs, quarterly and mid quarterly meetings, and review the progress of DTC and TU levels. Apart from these it is in his responsibility to conduct and co-operate in research work and in the districts and state. His division will also conduct Drug Resistance Surveillance (DRS) which is yet to start in Rajasthan. The STC reports to state tuberculosis unit, NTI Banglore and India Tuberculosis Division in Delhi.

According to the STC, 90-95 percent staff in RNTCP is trained. High turn over of the contractual staff call for constant need of conducting training for the new staff joining the programme. On average there are 6 to 30 persons for training and the duration of training varies with the nature of the group.[112] The training is necessary according to him, as the programme has laid down a clear strategy in terms of DOTS and methods of programme implementation including supervision, monitoring and reporting are strict.

The STC claims that since the implementation of DOTS in 2000, there are better results in terms of patients completing treatment, cure rates have gone up and with increased efficiency of drugs and strict monitoring under the programme, it is giving encouraging results. He adds that these are real results not manipulated, due to stringent monitoring tools. He also adds quickly that there may be 3-4 percent human error, but he declares that Rajasthan has the best result in the world, next only to one

[112] The duration of training (in number of days) is as follows; STLS 6-8, MOTC- 12-14, TB HV – 15, STS 6-8 , LT 10, MO-5, teachers 5.

country that he could not remember, due to rapid implementation. Analysis of every aspect of the patient, like female to male case detection rate is best in India and in Rajasthan. But he says that since Rajasthan is a big state keeping the programme in the same momentum is a big task.

He briefly talks about the staffing rationale in the programme. He mentions that the STS has to see compliance of drugs system in the field area and defaulter retrieval action and preparation of monthly and quarterly report. He also needs to register every patient put on DOTS and ensure timely follow up. 90-95 percent staff is permanent and works better. But in certain posts like data entry operator contract system works better. By strange logic, he says that anyone can do the work of STS because it is not so hard work as the data entry operator. He sounds happy at the fact that the contractual staff can be fired any day and asserts the fact that contractual staffs do not need to have any retirement or health benefits. Obviously he poorly rates the contribution of such staffs in the programme implementation, which are in actual terms the backbone of programme's functioning.

Expressing his view on compliance, he recognises the need to train all actors of RNTCP like, MO, NGOs, DOTS provider so that the patients take medicines as per the RNTCP. However in his view, lack of education tops the reason for default among patients. The disease is more common among the tribal due to poverty, alcoholism, smoking multiple marriages and more number of children so more poverty. All this increase their susceptibility to get the disease. In his experience, he asserts that there have been patients who could not understand the importance of taking the entire course of medicines, in spite of its being free. He further claims that all the service providers and the associated staffs are happy to work in the programme for the cause of 'controlling TB'.

His rational of including NGOs in the programme is getting better outreach in places where there is a lack of staff or difficulty of terrain or any other hindering

factor. Besides, the NGOs represent the people and are nearer to them, understand the context well and people also trust them. The programme also provides the NGOs with activities and they can employ more persons. He says, *"Because everybody needs a job."* In case the NGO is very keen on associating with DOTS, their staffs have to work under the ANM.

He identifies some aspects of the programme that need strengthening like more involvement of Medical Colleges along with registered private practitioners, because a great number of patients still have more trust in these practitioners. This will increase the cure rate further. However, the public health providers blame that many of these private practitioner follow shorter regimens to distract patients from the 'free' treatment provided by the government which is longer, so that these patients shift from DOTS to their own devised and highly varying and unsupervised therapy. The STC reasons out the motivation of the private practitioners to join the RNTCP, *"The private doctors are also doctors and they are kind hearted people, and they are also under the Hippocrates oath in which they believe strongly and are always ready to serve the poor and the needy. If these doctors get free medicines there is no reason why they will decline association with RNTCP. More over, there is nothing wrong if they charge a fee for their services."*

The STC gives a snap shot of performance of different districts in Rajasthan under RNTCP. He informs that Bhilwara, Tonk, Bara, and Ajmer are top four performing districts of the state as they are sustaining the results. In his view, assessing by the sustainability of the achievements, he grades Udaipur's performance as good to fair. Conversion and cure rate is less. There is no dearth of resources, but in past one year, there has been shortage of STS due to which some TUs have been underperforming. The other impediment to performance is because the district is largely a tribal area.

Stating his views on patient's expectation he says that proper behaviour, good diagnosis and proper medicines availability are the major expectations. He also lists free treatment, prompt treatment, getting well, availability of facilities near to their home are also some other expectations of the patient. He also speaks out about the limitation of the health services, e.g., when a person is ill, one tends to shout on the health services. But one should be aware about things like cleanliness, like in case of malaria. Prevention is better than cure and therefore has to be strong but curative has become more important in India. In his view, people don't understand the need to prevent. According to him there are certain things that the health services need and it can only come from the people. He admits that it is the job of the health services to increase awareness and education for prevention of diseases.

He suggests that the disease can be controlled only when education improves; people become aware of the symptoms and seek early help so that the disease is not spread by them to more them. The population needs to be controlled if tuberculosis has to be controlled is his next prescription because the health services don't expand at the pace of ever increasing population and all progress made is engulfed by the ever increasing population. He says that tuberculosis cannot be eradicated but can be controlled. Even this will take a minimum of 25 years when the Annual Rate of Infection (ARI) will come around 0.5 from the present 1.5. Nearly half of the population has the bacteria inside their body that can develop into tuberculosis. But only 1 percent of the population has the active disease. When the immunity decreases tuberculosis increases. This chain can be broken only when there are no sputum positive patients to spread tuberculosis. This will result in reduction in the pool of infection and then after sometime when no one develops the active disease it will be controlled. But, according to the STC, it will take a long time because it takes a long time for the disease in its natural course to happen.

He informs that the State government is giving salary of the regular staff and other benefits and the rest of the funding is from the centre. There is underutilisation

of 40 percent of the state funds allocated, which according to him should not be foregone and hence has been kept aside for meeting expanding demands of the programme like DRS.

The Retired DTO

The retired DTO (referred as MO in the rest of this interview) is coordinating medical colleges' involvement in RNTCP. He shares his views on the programme and the possibilities of dealing with the disease in a more effective way. He has been associated with both NTP and RNTCP.

He deems the current burden of tuberculosis as a shame because a curable disease like tuberculosis still exists in unacceptable proportions in spite of free treatment, massive resources, a network of providers and stringent monitoring. For this huge burden of the disease, he blames the other socio-political forces at work that are outside the ambit of the health services. He describes that doctors, nursing staff, ICDS workers and NGOs; all have come together and are participating at different levels in the programme. The NGOs especially are working in remote areas where the outreach of the health services is poor, thus are filling in the gaps.

The MO recognises that treatment of tuberculosis is a regular and continuous process for the health services. He feels sad because inspite of a free treatment, even educated persons also don't bother to get early detection. According to him, people are not conscious about the disease and try to delay seeking help, for if they know it could be tuberculosis they are afraid of the stigma. Many of them genuinely assume that it is a simple cough. Only when it worsens with fever and weight loss causing weakness, they reach to the doctors. Women, in his understanding, are suffering more due to this as they are not allowed to go out alone. Due to the social stigma they keep on coughing. Their nutritional intake is also poor, so the disease attacks them early. When they get tuberculosis which remains untreated, the others members of the

family are also vulnerable to contract the disease. Parents of young girls don't give importance to their daughter's illnesses, therefore delay the treatment.

The MO observes the changes from NTP to RNTCP and comments that the patients under DOTS have to come to the centre regularly for taking medicines and the supply of drugs is ensured. Once a patient is initiated on treatment it is assured that the patient is taking medicines as per the regimen. But in NTP because there was no such measure, the default rates were high. He also observes that investigation and follow up was not proper under the NTP.

He points out that there are a huge number of persons coming to Udaipur because the collective memory of people from the sanatorium days remain that treatment for tuberculosis is good in Udaipur. This is so, inspite of the fact that the facilities of diagnosis are same everywhere at all PHC and CHC and microscopy can be done in rural areas, and so much of publicity is done regarding the facilities available for the programme. Whether the patients are unaware of this or they have more trust in the doctors at the Udaipur city is not very clear, he says. Some do come deliberately assuming the treatment would be better at Badi.

The structure of RNTCP is such that the patient can be diagnosed at the PHC/CHC level so that seeking treatment is easier right from the point of diagnosis of the disease. The x-ray can be disputed but sputum testing has provided a confirmatory diagnosis. RNTCP has the aim that all sputum positive patients should be put on therapy as they are the one who spread the infection most. He refers this as a preventive measure so as to reduce the pool of infection. When asked if the patients reporting early, i.e. before three weeks of coughing, are turned away, he blames the service providers who follow the protocol blindly. Before this period patients are prescribed cough syrups and some antibiotics and are asked to report back. If they come back, they are tested for tuberculosis and if they don't, it is assumed that the treatment given was effective and the patient has got relief. There may be a high

chance that patients are going to the private doctors. Regarding the rampant x-ay and other unscrupulous practices among the public health providers, (especially at the DTC) he emphasises on the fact that x-ray is not the concluding test, therefore should not be done until sputum examination is done, also in accordance with the protocol of RNTCP. But he agrees that it is not being followed by the doctors. X-ray is also being done widely and the patients are duped. In such cases, he feels that the doctors don't think of the patients' plight.

The MO holds that DOTS is a very successful strategy if it is done properly. But he states that there are certain problems afflicting it that need to be dealt with. Firstly, DOTS is not being done as properly as it should be especially in the periphery. The main impediment to this is staffing as there is over burdening of staff with multiple tasks thrown at them. Coupled with this the staffs also don't remain at the base, he says, referring to high absenteeism. In such scenario, he accepts, implementing DOTS with the desired effectivity is not feasible. To counter such problems, RNTCP allows any educated and responsible person from the community to carry out DOTS. But in practice, if there is no such person available or willing to do such work, how would the nurse handle her tasks arising from the other health programmes. According to him this is a country wide problem. In case of default cases the health providers are not able to do home visits as prescribed under the programme. It is burdensome for them. Secondly, at the physician's level, there is lack of skills to handle even simple aspects like proper categorisation of patients. Many doctors prescribe medicines from the market, inspite of specific order from the government that tuberculosis medicines should not be prescribed. They are also being prescribed with tonic and protein supplements. Thirdly, he points out to the problem of poor and irrational referrals; he gives examples from his experience that when a patient comes to him for tuberculosis treatment he informs the patient about the treatment, specifically that he/she needs to take the medicines for 3 days every week. For further treatment he refers them to the nearest PHC or DOTS centre. There are

some irrational referrals like a patient being asked by the doctor at the general hospital, to come back for sputum testing. But in effect the patient for coming back to the hospital is staying in the city for two days, which is adding to the cost and inconvenience of treatment. This will in turn go into the memory of that community of the patient who will then like to seek treatment from unregistered (unqualified) doctors nearby; who will not make things so complicated for them, but may not cure their disease. Most probably the patient will not turn up the second day. So according to him, mere free treatment is not enough. The doctors don't think that when the patient comes to the city they have to incur many costs like boarding and transport, and most likely the patient is accompanied by one or two more people which add to the entire burden of cost of treatment. He suggests to doctors that patients should be informed properly and sent back to the nearest post for treatment. He also acknowledges problem of supply of medicines that is declared to be solved with the advent of RNTCP and DOTS strategy. There are cases when the patient, in spite of registration, has to follow up at the DTC for despatch of medicines to the DOTS centre.

The MO lists down the expectations of the patients as free treatment including free tests implying that unnecessary medicines will not be asked to be bought. Doctors should speak kindly to them. All the staff should be polite to the patient. The MO speaks his view regarding compliance to treatment as resultant of the faith built by the service provider in the treatment. There have been a lot of improvements in the programme, but in his view, in effect they have not benefited the patient as much as they should have. He welcomes NGOs involvement in RNTCP and cites them as effective agents to carry out this programme because of their accountability lies towards the community, unlike the government health workers.

Mukundlal (STS)

Mukundlal is truly an exception to his other para-medical colleagues at the DTC who are either trying to follow the programme protocol as monotonous routine

duty or are overpowered by the 'de-motivating forces' around to carry out their work with any zest. Mukundlal, in his late sixties, is the driving force of the DTC's day to day functioning. On records he is working as a supervisor at a CHC, but is almost indispensable for his seniors and subordinates at the DTC in Udaipur. In his interview he talks about the issues, problems, achievements and scope of betterment of the programme and gives a perspective of ground functioning of national programmes for tackling tuberculosis.

Trained as a sanitary inspector, Mukundlal joined the state health services in 1960. Later he also underwent a lab technician training, and was posted in a diagnostic lab at the hospital. Mukundlal was fond of field work and soon got discontented with his sedentary job at the lab. He was posted in the NTP but sometime afterwards was transferred to the National Malaria Eradication Programme to which he was impassive, he admits, and therefore got back to tuberculosis. His inclination to serve tuberculosis patients came naturally, he says, as he lost his mother to the disease and his job has been geared with personal motivation. Mukundlal is a part of the RNTCP since its implementation in Udaipur. He retired from the services in 2001. Even after that he continued to work without any compensation for a good seven months. Later he was recruited as a contractual supervisor under the RNTCP. His contract is renewed every six months.

He narrates, that during the late 1960s till 1990s, Udaipur was an important place for tuberculosis treatment. Patients from far away places, even from other states, came to the TB hospital at Badi for treatment. In the earlier tuberculosis control programme (NTP) the death rate was high as default was also high. The duration of taking medicine was very long and cure rate was low. Thus, according to Mukundlal, the revision in the programme, primarily the adoption of DOTS since 2000 (in Rajasthan) has brought in more action and result.

Mukundlal's main tasks are monitoring and supervision of the DOTS provider, maintenance of records, preparation of progress reports for the DTO along with the data entry operator and other colleagues, organisation of training and meetings at the DTC and ensuring the supply of medicine to the requisite centres, sometimes carrying the medicines to places himself. He travels for at least first two days every week for routine monitoring. A monthly meeting is held of the Senior Tuberculosis Supervisor (STS) and of Senior Tuberculosis Lab Supervisor (STLS) at every TU for routine progress reporting. These monthly reports are compiled by the respective Medical Officer Tuberculosis In-charge (MOTC) of their area for quarterly reporting meetings. The latter meetings are important and are presided by the DTO and the WHO consultant of the region[113], while most of the monthly meetings are presided by Mukundlal himself. Most of the discussions during these meetings are centred on confirmation of progress reports. *"The targets of 90% case detection rate and 85% cure rate come from Jaipur, and are provided by the WHO. Any deviation from that has to be explained"*, Mukundlal tells about the pressure under which he has to work.

DOTS compliance and default

DOTS, according to Mukundlal, is an effective strategy for tackling tuberculosis, especially over the previous NTP wherein the patient was responsible for taking medicine. *"The patient under DOTS feels that there are so many people concerned for his wellbeing, therefore he also feels the responsibility and takes the medicines regularly"*, points Mukundlal. The main thrust of the programme implementation staff is on defaulters. *"Most of the patients defaulted in the earlier regimen and had a high threat of turning resistant and also of infecting others with it. DOTS is effective in pushing the patient for complying and completing the treatment. It is also in the interest of the patients. Since all the medicines have some side effects, they need to be administered before the provider so that any severe reaction could be*

[113] Udaipur is significant, as it is the head quarters for WHO in some 9 districts of the region.

checked. It also boasts the moral of the patient who may discontinue the medicine if the entire course is provided to the patient to be taken at home on one's own sweet will", Mukundlal explains his preference for the RNTCP over the NTP.

Mukundlal admits that DOTS is not very convenient for the individual patient, but argues that it is equally bothersome for the same patient to keep on popping medicines for six to eight months on one's own, especially when the IP is over and there is a remarkable improvement in the patient's condition. The long treatment requires a reinforcement that the DOTS provider gives. He feels that it was entirely due to the absence of this clause that NTP did not succeed. It was the high default rate, according to him, that took the biggest toll of the otherwise completely curable disease. Therefore he strongly supports DOTS, and as far as of inconvenience for the patient is concerned, the government has taken measure to make treatment extensively available by making an array DOTS provider, from ANM to school teacher, *sarpanch* (elected head of PRI) and even a cured patient, anyone could become a provider. Interestingly he admits that in such cases the ability of non health persons to provide any action or persuasion in case of side effects can be affected which will require referral to the ANM or PHC.

In case of default, *"The staffs have to run after the patient. At times, in spite of a lot of persuasion and cajoling, the patient refuses to continue the medicine. We then ask the patient to give his refusal in writing or get a contact person to do so. Many a times we involve the Sarpanch to persuade or even write down the refusal by the patient for us to convince the authorities above that adequate follow up action were taken to get the patient back on treatment. This also acts as a retrieving juncture if the patient understands the gravity of the situation and decides to continue"*, he explains the strategy adopted by the staff to save their heads in case of defaulting patients.

He further explains lack of awareness and education to be the foremost factors for default, *"Most of the patient are ill-literate and they don't understand. They prefer*

to turn to 'Bhopas' (traditional healer) instead of taking the more sane way of continuing the treatment." The other reasons arise out of undue hindrance by private practioners, Mukundlal says. They try to convince the patient that since the treatment is free, it would not work or they promise to shorten the duration of treatment. In a few cases, the side effects may make the patient nervous. *"There is no reason why a patient will not recover completely if one takes the treatment as we say. I believe this as firmly as I believe in the God above"*, he says and later adds with an intended pun that, *"both are matter of belief after all!"* On a more serious note, he maintains that the regimen is effective in most of the cases and treats the disease within the stipulated time. This thought strengthens him to go on with his crusade against tuberculosis.

In situations when the DOTS provider or the MO feels that the patient might not comply, the staffs then seeks help from the DTC and takes the DTO in confidence. They refer the case to the DTC for further action. Mukundlal denies the possibility of any self selection of patients by the staff on the ground that the patient would default. There are instructions under the protocol that no patient coming to the services be denied treatment and it has to begin within 8-10 days. He says, *"it is a double edged sword for us. We cannot deny treatment and in case of default we have to do all the running around to get the patient back. The patient is the VIP. Most of the factors for default are beyond our control but still it is dealt in a manner by the superiors as if it is our fault. That is why we have started this practice of getting the refusal of treatment in writing from the patient. Such a measure is not stated in the protocol, we have started it."*

The provision of appointing a contact person to whom the DOTS provider gives responsibility of compliance by the patient is in the protocol. In case of default, this contact person is held liable. For further effectivity of this measure, this person is identified outside the family. We take this as an excellent measure to ensure compliance as it creates a social pressure and to an extent fear of social stigma if the

word spreads. This is called as 'social blackmail' by the staff. Although, they claim of taking precaution as not to frighten the patient too much to daunt any treatment at all, but in many cases it works well if applied with caution.

Mukundlal gives some insights to measures taken in case of 'underperformance', which is determined on the basis of the targets of achievements (although the term 'target' is not used). In case of repeated underperformance, the staff is served a show cause notice. The staff may also be sent to Ajmer for a repeat training.

Training

Mukundlal's last refresher training was of in 2003. The training is usually for 6 days and three different people act as resource persons. Exposure visits to well performing area is also organised. Under the exposure visits, he recently visited Pushkar in Ajmer district, where he acknowledges that the programme is actually going on very well. He lists certain points to validate this claim, such as almost zero default rates due to prompt and regular home visits, energetic staff due to high focus and tight monitoring. In case of any defaults, the staff makes an immediate home visit. Sighting out the problems of doing the same in Udaipur, he says, Pushkar is a religious city that attracts tourists from within and outside the country so they have to be on their toes.

Mukundlal is confident that if there is proper monitoring the programme would have higher achievements. The foremost problem, he sights, is of overload and multiplicity of work at the grass root, *"The ANM has to do too many things. She is the main DOTS provider, especially in the rural areas. She has to produce equally impressive results in family planning, polio campaign, and malaria, coupled with the difficult terrain of the region in which she has to cover long distances."* His solution to the problem is to have exclusive staffing for RNTCP even at the grass root level.

Mukundlal also feels that the staffing pattern under the RNTCP, consisting of permanent and contractual staff doing similar work, has brought in some chaos in programme implementation. According to him, it is the contractual staffs who work the most, whereas there are ample grass root level workers in the field that are permanent government staff. If the supervisor is contractual and the lower level staff is permanent, then there are contentions. He says, *"How is it possible to supervise someone who is not liable to you for his/ her service? It is difficult to monitor a permanent staff being a contractual staff."* He points out the classic case of hierarchy confusion at the DTC itself. The DOTS provider is a staff nurse who actually comes under the MOTC but should be supervised by the STS. The STS monitoring her is new and the nurse is about 8-10 years old in her job. Mukundlal says that her standard reply to any remark or objection put by the supervisor is that he may do whatever he wishes; even the president of the country cannot remove her from the post. *"She is clearly beyond our measures of monitoring. Negligence and laxity in her work are a routine. DOTS is not followed, we know it, but since the seniors don't object to her ways we try to fill in as much as possible regarding her work for the sake of the patients. There is no dearth of such examples in the field. Many are even worse. In the case of the this particular nurse, she complains of over work even though she leaves the DTC by 2:00 pm and is never in until 10:00 -10:30 in the mornings. Even if there is no shortage of funds and drugs, how could the programme succeed if such aspects are overlooked?"* Mukundlal finishes bitterly.

Upon asking if he is also overloaded with work that is far too much for an individual, he smiles and says that *"words like over work or too much of work do not exist in my dictionary. I am contractual so I am always a 'yes sir' person".* Mukundlal is not bothered if his work is not deemed as important by others. He speaks about his motivation, *"I believe the best policy is to brush such things aside and move on because if one has to work, such thoughts only divert your attention and energy. My highest and lowest points are related to patients more than to my*

superiors or subordinates. I get very low if I see patients not taking the treatment seriously, dropping out when they should not. I am happiest when I see a patient getting well. There is no better reward than that and perhaps no worse retribution than seeing a patient suffers needlessly either due to his own misgivings or of others."

Grading the services

He was asked to put a grade similar to patient's grading (of five categories) on the basis of the treatment that the programme provides to its clientele i.e. the patients. He grades the services as 'fair', the middle of the five-point scale. He feels there is lot of scope for improvement. According to him the programme could do much better as there are ways of following DOTS in a manner that can actually benefit the patient and make it easier for the patient to comply with the treatment. For example, he sites, proper home visits and good behaviour can be strengthened. *"The mantra to increase compliance is to build the trust of the patient towards the medicines and services"*, he says and adds, *"Suppose a patient is going out, say for a wedding, and requests to give one or two dosage for the time when he is away, the provider should give it to the patient as such small steps could add to the patient's faith and he is likely to cooperate better. Although officially this can be termed as violation of DOTS, but these are certain basic realities one has to realise and the programme should also acknowledge them."* He says that the patient only wants to get well in the least possible expenditure. The expectations of good behaviour or of basic amenities and dignity seem to be far fetched from the reality. In his view, basic amenities vis-à-vis facilities of treatment are important, and not of seating or drinking water or even of long waiting time because treatment is the core of the problem. He feels that the patients could endure all difficulties if they are sure of getting correct treatment. He sites correct and free treatment as the only motivations for people coming from faraway places, and these two are enough areas to work upon by the health services. He admits that the patient do want confidentiality due to the stigma attached to the disease, and more so among the rural people. Interestingly, earlier in the interview this

is the point that staff uses confidentiality to push compliance. The staffs call it '*social blackmail*' which if understood in the WHO domain of responsiveness is not being met.

Asha (DOTS Provider)

Asha is a trained nurse and works as a staff nurse at the DTC. She is 28 years old and has been working for the past 8 years. Asha got married when she was just 15 years and by the age of 19 years, she had two children. Now both go to school. Her husband works as a helper at a local sweetmeat shop and earns Rs. 2,000, while her monthly salary is Rs. 8,000 plus the other public service benefits. She feels grateful to her husband for allowing her complete her nursing course and work, which is not a common occurrence around her, where women are often forced to leave their vocation after marriage.

When RNTCP was initiated in Udaipur in 2000, she was given two-day orientation training and refresher training after a gap of one month, for programme implementation. According to Asha, her position in the hierarchy of the health services is below the MOTC Medical Officer - Tuberculosis Control (MOTC). No one besides the MOTC or the DTO should monitor her, not even the STS who monitors the other DOTS provider of the TU (Tuberculosis Unit).

Asha describes the programme and the transition of her role during NTP to RNTCP. Under the previous NTP, the patients did not get treatment close to their place, so they would came to Udaipur for treatment, also because the "*treatment and staff here was good*", she says. She had to keep track of 150-200 patients coming every month for treatment and medicines. She says, *"I had to give them medicines, make their entries and manage the OPD. Then I also had to keep track of the store. When DOTS started in 2000, I was told to give medicines to patients in front of our eyes. Since then I keep water here and make patients' cards and keep their records. Medicines for other patients in the periphery are also supplied from here* (the DTC),

so I have to keep a record of that as well", Asha gives an account her responsibilities that have shifted from managing OPD to providing DOTS, keeping records of patients and managing two stores. She has 60 patients on average including IP ad CP for DOTS.

In Asha's understanding, RNTCP is an improvement over NTP as the new drugs have reduced the duration of treatment and DOTS has increased the effectiveness of the regimen. These two factors have resulted in better cure rates and reduction of deaths due to disease. *"Earlier, since the course was very long and patients had to take medicines on their own, it was very likely that the patient would default in taking treatment. Such cases then would result in MDR tuberculosis, many of whom would die"*, she explains. She points that cases that remain a challenge in RNTCP are patients who default in treatment, those who do not give their correct history of treatment fearing that if they disclose they have defaulted they may not receive the treatment and cases of MDR tuberculosis. She highlights the programmes assertiveness to treatment upon the patient, *"For example under NTP, there was no system of calling upon the patient in case of default. In such cases, the patient's name was put in the default register. Since patients came from far off places, it was not possible to go and call them. A postcard was sent to them, but most of them being illiterate would not respond or did not take it seriously. But now, under RNTCP, we have to go and see the reason why the patient has not come and motivate the patient to continue with the treatment. So this programme is better in many ways."* Her foremost task is providing DOTS to patients registered in the area. Her responsibilities as a DOTS provider towards the patient include doing a home visit prior to start of treatment for address verification, providing medicines according to the regimen and the dosage, keeping them compliant to treatment and to follow up in case of default.

Default and compliance

She explains to patients the importance of compliance and that 'default' would lead to aggravate the disease and then it would become untreatable. If the patient defaults in spite of all her persuasion, she has to make a home visit to find out the reason of it and to make effort to put the patient back on treatment. Asha also accepts that DOTS is there because the patient could not be trusted to take so many medicines for such a long time on their own. *"They* (patient) *have to be told repeatedly the merits of compliance. I tell them that if they don't comply, they would cough all their lives and become like consumed tuberculosis patients, would not be able relish food ever, and so on, and in case of reoccurrence of the disease due to incomplete treatment, no treatment would help them. The doctors often tell patients that the cost of medicine would be recovered from them if they default, since the box in their name has been opened and would go waste for which they* (patient) *would have to pay"*, Asha reveals ways of pressurising the patient to adhere. She laughs that it is like scaring children when they refuse to eat. In her view the motivation to recover completely and not to suffer again is strong enough to drive home the point.

Asha raises certain issues in her interview. Foremost is her dealing with the patient is the issue of compliance. *"Several patients are reluctant about coming every alternate day to take medicines. Their common complains are that they have other works to attend and coming to the centre every alternate merely to take the medicines is not feasible"*, she narrates. Asha agrees with most of the women patients in this, as it is not easy for them to come out of their homes every alternate day for medicines. Moreover, women patients who have small children do not want to bring their children to the DTC, in the environment of disease and infections as they may also get the disease. But many of them do not have a choice. On the other hand for the men patients, she presumes, it is not difficult since most of them do go out of the house at some time of the day for some work or running an errand and they can come easily for DOTS. Asha accepts that at certain exceptional times when the patient has to go

out for a day or two, she gives them the dosage for those days. But she claims that, by and large, she refuses requests for taking medicines at home[114]. She says, *"There is no other way to insure that the patient is taking the medicines regularly or throwing it away. In spite of all the explanation about the treatment and the importance of complying with the treatment, there are some patients who still default. They assure me that they would come for their next dose and not default, but still don't turn up even after repeated home visits. I find ineptness in dealing with such cases."*

Another prominent reason of defaulting according to Asha is side effects of the medicines. The way of dealing with it is not a simple one, as Asha says, *"I do not tell the patient about the possible side effects before starting the medicines since it may shun them away. At the start I explain that they should come after a meal and shouldn't miss any dose. I then give the medicines with water one by one till the patient can comfortably swallow them. Initially it takes them about half an hour, later it is done in five to ten minutes. After the first few dosage when they come next, I ask if they had any uncomfortable feeling after taking the medicines. If they report any discomfort I tell them ways of dealing with it, like having lemonade to curb nausea and vomiting."*[115] If patient reports of vomiting, she sends them to the doctor because it may lead to failure of treatment.[116] She also explains the patients of the precautions that they should take while the treatment is on, like separate bedding, not to eat very spicy food, not to have tamarind and unripe mangoes as these may induce coughing, etc. But her primary objective in all this is to keep the patient compliance with the tuberculosis treatment.

[114] Patient case studies prove this claim by her as in valid as three cases have established beyond doubt that she is giving medicines without DOTS, and is not making any home visits.

[115] This is conflicting information being provided to the patients, as most of the patients in the interview have been asked to avoid sour food like lemon.

[116] Interestingly her motivation is not the comfort of the patient rather the effectiveness of treatment.

What does she like doing the most?

"I like to do paper work", she admits, *"Home visits to patients are difficult. Finding addresses alone for a woman like me that too in a Muslim dominated area is not easy. You never know what they may tell you. To top that people are very conscious of not letting others know about their illness. In that case when I search for an address in the neighbourhood of the patient, people who know the patient or the family ask for the reason of my inquiry. I have to pretend being a family friend. Even then it makes people suspicious and makes me feel awkward with all kinds of suspicion especially in case of a male patient. I don't know what kind of people patients are for their society."* As the researcher talked to Asha, a young girl's well to do parents were waiting outside with their car for Asha to take her for pre-treatment home visit so that their daughter's treatment could start. This procedure was told to them by the doctor of the DTC. Asha kept them waiting with the assurance to go with them. They had requested her to come along because if she had to search the address on her, the neighbours might come to know about their daughter's disease. After an hour's wait, she declined to go explaining the reason of her refusal, *"I don't go with patients like this. If I have to go at all, I would go myself with my convenience. How do I know it is safe like this?"* According to her, there are no security mechanisms to ensure the safety of staff personnel like her while on duty.

Asha's other worry is of contacting the disease as she is in close contact with the patients, she describes, *"I tell patients to keep their mouths covered while coughing and keep some distance while talking in the initial phase at least, since it is very contagious. There is no way that we can guard ourselves from the disease. They should keep this precaution even with their family members and while coming for DOTS. But many of the patients do not agree still and disbelieve that a disease can spread like this."*

So is RNTCP is effectively tackling tuberculosis?

According to Asha, it is defiantly a better way to deal with the disease, but she puts MDR tuberculosis as he main culprit, especially those arising out of default in treatment. *"They are still spreading tuberculosis and that too which cannot be tackled by DOTS. Unless there is something to treat this, the number of patients out there is likely to remain the same. So I feel if our efforts here have to be fruitful, MDR TB has to be tackled simultaneously"*, she tells.

Although Asha herself is well aware of her own shortcoming of dealing with the patients in the DOTS mode of treatment, and admits that DOTS is not convenient for patients, but her prescription to overcome impediment to RNTCP's success, is to extend DOTS till CP the way it is in IP. The reason she gives is because the patient after getting better is more likely to default and therefore needs direct observation similar to the IP. She points out, "*drugs are reduced in CP and then observation is also reduced. This is a reason why patients are coming back with the disease*"

According to Asha, there are no costs borne by the patient for seeking treatment. The only costs incurred are when the patient keeps on moving from one doctor to another and is not diagnosed for tuberculosis. After reaching the RNTCP staff, there are no costs except for commuting expenses for DOTS. They mostly come through informal recommendations. She denies any knowledge of patients being sent outside for x-rays and protein supplements or other medicines. Asha doesn't acknowledge of such practices, but she does feel bad if she comes across any undue advantage being taken of the patient, because she is working hard for retaining the patient and such practices may be driving them away from seeking treatment. But Asha chooses not to raise her voice about this, *"Whom to complain about this? Since it is the doctor's discretion, I don't speak out on this. This is a government job and one should keep to one's own business. My patient should not have any problems due to me."*

She doesn't acknowledge any pressure regarding work from her seniors, except for inspections from senior officials or WHO, but acknowledges that there are pressures from above to keep cure and compliance rates high and admits that some of her colleagues are often scolded for things that they cannot control. *"We get the salary for being used as punching bag"*, she laughs. Asha feels good being a part of the programme and seeing a patient getting well gives her immense satisfaction. She grades the programme as 'very good' because there are very few patients that relapse or develop MDR. Patients are getting all what is laid down for them. There is no hindrance to patient's treatment. According to Asha, the foremost expectation of the patient is to get well, then of free treatment and they will never have the disease again after having the treatment as per requirement. Asha feels that the patient should know that he/ she is suffering from tuberculosis because only then they can take the necessary precautions and deal with their suffering in a better manner. She admits that good behaviour is important to help her/ him to cope with the disease. The patient according to her may not get well in spite of all the treatment if not behaved well with.

Interestingly, uninterrupted drug supply in RNTCP does not figure in her view even though she has the store's responsibility with her. Patients are asked if they have taken treatment for before at any point in their lives. This is important since there is no system of keeping history of patients that is accessible to the service provider, like to all public health services providers if the patient as had treatment from anywhere from the public sector.

Bhanwarlal (Peon)

Bhanwarlal will retire as a class four employee at the DTC in August 2005. He belongs to a village about 20 kms away from his work place where he owns 5 *bighas* of land. Bhanwarlal is a 2nd standard dropout, but tries to speak English with a mix of Rajasthani dialect as his medium of interaction during the interview. This is not the only exception in doing what he has not learnt through formal training. The other

exception is that he administers injections to patients on a regular basis and feels proud to declare that he can not only do x-rays but read and conclude from them as well, and can also give medicines, inspite of knowing that his doing such is not right. Obviously, his claims must be based by having done these tasks in the past.

Bhanwarlal's monthly compensation is Rs. 6,700[117] apart from the other benefits for a Rajasthan government employee and his scheduled tasks includes carrying post, lining up and sending in patients that come to see the doctor and some other errands. But in effect he has also been doing jobs like writing out x-ray reports, which he says he does under the supervision of the doctor, taking stock of medicines, filling up patient cards and forms and so on. He also does odd jobs for the DTC DOTS provider like address verification and patient follow ups but for a small reward, an evidence of which is found in two patient interviews.[118] This suits the interests mutually, the nurse doesn't need to run around for home visits and he makes some extra money by doing simple tasks. *"It is doing no harm to anyone; rather the programme is running smoothly, so why should any one bother about this kind of arrangement between us. I can do everything that she (nurse) can. In fact it is a better arrangement as the poor woman doesn't need to go around searching for addresses and walking all the way"*, he asserts. But he refrains from acknowledging any rewards and in extending the same argument for giving injections to patients instead of the nurse, who informs that the other staff doesn't want to 'touch' the tuberculosis patients as they are 'sick' and 'unclean'.

To Bhanwarlal the patient is a 'customer' - they are welcomed to get the treatment. *"They (patients) are God for us because it is for them that I have an income"*, says Bhanwarlal reflecting a private practitioner's line of thought. He says

[117] This is higher than contractual staffs' monthly pay in the same programme that ranges from Rs. 4000-5000 for supervisory levels who also are not entitled to get the other benefits of retirement e.t.c.

[118] These interviews are of patients Ida Bano and Nazneen, both of whom were recommended by the staff nurse (also the DOTS provider at DTC) for interviewing. See the interviews for details description. The reward part is told by other staff of DTC.

that the patient doesn't need to pay as the government is providing them with free medicines for the treatment of tuberculosis. Good behaviour is an intrinsic part of care according to Bhanwarlal. In his opinion, the human dimensions are important as he says, *"half of the cure is done if we and above all the doctor behave kindly with them. It also builds our reputation as good people, and that the place has good workers and doctors These are people who are in desperate need of treatment and probably have come here as the last resort."* This acts as word spreading mechanism as the patients who are getting treated here spread the word of the treatment and the staff, due to which other patients are also motivated to come here for treatment.

Bhanwarlal comes from a similar socio-economic background as most of the patients, but is hesitant in speaking out about the everyday happening at the DTC which are all not in accordance to the programme. He is also a part of the same system and is silent because of the patronage that he enjoys through employment. In his first go he gave the highest grade to the health services for excellent performance. But after speaking about patient's expectations, he mellows down as there are certain aspects like purchasing of medicines form outside often unneeded or provided by the government for free and other such undue benefits accruing to the doctors because of vulnerability of the patient, he grades the programme 'ok' and not very good or excellent.

NGO service providers

RNTCP is partnering with NGOs in areas where public health services are scant or health worker is absent. The basis of involvement of NGOs is their better association with the communities that can lead to better case detection and compliance. Two such NGOs; Seva Mandir and Action Research and Training in Health (ARTH) are looked into for understanding issues of responsiveness of RNTCP and health services towards tuberculosis patients. Both the NGOs are involved at Scheme-2 and are pitching for Scheme-3 for greater involvement. Their personnel

heading health programmes give their views on the functioning of RNTCP and their role in dealing with the problems, responsiveness of the programme at the ground level.

Programme Manager, ARTH

The Programme Manager, views that conceptually responsiveness will imbibe both the clinical and non clinical aspects of care. Health providers have to bear the responsibility of both elements for health care. In his interview he shares his experiences and raises programmatic aspects as issues affecting responsiveness of the programme towards the patients.

His foremost comment is that RNTCP's outreach towards women is smaller. Due to the lower proximity of women to the health worker and their own limited mobility, seeking help in cases of women is delayed. Coupled with this is the chronic nature of the disease that allows the patient to live with the sufferings of active tuberculosis for a long time, unlike malaria. Treatment seeking has costs and the family pays lesser value to the disease in the case of women or girls than in the case of men. These costs hinder help seeking in any case with varying degrees according to gender and socio-economic background of the patient. Due to stigma and lesser mobility, the requirement of repeated contact with the health services puts the treatment farther for them. The Programme Manager also points out that the possibility of delay in seeking treatment and often lower detection in case of women is also because it is deemed culturally in appropriate for women to cough loudly. It may be a high probability that even in sputum examination women are giving more saliva than sputum as the sample and the density of the bacilli in it is high for detection of presence of the disease. Thus the sample collection requires the patient to cough really hard that due to cultural factors may not be happening and further, health workers do not recognise this as a point to intervene and brief the patient. But according to him this aspect needs further probe to be established as an issue. But inspite of the above impediments to diagnosis and lower priority on women's health,

according to one study of ARTH, about reasons of mortality among reproductive age group women in an adjoining block of Udaipur district, tuberculosis surpassed maternal reasons of death. This indicates that there is a high prevalence of tuberculosis among women.

He raises a second set of concerns as programmatic lacunae arising out of contextual reasons. There are certain factors that are making access of the patient to the services difficult in seeking treatment for tuberculosis; for instance, the three sputum testing for which the patient has to go to a DMC twice. Many a times these two consecutive days of availability of the service providers and the convenience of the patient do not match[119]. So there is a high chance that the patient may need more than one visit to get on with diagnosis for tuberculosis. In the entire process from the point of reaching the services till the initiation of treatment, on an average 2 weeks' time is gone, during which the real challenge lies in retention of the patient. For this no effort is made by the health services, like a home visit if the patient fails to come for treatment. So with the given state of absenteeism, it is very likely that the patient may start seeking help somewhere else, probably by a private practitioner.[120] Besides for those who would seek treatment, it is a long drawn process charged with stigma and especially troublesome for a migratory population. The programme doesn't accommodate these factors from the patients' side in treatment.

The Programme Manager point that the problem on the diagnostic front is of a large dependence on skills of the lab technicians in picking up the bacilli in the sputum sample to make it a valid case of tuberculosis. According to him, there is a high clinical possibility that tuberculosis cases may not be diagnosed. But he maintains that this requires more investigations. The private sector, according to the

119 A study found that absenteeism in public health facilities was rampant. 45 per cent of auxiliary nurse-midwife posted in sub-centres are absent on any given opening day: Health care and health status: A Closer Look at Tuberculosis unpublished paper by MIT and Vidya Bhawan Society Research Team (Udaipur)

120 households rely mostly on an unregulated, unqualified, private sector : Health care and health status: A Closer Look at Tuberculosis unpublished paper by MIT and Vidya Bhawan Society Research Team (Udaipur)

Programme Manager, has been left largely unregulated that is not helping in dealing with the situation of tuberculosis. There are a substantial number of private practitioners, even those who are qualified and registered, prescribing irrational drug regimens. They don't know the categorisation and are giving out the same treatment to all, often repeating the same Category-I six month treatment in case of default, failure and relapse as in the case of new sputum positive. Interestingly RNTCP is a heavily regulated programme from within and absolutely no regulation outside it. With a population heavily relying on private practitioners of all shades the situation demands high concern.

The Programme Manager cites from his experience working with the rural population of the region that long and unpleasant memories of interaction with health services are held collectively by the community, leading to further shrinking of help seeking behaviour from qualified practitioners of any sector. However, he opines that all private practitioners and pathologists need not remain outside RNTCP net. With effective regulation, their inclusion especially where the public services don't hold the same trust as they do, can be incorporated to the benefit of the patient because the patients are seeking treatment from them. There is a parallel industry of dietary nutrition is going on which is not necessary for recovery of the patient.[121]

The Programme Manager also points out to the problems of treatment of symptomatic sputum negative patients in spite of the scope of their treatment in RNTCP. But since the thrust of the programme is towards sputum positive and taking the diagnosis of sputum-negative cases as non-tuberculosis and treatment accordingly leads to severity of their suffering.

Programme Manager, Seva Mandir

The Programme Manager from Seva Mandir echoes similar facets of responsiveness as from ARTH. She gives an insight into RNTCP and involvement of

121 Echoes Dr.Sharma's opinion upon scrupulous practices rampantly going on in RNTCP

Seva Mandir that is working closely with the community and developing community leaders to come forward to participate in RNTCP.

The Programme Manager describes that RNTCP acknowledges the need of NGOs involvement due to their deeper and trustworthy relations with the communities and thus in a better position to motivate them to seek treatment. But the NGOs face a different set of problems. Besides the problems pointed out by her associate from ARTH, she adds that the expectation of the patients from the community leaders or health workers of the NGOs has escalated so much that patient wish to be escorted by them for all times of getting treatment. The NGOs cannot afford the costs of this; neither does the scheme provide any money for this. In fact the provision of Rs. 175 per patient cured for the NGOs is also inadequate. DOTS has made things more difficult for them as the NGO worker cannot go with the patient every time. But she views that with the given societal order, the low confidence of people is understandable. She says that tuberculosis treatment is an onerous and long stretched process and the DOTS strategy is pushing people deeper into bearing the disease than seeking help also due to the stigma attached to the disease, and repeated visit to the centre for getting DOTS can land them into trouble. Since the communities are close-knit and low resourced they often cannot afford to take treatment due to stigma as this stigma itself can lead to alienations. The Programme Manager points out that there have been several cases where wife has been left by her husband and family upon the pretext that she suffers from tuberculosis. She cites the importance of counselling and building trust of the community in the treatment as an important aspect of responsiveness for the patients and important for the effectiveness of the programme, as patient care and public health in her view are two parts of the same coin.

The Programme Manager says that the expectation of the patient are basically on two aspects. One, that they will get treatment that will make them well. This may not be completely free, but within their decent means. They can pay a small amount

like they pay for bus tickets, a nominal amount of Rs. 2 or 5 if needed to be paid at all. But the treatment in any case should be effective in comforting them. The second set of expectation is to be treated in a humane way. This according to her is seldom expresses. They are poor and uneducated, as the service providers often think especially in the public services, but it doesn't imply they can do with lesser respect as the public services give them. Since tuberculosis treatment requires long term contact, attention to these aspects can enhance compliance. Many a times people, especially who are slightly better off or can afford even by borrowing, prefer to go to the private practitioner and spend huge sums of money for a softer behaviour by the doctor who doesn't blame the patient for the disease or for the lack of compliance to treatment. In the view of the programme manager, too much of push on compliance doesn't work, on the contrary back fires as the patient is held as the culprit.

The Tuberculosis Register

Records of patients who are registered for treatment under the RNTCP are maintained at each TU in a tuberculosis register. The tuberculosis register has a detailed format to include the following data for each patient:

- TB Number[122]
- Date of registration
- Name in full
- Sex (male/female)
- Age
- Complete address
- Name of treatment centre
- Date of starting treatment
- Regimen/category

[122] This is unique for a patient registered in a year

- Disease class (Pulmonary or extra pulmonary)
- Type of patient - new case, relapse, transfer in, failure, treatment after default, others
- Four sputum examination test results with laboratory number and date (pre treatment, at the end of IP, after 2 months in CP and at the end of the treatment)[123]
- Date when the treatment was stopped (Due to reasons - patient got cured, treatment completed, died, failure, defaulted or transferred out)
- Remarks

These data are compiled at the TU level every month to prepare the progress report. Monthly progress reports of the TUs are compiled every quarter to prepare the district progress report which is communicated at the state and national levels.

The data collected for this study from the tuberculosis register pertains to 285 patients registered at the DTC, Udaipur who have completed treatment (or should have been completed treatment according to DOTS protocol) between March 2003 to March 2005. Out of the sample of 285 patients, 185 (65 percent) are male and 100 (35 percent) are female patients. It seems that on average, women are getting the disease at a younger age than male. The average age of male patient is 35 years (age range between 1 – 86 years), whereas the average age for female patient is 29 years (range between 9 – 77 years). 81 percent of the male patients and 72 percent female patients suffer from pulmonary tuberculosis. Prevalence of extra pulmonary tuberculosis seems to be higher among the women, with 28 percent women suffering from extra pulmonary tuberculosis against only 19 percent of male patients suffering from extra pulmonary tuberculosis.

An appreciable aspect of the record keeping at the DTC is that even though the revised format does not require the dates of various sputum tests, staff at the DTC is

[123] Recently a revised format has been introduced which does not contain the date of the sputum examinations

keeping record of the same. The dates of various sputum tests are important for monitoring the patients' progress and adherence to the programme protocol. However, the overall quality of record keeping at the DTC is worrisome. Crucial records about the patients, especially on periodic smear tests are not available. The following table depicts the gender wise proportion of patients (out of the sample of 285) for whom information is not available on various accounts.

Table-2: Percentage of patients for whom data is not available on various counts

Sl.	Information head	Patients for whom data is not available in the register (%)		
		Male (N=185)	Female (N=100)	Total (N=285)
1	Date of registration	11.35	8.00	10.18
2	Age	3.78	2.00	3.16
3	Patient type	9.19	11.00	9.82
4	Pre-treatment test	18.38	31.00	23.16
5	End of IP test	18.92	27.00	21.40
6	2 months in CP test	57.30	70.00	61.75
7	End of treatment test	38.38	47.00	41.40
8	All the test (4-7)	4.86	14.00	8.07
9	Cured or treatment completed, died, failed, defaulted or transferred	42.70	35.00	43.85

The non-availability of data on various aspects can be possible on two accounts:

1. Poor quality of record keeping: In this case one would assume that all or most of the treatment procedures have been adhered to and all the required sputum tests have been carried out, but the records and results of such procedures and tests have not been entered into the register. If so, then the authenticity of the progress and performance reports of the RNTCP based on compilation of these poor quality data at the district, state and national levels become highly questionable.

2. Non-adherence to procedures: Data gaps could be possible simply because the procedures have not been followed and various required sputum tests were not carried out. This is highly plausible since had there been just poor record keeping, then it would get reflected equally across the male and female patients. However, one finds that 31 percent female patients have no record on pre-treatment test, against 18.38 percent male patients. Similarly, disproportionately high female patients have no record on end of IP smear test, 2 months in CP smear test and end of treatment test – the respective figures being 27 percent, 70 percent and 47 percent for the female patients against 19 percent, 57 percent and 38 percent for the male patients. Not even a single test result is available for 4.8 percent male patients and 14 percent female patients. It is not a surprise, given the gender biased socio-economic and cultural setup, that the female patients are getting significantly less attention as compared to the male patients. What is surprising, and also reinforcing the gender bias, is the fact that despite of significantly lower proportion of female patients undergoing periodic sputum tests during the treatment, the percentage of women patients declared cured or completed treatment (65 percent) is higher than their male counterparts (57.3 percent). It suggests that the data gaps can be attributed, to a large extent, to non compliance of the treatment protocol by the service provider. The same is observed in the ten detailed case studies done by the researcher.

If we analyse the data from the DTC register for conversion of sputum smear positive cases to smear negative cases by the end of the treatment, or even at two months in CP, the RNTCP does not seem to be responding well to the disease unlike reflected in the official performance reports (see Table - 3).

Table-3: Conversion of sputum positive cases into sputum negative

Patient Category	Pre-treatment	End of IP		2 months in CP		End of treatment		Conversion rate for Udaipur district as per the official report (2004 2nd quarter)
	No. of sputum +ve cases	Cases converted from sputum (+ve) to (-ve)	No. of cases with no test result	Cases converted from sputum (+ve) to (-ve)	No. of cases with no test result	Cases converted from sputum (+ve) to (–ve)	No. of cases with no test result	
Regime 1	111	94	8	70	40	76	34	
Regime 2	32	23	5	13	17	18	14	
Total	143	117	13	83	57	94	48	
Conversion rate		81.8%	9.0%	58.0%	39.8%	65.7%	33.5%	88.0%

V. UNDERSTANDING RESPONSIVENESS

"When someone dear to you is ill, you don't want to find out whether the doctor is taking advantage of you, fooling you to make some more pennies, the equipments there are working or that you're just being tricked into getting the tests done outside. You don't think about all these. Your sole concern at that moment is to get the person well, to relieve her from the suffering by getting her the right treatment. I know that many a times the doctors at the DTC did try to make me run needlessly for some bucks. But one has to do it because it is the question of your dear one's well being or even life. In my case, my daughter might have just died if I didn't do what I did. In those moments, the doctors are Gods and we are puppets. We have to dance to their tunes. And possibly, literally dance if they want us to."

-Bhagwatilal (Hemlata's father)

Tuberculosis has caused disruption in the lives of Sitaram, Nazneen, Manju and their likes, not once but twice. Many of them like Ida Bano, Parasram and Udaylal, who contributed to their family earlier are now dependent upon their family members for the very basics of life due to the disease. With the belief and expectation that the health services would treat their disease, and thus alleviate their sufferings, they seek help from the health services. How has the health services responded towards their needs of dealing with this disruption? What are the crucial elements of responsiveness of the health services that could address the sufferings of these patients caused by the disease is the key question of the research. In order to understand this, it is important to first analyse the patients' endeavours of seeking treatment.

Seeking Treatment

All the patients experienced frank symptoms of the disease like coughing, fever, weakness and acute discomfort in carrying out their hitherto normal life. Most of them delayed seeking help from the help services to the extent possible. It was only when the suffering became unbearable, they sought medical help – private or public.

Bhagwanlal postponed treatment till he fell unconscious after vomiting in the first episode of illness and till he coughed blood in the second episode. Manju's treatment was also deferred till she vomited horrifying amounts of blood. Ida Bano had to suffer for months together to even get to the *hakims* in the vicinity. Is it that Bhagwanlal for his own sake, Shankar for his wife Manju or Nazneen's father delayed seeking treatment deliberately because they simply 'do not understand' due to their 'poor education', as reasoned by the DTO, or they have tougher threshold of bearing their sufferings? Almost all the patients studied here knew the severity of their condition in the second episode of illness and suffered just as much discomfort that it could possibly bring, but still delayed seeking help, not because they were ignorant of the possibility of their condition being the dreaded 'tuberculosis' but because they were struggling with the accessibility[124] of the services and made their choices accordingly. This is evident in the second episode of illness, when the average time of seeking help has ranged from 1-2 months of bearing similar symptoms as during the first episode of tuberculosis. The availability of health services in terms of distance, cost, and timings, as well as accessibility that impact the patient's vulnerability vis-à-vis the health providers are pertinent aspects in service seeking and therefore important to understand. This becomes even more significant in view of passive case finding strategy adopted by the RNTCP.

The patients' experiences of interactions with the health services well explicate the issue of accessibility, and hence delay in seeking treatment. The distance from Parasram's house to the CHC is just about 2 km, but he goes almost twice this distance to seek help from a private practitioner whose credentials are not unambiguous. Hemlata's uncle's house is located within 1 kms from the nearest PHC; still he took her to a private practitioner when she fell ill. Both Nazneen and Ida Bano live within 3 km of the district general hospital. For Udaipur city these are not

[124] Not in terms of availability or distance, but in terms of access defined by the economic and socio-cultural hierarchies and un-equal power relationship vis-à-vis the service provider.

hindering distances, neither any of them complain about distance being an impediment in seeking help from these public services. Udaylal seeks help from his employer to help get medical help, rather than going to the nearby PHC at a stone's throw distance from his house. The deterrence from the public health services is a reflection of a larger collective experience with the health services that people undergo repeatedly in their lives. The patients' experiences here have been no different either, when they ultimately reach the public health services. Nazneen reaches the district general hospital after suffering for over a month from frank symptoms of the disease. There, her mother is told by the physician how she herself was responsible for her daughter's awful condition. She is told that she has produced too many children without even thinking about raising them well, and that she was careless about their welfare. At the hospital Nazneen is treated first for weakness. The doctor failed to take notice of her symptoms and discharge her without doubting that she might be suffering from tuberculosis. Interestingly, a lower staff suggested Nazneen's father to take her to the DTC for ruling out tuberculosis. In other words, Nazneen was not referred to the DTC but going there was purely her father's initiative. Fully aware of their vulnerability, Nazneen's parents seek recommendation from Farida's employer to get their daughter to the DTC. Although Nazneen might have got treatment even without the 'approach', but her parent's fear was not baseless. Shankar had to tip the staff at Badi hospital to utilise some of the facilities available officially free of charge. Radheya had to do the same and also take help from a family friend to feel confident at the Badi hospital.

Most of the patients (six out of ten cases under study) resort to private practitioners as their first help. Bhagwanlal upon falling ill was taken to the nearest nursing home in case of emergency in late night because he could be easily admitted there, even though exorbitantly expensive. Even upon reaching the public services through the private practitioner, Udaylal never found the public health services convenient due to long waiting times, crowding in the OPD and the distance that he

could not cover in his weak condition. Moreover it seemed irrational for him to go so far, spending an equivalent amount on transport, when the same doctor is available nearby privately. In spite of a fee for consultation the doctor gives Udaylal more time, there is lesser waiting time and most importantly, he feels the doctor pays more attention because here Udaylal is not just a patient; he is also a 'customer'. In his perception the payment of a fee for the private doctor's services, makes him attract more attention as compared to the free public health services. A repeat of this can be seen in the case of Hemlata. Her uncle resorts to private practitioner for seeking help for Hemlata, because there they get consultation, medicines and even injections in the same economical package of Rs 25-30, which is good because it provides relief without being advised scores of tests.

All the patients, however, reach the public health services when the private practitioners could not relieve them of their sufferings. This indicates that people still put greater value on the treatment credentials of public services than the private practitioners. When they do not get relief through the easily accessible private practitioners, they continue to look for other options and through collective memory[125] of availability of treatment for such symptoms at the public health services, they resort to it.

The Treatment

Finally when the treatment of tuberculosis starts at the public services, it begins with a pressure by the service provider on the patient to take nearly a solemn oath to abide by treatment. Upon this condition RNTCP through DOTS 'guarantees' cure from tuberculosis. But before start of the treatment, according to the programme protocol, the patients have to furnish a proof of permanent residence. The DOTS provider has to verify it. Address verification and identification of a contact person is conveniently overlooked by the provider. Except in the case of Kheyalilal, Parasram

[125] Most of them reached the public health services from informal referrals.

and probably in case of Ida Bano[126], no address verification has been done. No patient has any knowledge about their DOTS contact person. Every patient and caretaker is told about the importance of compliance to the treatment, including Nandram even though he is not told that he is suffering from tuberculosis. This 'compliance' is limited in terms of presenting oneself for taking medicines at the DOTS centre every alternate day during IP and first day of the week during CP. 'Default' is a serious neglect by the patient and may lead to denial of treatment, as perceived by patients, like in the case of Manju. In between, many patients' caretakers like Bhagwatilal, had to do several rounds of the DTC for dispatch of medicines to their assigned DOTS centre. Nandram and Bhagwanlal had to go to the DTC in any case for getting follow up tests even though the DOTS centre i.e. PHC in their case is within a kilometre of their residence.

None of the patients at the start of the treatment are informed about the possible side effects of the medicines. Few of them who muster the courage to ask after enduring the side effects for a while are not taken seriously by the service provider. For example, in case of Nazneen who endured painful injections, her physical weakness is said to be the reason for the side effects. Most of the patients, however, do have side effects that they do not report in fear of causing any annoyance and the consequent wrath of the service provider.

Although the RNTCP is rigid on the patients about compliance, there are enough instances of non-compliance to DOTS by the service provider themselves. Sitaram, Hemlata, Nazneen and Manju[127] struck convenient arrangements with the DOTS provider to get their supply of medicines at home fetched by some family member. While this arrangement might as well have facilitated their compliance to the treatment, it is neither sanctioned nor acknowledged by the RNTCP. In disguise of

[126] Although Sakeena claims that the nurse visited her residence before starting of Ida Bano's treatment, but this highly doubtful.

[127] As long as she was under DOTS. Later she was shifted to the conventional regimen.

promoting public health concern of reducing the pool of infection, patient care takes a back seat as if public health concerns and patient care were mutually exclusive. It is not recognised that in case of a disease like tuberculosis where the public health concern of reducing the pool of infection in the population can be achieved only through treatment of the active cases and compliance by the patient to the treatment, patient care becomes central to the success of the disease control programme.

The DOTS providers, while relaxing the non-negotiable direct observed therapy under the RNTCP, do not care to inform the patient about the method of taking medicines. The correct way of administering the medicines is not even followed in DOTS, leave apart informing the patient. Two of the medicines under the regimen, Rifampicin and Isoniazid are prescribed to be taken half an hour before meals. However, as a convenient way out, patients are called for DOTS after meals and take all the medicines together in one go. Patients who are able to get the medicines at their home state one more advantage of doing so. They need not popup all the seven medicines within five to ten minutes like at the DOTS centre, but can take it at their convenience. As a consequence of not informing the patients about the correct method of taking medicines while striking a deal for medicine supply at home, patients like Sitaram devise their own unique way unaware of its effect.

The RNTCP protocol requires periodic follow up sputum tests to monitor the progress of the patient. Follow up tests are prescribed at the end of IP, i.e. 2-3 months after initiation of DOTS (based on patient's category), two months in CP, i.e. 4, 5 or 6 months from the start and one at the end of treatment. Except for Hemlata, none of the patients under study had all the prescribed tests done during the first episode of treatment.[128] However, they were declared cured after taking treatment for the standard six months of DOTS for Category-I patients, i.e. new sputum positive cases. The same is found to be true from the DTC tuberculosis register as well. Results for

[128] This does not apply to Udaylal as he was sputum negative and not treated for tuberculosis.

sputum test at the end of IP are not available for 21.4 percent cases. This figure increases to 61.7 percent in CP and is 41.4 percent at the end of treatment. Most of the patients undergo the sputum test at the end of IP because, according to a supervisory staff, the CP cannot be initiated without the test report. Also, the result of end of IP test forms the basis for calculating 'three months conversion rate of new smear positive patients', an important performance indicator of RNTCP. It seems that rather than curing the patient, the focus of the treatment is just to convert the new smear positive cases into smear negative that would no longer spread the disease in the population. This focus of RNTCP is further strengthened by the fact that every dose during the IP is directly observed. This is also the phase when the patient suffers most from the symptoms and is therefore motivated to take the treatment to reduce the discomfort and suffering caused by the disease. Ironically, during the CP, by the time when most of the patients experience symptomatic relief and therefore default according to the service providers, direct observation is relaxed to once a week, i.e. once for every three doses. This form of DOTS is also inconvenient for the patient. When the patient suffers most, he is expected to visit the DOTS centre every alternate day, whereas when his condition improves with two months of treatment and needs more motivation to carry on the arduous treatment, the monitoring reduces.

Relapse of disease

All the patients under study complied with the regimen during the first episode of their treatment to the best of their knowledge. Their single objective was to recover from the disease. If complied properly the programme promised 'guaranteed cure'. The fear of the disease was so much that Bhagwanlal and Nandram continued to visit the DOTS centre for every dose even during the CP, so that they would not forget and miss any dose. The entire treatment for them was DOTS in true sense. For the other patients also, there is no reason to believe that they would not have adhered to the treatment. Yet, the 'guaranteed cure' did not materialise in their cases. Their experiences raise concern about the efficacy and sufficiency of the treatment.

Second Episode of Disease

All the patients revert back to the same public health services even though the much acclaimed 'guaranteed cure' failed. The simple reason for this is that their previous treatment had helped them get relief from the same set of symptoms. However upon seeking help second time, they are grilled about their commitment to the treatment in the last episode. Ramli, for example is not believed even when she claims that Nandram's treatment was completely complied with. In spite of these accusations, patients do not prefer to go to the private practitioners visited by some of them in the beginning of the first episode as it could not provide satisfactory relief. However they do go to the chest specialist at his private clinic and even at Badi because the DTC has not been able to engender confidence in diagnosis and treatment. They continue to stay with the public services because it again 'guarantees' cure from the disease. Relapse of the disease is almost never explained to the patient. The same doctors have expressed shock time and again pretending it to be the first case in their practicing history. However, this shock doesn't help the patient in any way to know that relapse of the disease has arisen out of a rare condition. On the other hand, this experience has definitely made a dent on the patient's faith on the treatment and confidence of cure from the disease. Their immediate concern is to get relieved from the suffering caused by the disease.

Shankar reached for help to the local charity hospital when Manju fell ill with the side effects of DOTS. He feared, based on his experience, that he would surely be shunned away at the DTC, for Manju had 'defaulted' to the treatment which was equivalent to an unforgivable sin. It is different story that the severe intolerance to the DOTS drugs was the reason of this 'sin'.

Hemlata was discharged without any further referral for treatment of her condition. It was again through informal channels that Bhagwatilal was advised to seek help from the chest specialist, a step that was an important link in the detection of Hemlata's tuberculosis. But for Udaylal it was beginning of a gruelling exercise,

since his condition was brushed a side for the lack of bacilli in his sputa which is not a confirmatory test for tuberculosis. The physician didn't apply his discretion but went along the protocol leaving behind patients that don't fall into the majority cases.

Cost of Treatment

For Ida Bano, her dependency on her daughter in law is more than Sitaram's dependency on his son for seeking treatment. Ida Bano has almost no say in the decisions of help seeking, while at least as the headman of the family Sitaram has, which he foregoes due to financial reasons. These factors might have added to the delay in seeking treatment, but upon reaching the health services at DTC, both of them and their likes face the same hardship. Almost all the patients have to get x-rays done from the market, which forms the basis of further diagnosis that is sputum microscopy.[129] As per observation of the researcher for over two weeks at the DTC, all the patients coming to the DTC were advised to get chest x-ray, in many cases even for the extra pulmonary tuberculosis of the neck region. Many attendants accompanying the patient are also advised to get their chest x-ray along with the patient especially in case of a woman attendant from a village, even if the attendant reports of no symptoms. It is plausibly a case of tacit contract between the doctors and the 'x-ray shops' queued up outside the DTC. Aziz had rightly questioned the DTC doctors about usage of the x-ray machine at the DTC which is used selectively and in majority of cases is not used on the pretext that it gives 'unclear' image. Most of the patients are also asked to buy protein supplements and cough syrups. It is worth noticing that the doctors put substantial pressure on the patients to get these, as Shankar clearly narrates. The same practice has been observed by the researcher as well.[130] In some cases these supplements may be necessary but in majority, it is motivated by the same other intention, as in case of x-ray. The retired DTO and the chest specialist accept that these practices do exist at the DTC, which they disapprove

[129] Sputum microscopy is the determining test and x-ray is lesser relied upon in RNTCP and is a major shift from the diagnostic thrust of NTCP.

[130] Before the interview with Shankar (Manju)

but cannot do much about. As a consequence, the 'free treatment' provided by the RNTCP does not remain free for the patient. The patients studied have incurred expenditures ranging between Rs. 1,000 to Rs. 30,000 depending upon the severity and complexity of the disease, duration of hospitalisation, etc.

How do Patients' Experiences Translate into Elements of Responsiveness?

This section examines the elements of responsiveness of health services conceptualised in Chapter-III against the patients' experiences with the services in order to gauge an understanding of what constitutes 'adequate responsiveness' for the patients when interacting with the health services for seeking help to alleviate sufferings caused by the disease.

Treatment

The first element of responsiveness relates to treatment, i.e., 'the health services address the suffering of the patients by treating the disease and in case of a curable disease cures'. All the patients expect the health services to relieve them of their sufferings caused by the disease. They develop this expectation also after enduring the symptoms and postponing treatment to the extent possible. When they first visit the health services they are not aware of the particular disease inflicting them, or at best make a guess based on their knowledge and past experiences. The patients' expectations from the health services, i.e. of treating them, in clinical terms translate into correct diagnosis and treatment consisting of proper advice and medication. Although most patients feel disappointment on of the way the health professionals interacted with them, or that they had to run to the DTC to get their medicines despatched to the DOTS centre, the main reason of their frustration has been the relapse of the disease even after complying sincerely to the so called 'guaranteed' treatment. When it comes to grading of the services, their judgement is mostly based on the treatment. Most of the patients grade the services to be fair to

poor because the treatment failed in their view, and they have to suffer again due to the same disease. However, the reason for some of the patients for grading the services as good is not that they were happy with the treatment, but that the treatment was free. The expectation of getting well from the treatment is a universal expectation of all the patients seeking help from the health services. After all, the defining goal of the health services is 'better health' of the population it is intended to serve, that will in fact result from treatment in case of a disease. Thus the expectation that 'the health services address the suffering of the patients by treating the disease and in case of a curable disease cures' is the most 'legitimate expectation' of the society (which interacts with the health services as individual patients) and should be the most important element of responsiveness of the health services.

The treatment of tuberculosis requires not only accurate diagnosis, but patients to comply with the treatment for a long period of 6-8 months. The given state of poor utilisation of health services,[131] low information sharing, huge social distances, the getting well part of the disease, or in other words, being cured from a curable disease requires an adequate level of responsiveness from the health services. But on the contrary, the patients, evident from the patient experiences, are time and again compelled to comply with the treatment, to endure troublesome side effects as also bear the blame for the relapse of the disease. Various issues pertaining to treatment arise from the patients' experiences as well as the service providers' perspective that need to be responded if the RNTCP has to address curative needs of the tuberculosis patients to achieve the public health objective of reducing the pool of infection and controlling tuberculosis. Many aspects of seeking help coming up from the patients' experience fall in the ambit of treatment and pose bigger questions of responsiveness; such as diagnostic tools, drugs, treatment regimens and the programme's inclination towards reduction in the pool infection rather than patients' care. To begin with

[131] Households rely mostly on an unregulated, unqualified, private sector. MIT and Vidya Bhawan Society, 'Health Care and Health Status: A Closer Look at Tuberculosis', unpublished paper, Udaipur.

reaching the right services becomes important in saving valuable time. The RNTCP operates in a vertical fashion is evident from the poor linkages it draws from its own sister institutions like the district general hospital from where Nazneen is not referred to the next door DTC. The next hurdle is at the diagnosis level. Udaylal and Hemlata faced difficulty in getting their tuberculosis traced plausibly due to the efficiency of diagnostic tools i.e. sputum smear microscopy in tracing the bacilli, which some studies say detects only 45-60 percent of all pulmonary TB cases.[132] The argument given by its advocates is that the risk of excluding some patients from treatment was outweighed by the overall benefit of treating more infectious patients. The patients that cough up fewer bacilli in their sputum therefore are likely to be put behind in the priority of the attention of the health services, even if their sufferings are no less than the highly positive patients, like Udaylal. They are forced to wait for their turn for treatment of tuberculosis till they develop the disease with more severity.[133] Dealing with side effects of the drugs and compliance to treatments are singularly put on the patient.[134] In effect, the patient has to choose between bearing the suffering due to the disease, and suffering due to taking the medicine. Udaylal puts it rightly, that if he has to get well, he should bear the side effects. 'One size fits all' approach has resulted in an absence of any positive discretion applied by the doctors to the benefit of the patient. Udaylal and Manju both are its victims. Udaylal is not diagnosed with tuberculosis, and Manju is given a fixed regimen. Ida Bano is never asked about her previous illnesses besides tuberculosis, nor informed about the choice of treatment she has between DOTS and conventional. All this show a great apathy of the service provider and programme strategies towards patient's treatment and care.

---

[132] Médecins Sans Frontières, *Running Out of Breath? TB care in the 21st century*, March 2005, MSF, Geneva

[133] TB requires 5,000-10,000 bacilli per ml of sputum, the tests sensitivity is reduced in the early stage of pulmonary patients

[134] S. R. Atre and N. F. Mistry, 2005, 'Multi Drug Resistant Tuberculosis (MDR-TB) in India: An Attempt to Link Biosocial Determinants', *Journal of Public Health Policy*, Vol. 26, pp. 96-114.

There is a high level of anxiety among patient regarding the efficacy of the treatment, given the fact that their disease has relapsed, despite an earlier round of total compliance. Because of the little communication between the doctors and the DOTS provider, it is very unlikely that other cases like Manju suffering sever side effects would be reported. There is no provision of any follow-up test after an appropriate time gap after completion of the treatment, by when the medicines would have been washed away from the body, to confirm the cure. Even the prescribed follow-up tests are not being conducted. As the DTC tuberculosis register shows, the sputum test results at the end of IP are available for 78.6 percent cases; test results in the CP is available for 38.3 percent and is 58.6 percent at the end of treatment. There are also no facilities to know if there are cases of drug resistant tuberculosis.[135] With the given levels of information shared with patients and their own modifications in dosage, like in Sitaram's case,[136] it may be the case that some of these patients could be suffering from MDR-TB that has not been addressed by the providers. The programme does not provide for meeting such outcomes of treatment itself for patients. This is due to lack of availability of diagnostic tools and low rate of end of treatment tests. The test facility for MDR-TB is only available at Jaipur (capital of the state of Rajasthan) and the cost of getting tested is very high for the patients. The responsiveness of the health services even in terms of public health appears to be poor as in the case of MDR, which results from poor health infrastructure. It is estimated that MDR-TB may be spreading as fast as by 250,000-400,000 new cases each year globally.[137] The public sector through poor referrals and private sector through irrational drug regimens compound the issue of MDR-TB further. There are also concerns about the wide spread practice by the providers of unnecessarily prescribing x-ray, protein supplements and other medicines like cough syrups etc. to be bought by

[135] MDR-TB defined as resistance to at least Rifampacin and Isoniazid, the two most powerful drugs.

[136] Drug resistance including both the primary and acquired can result out of inadequate treatment, substandard drug use, inappropriate drug combination preparations, or "mono therapy". Atre and Mistry, 2005, 'Multi Drug Resistant Tuberculosis (MDR-TB) in India, p. 100

[137] MSF, 'Running Out of Breath: TB Care in the 21st Century.'

the patient. The appropriate use of information and a strong referral system are also part of the same treatment related responsiveness.

The second group of elements of responsiveness proposed for examining against the patients' experiences are those enlisted by the WHO. This group consists of seven elements, conceptualised as operating in the non-health domain by the WHO. The seven elements are being analysed one by one as follows;

Dignity

In WHO's conceptualisation this refers to respect for dignity of the person, i.e. not humiliating or demeaning the patients. Service providers, e.g. Mukundlal, claim to behave with the tuberculosis patient as a 'VIP' i.e. very important person, as told to them during the trainings of RNTCP. But how does this translate in reality when the patient seeks treatment from the health services is an interesting process. Knowing the cause of their illness as tuberculosis is troublesome for the patient because of the stigma attached to the disease and the long treatment. This is their first blow to their social dignity. As a service provider reports many women are left by their husbands on account of having tuberculosis. DOTS hammers this demeaning aspect of the disease further into them. Patients suffering from tuberculosis many a times perceive the directly observed treatment as demeaning because it makes them feel as if they are incapable or irresponsible with their own health. For example, Nandram started believing that he may not be very responsible in taking medicines and resorted to taking each dose under direct observation. The same is echoed in other patient base studies, "some patients even view DO (direct observation) as demeaning or punitive".[138] In the inherently unequal relationship of the patients and the service provider, dignity doesn't figure as a high expectation of the patient. However, it is certainly an element that the patient wishes to protect while seeking help from the health provider. In all the cases, the patient has been very careful not to ask questions

[138] CDC, Patient adherence to tuberculosis treatment. Cited in MSF, 'Running Out of Breath: TB Care in the 21st Century'

from health providers as it may cause irritation and lead to not only denial of treatment but a scolding from the provider, as cited by Kheyalilal. Rebuking patients coming to health services is not uncommon, but definitely regarded inappropriate by patients and thus should always be avoided in their view. Sitaram for instance is asked loudly to cover his mouth, which he distinctly understands as demeaning tone. It impacts help seeking of patients as they tend to take caution by not inquiring about their illness and ask fewer or even no questions, leading to Nandram not even knowing the name of his disease. Patients such as Sitaram and Manju's husband Shankar are devoid of any hope of decent relation based on information sharing by the provider or themselves to share their difficulties in taking treatment. They do feel it important but dare not even attempt it as they know it would be a self defeating exercise. The impediment to treatment due to this element of responsiveness is that it leads to hindrance of communication from the patient to the provider as in the case of Manju. Shankar was afraid of reporting his wife's severe intolerance to treatment because he was sure to be 'shunned' which definitely has a demeaning connotation for Shankar and in spite of inconvenience due to the distance he seeks help at Badi to relieve Manju's discomfort.

The other aspect of this element is evident in the reflection of larger socio-political inequalities of the society in the health service providers coupled with the unequal patient- provider relationship. Nazneen' mother Farida while seeking help for Nazneen is rebuked by a physician at the district general hospital with a clear bias against her religion, often accused by the likes of the physician as the culprits for the country's 'population explosion'. She is accused of producing 'too many children' and being an irresponsible mother. Helpless Farida, understanding her vulnerability, doesn't even counter this allegation. The doctor's role here is central in making the services inaccessible to this section of people. This inaccessibility is not created due to any shortage of recourses, the often cited reason for the ill functioning of the public health services, but purely on the larger majority mindset getting reflected in the

health services also. Such demeaning aspects of patient care are not separate from the treatment process itself. This can be seen the other way round when Sitaram says that if the patient wants the 'doctor to 'soft talk', the patient should seek help at the doctors' residence in their hours of private practice. Dignity has a price that people are forced to pay. They deem it as a useful way of cutting across social distances of caste and class hierarchies. There is enough evidence across states that health seeking for out-patient care is done on private basis that renders them in heavy borrowing,[139] where as for in-patient care this turns around primarily due to high costs which high and beyond the means of the people seeking help.

Dignity, as an element of responsive is definitely important, but it is not limited to the non-health domain as in the WHO framework. It affects significantly treatment seeking of the patients and could not be separated from the health aspects of the services.

Confidentiality

The issue of confidentiality is important as there is stigma attached to tuberculosis. DOTS as a strategy is insensitive to confidentiality and fails to understand stigma of the disease. Due to this Hemlata and to certain extent Sitaram find following DOTS troublesome. Patients do expect a level of confidentiality due to the nature of the disease. The concept of 'social blackmail' being adopted by the service provider (as stated by Mukundlal) is used as an instrument to build pressure on the patient to adhere to treatment. This element of responsiveness is also not divorced from the health aspect as it is affecting treatment directly and therefore cannot be segregated. People, especially in case of female patients, resort to striking arrangement with the DOTS provider to take medicine at home. Apart form this, the initiation of DOTS after address verification is problematic for families like the parents of young girl who came requesting the nurse to make a home visit with them

[139] According to the MIT and Vidya Bhawan Society study over 80% of the Indian rural debt is due to health reasons that it treatment.

so that she doesn't land up asking their neighbours for the address, resulting into the whole neighbourhood knowing about their daughter's disease. If DOTS holds any incremental value over non DOTS in betterment of compliance, the threat is that this unobserved DOTS could be leading to resistant strains of TB due to incomplete treatments. This reflects another aspect of hurried responsiveness of the health services to the requests of Sitaram, Manju, Hemlata and Nazneen. Although the arrangement of taking medicines at home have added to the patients' convenience, but the health services has also conveniently abandon its responsibility of responsiveness to the needs of the patient.

Autonomy

Autonomy, implying the right to participate in choices about one's own health (including help to choose what treatment to receive or not to receive) is considered important by WHO for respect of the person. Drawing from patients' experiences, this part of responsiveness is again an intrinsic part of seeking care itself. But, this aspect is also not acknowledged by DOTS at all. The treatment regimen is determined by the availability of the patient and the permanency of their address rather than upon their condition. In case of Manju when she develops intolerance Shankar is hesitant to bring her to the DTC because leaving apart choice of treatment, he is afraid of being shunned away by the service providers at the DTC. In other words, he fears the denial of treatment and tries out other methods like going to Badi hospital and resorting to a nearby charitable hospital for getting help for his wife. In case of Ida Bano, Sakeena is not told about the choices of treatment that may have been more suitable for a like patient Ida. Autonomy of choice of treatment can be useful only if the patient is informed about all the choices available, and is helped in choosing the suitable one. This aspect as well, as evident in the cases of Ida Bano and Manju, is not detached from the clinical aspect of treatment. Manju's health could have been better if the DTC had offered her an alternative treatment. 'DOTS works for all' approach hardly leaves any room for decision making on the part of the patient about their treatment.

Prompt attention

Prompt attention, as an element of responsiveness by WHO understanding means immediate attention in emergencies and reasonable waiting times for non-emergencies. Prompt attention is therefore for the very treatment of the disease and this by its very virtue cannot be 'non-health' as conceptualised by the WHO. This is an important expectation emerging from the patients' experiences in seeking treatment. Many of them complain of long waiting time in the public health services. This is the reason why Udaylal prefers to go to the same public services practitioner who sees patients during evening hours on a private basis. This element becomes important for in-patient care. Bhagwanlal, upon developing acute haemoptysis, was taken to the nearest nursing home at a high cost, even though the district general hospital is 5 kms away from his residence. But due to poor accessibility and the poor referrals as seen in the case of Nazneen and Manju, it was rather wise of Bhagwanlal's family members to take him to the nearest private facility that gave him prompt attention, the most expected aspect from the provider at that point of time. It is the failure on this front that has lead people to increasingly depend upon private providers as they are not shunned away for their problems as in the public health services. Manju's case makes a case for the necessity of this element of responsiveness, as she upon developing side effects due to drugs and herpes anticipated, and also later denied, treatment from the tuberculosis related facilities. Shankar thus had to resort to the near by charity hospital for help.

Quality of basic amenities

According to the WHO's conceptualisation this element of responsiveness translates into decent cleanliness, hospital food etc. De Silva points out that responsiveness domains will vary in their significance with socio cultural milieu and the legitimate expectations will vary changing these domains. For example inadequate infrastructure; sleeping on the floors is generally acceptable in tropical countries but not in developed or cold countries. The most important variation to this is however,

the quality of the basic clinical amenities like a functional x-ray machine and not about the benches and floors, as seen from the patients' experiences. The inadequacies and non availability of diagnostic infrastructure for example have led the patients to get tests done from the market which has formed most of the direct cost borne due to illness. Thus the core of this expectation pertains to the treatment itself and cannot be divorced from it and therefore cannot be put only as non-health. Similarly non-functioning of the staff, like delays in reaching of medicines in case of Hemlata are also lack of this intangible aspect of infrastructure. There is another dimension of this element coming from the patients experiences, and closer to the understanding of WHO, but has implications on the treatment. in cases where in-patient admissions are required, like in the case of Bhagwanlal, who has to be taken care of by his wife, Radhey who is non-literate and feels insecure of the idea of going to Badi hospital. She seeks help by tipping the lower staffs at the hospital. Manju, similarly is discharged from the hospital when there is no one to attend to her at the hospital. It is evident from Manju's case who is in a way denied of the required in-patient care due to lack of availability of in-patient care staff and also the plight of the family members for whom it is difficult to take care and attend her in the hospital. Shankar describes the tactics he uses to get the hospital staff support indicates the lack of this element of responsiveness in care from the health services. The lack of this element adds to the direct and indirect costs like loss of income for Shankar while attending to his wife. The requirement of a family attendant is a very common phenomenon in Indian public sector hospitals. Whereas, there are almost no facilities for theses attendants in the hospital that can support or facilitate their stay there, instead they are rent seeking sources for the support staff who become as important as the doctor during in-patient stay due to the same vulnerability and dependency. Examples of inadequacy of this element can be seen from the outsides of any public hospital in terms of various diagnostic facilities queued up outside and scores of people, in the premises who are there for looking after their near and dear ones, cooking and sleeping on the floor sometimes for many days together.

Access to social support networks

This element identified by the WHO means, access to social support networks from family and friends for people receiving care. This element also undergoes change in view of the long process of treatment seeking and frequent interactions with the health services, the sufferings caused by the disease, and discomfort due to drugs and the stigma related to the disease. These all bring it nearer to treatment. Since there are no counselling supports, a much needed component in the programme, the significance of this becomes high. The patients experience shows that there is a high need of looking after the patient due to his/ her condition. The patients interviewed have such support from their families. Since the region has high rates of seasonal out migration, and also in cases of women who have been left by their families on account of their disease, there is a need of support systems to continue with the treatment. This is a complete blind spot for the RNTCP. Rather than providing support to such patients, it uses 'social blackmails' to push the patient towards the unconditional compliance. There is no scope in DOTS for patients to register their frustration and if this is not taken into account soon, it may lead high rates of unreported[140] treatment interruptions.

Choice of provider

In the WHO framework, it means the freedom to select which individual or organisation delivers one's care. The patients[141] do make a choice and this is intrinsically linked with the treatment. But this freedom of choice is 'freedom' in its true sense only when there is uniformity of information. On the face of the freedom it appears to be a consumerist freedom arising out of the choice of various providers available and the patient is 'free' to make his 'best' choice. But, due to the very nature of unequal provider-patient relationship which is reinforced by the asymmetry of

[140] The abysmal reporting condition is evident from the state of the Tuberculosis Register kept at the DTC. One can expect even lower attention to record keeping in the peripheries. Interestingly it forms the basis of monitoring and reporting and Rajasthan and Udaipur comes under the 'well performing districts.

[141] Family members on their behalf.

information this is not a simple choice.[142] So the guiding principles are devised by the patients based upon availability, accessibility and intertwined in this getting a definite cure through a line of treatment to alleviate sufferings. However, this principle in reality has many flaws. Can Nandram who doesn't know the name of the disease he is suffering from make a 'rational choice' regarding his service provider? But he actually is as he is getting treated by rational regimen proposed by the international body WHO. He doesn't need to know all these details to make his choice because a public health services is present where he can get treatment without being duped much.[143] But even in the best conditions of patient awareness, this is of limited use as the patient's vulnerability can only be protected by a publicly regulated health services system.

Some patients studied in this research exercised the choice making in terms of seeking initial help from private practitioners but since the relief was short lived they resorted to the public health services. Availability of 'free and guaranteed treatment' makes it a viable option for the help seekers. Although there shouldn't be any coercive method used for the patients enrolled for treatment, especially for a treatment regimen like that of DOTS, this element has limited applicability in a the context of India, where health utilisations are low, debt due to health is high, and other indicators like mortality and morbidity denote a poor performing scenario.

Information sharing

Another element of responsiveness conceptualised for the study is the information sharing between the service providers and the patients. Information sharing means health service providers share proper (and correct) information with the patient/family regarding the cause and treatment of the disease, including the possible side effects and precautions to be observed during treatment. The known possibility of recovery from a disease condition etc. is shared with the patient/family.

[142] The patient having less information vis-à-vis the provider i.e. the physician.

[143] Only due to the unscrupulous practices of the providers.

This element pertains to treatment and the also assists the choice made by the patient. It involves the participation of the patient, which is completely absent in the cases of patients studied. Information sharing is minimal on account of 'illiteracy' or 'ignorance' and plausibly also to maintain the knowledge supremacy by the service provider by maintaining the gulf of information as wide as possible to further the 'patron-client' relationship and rent seeking. On the other hand the patients have been reluctant in communicating with the provider. The lack of communication due to the possibility of inviting the wrath of the provider has resulted in un-prescribed intake of drugs in the case of Sitaram. It has resulted in non- reporting of side effects in the case of Manju and Kheyalilal. Kheyalilal sought the help of the DTC rather than his own DOTS provider or the doctor at the CHC from where his treatment was going on. He further doesn't report this help seeking to his doctor on account of inviting his irritation. But the classic case of lack of information is that of Nandram, who apart from not knowing his disease participates in a tuberculosis awareness rally on the occasion of World Tuberculosis Day.[144] But the reason of this dummy participation is to keep the service providers happy by doing what he is asked to do. The inequality of the relationship can be utilised in a positive manner as done in the case of the chest specialist, who gives the only reasonable answer i.e. in the case of Manju where he admits that the disease can reoccur and explains reason of it in lay person terms, unlike his associates at the DTC. It is established from these case studies that having information on certain key aspects of the disease and suffering helps, e.g. name and nature of the disease, the precautions to be observed and till when, the importance of taking treatment without defaulting, and the chances of getting well. In reality, however, a twisted route is taken by the service providers like giving little or no information regarding the nature of the disease, overemphasis on compliance with the sole focus on DOTS, assuring a guaranteed treatment and expression of shock and victim blaming when reporting back of symptoms. There are other strategy adopted

[144] On the 24th March 2005.

by the service providers like that of obligation in striking a convenient arrangement for a non-DOTS treatment like in the case of Hemlata, Sitaram and Nazneen, and in availing of free treatment of relapse tuberculosis in case of Nazneen by the doctors. In the words of Ramli, "*We don't expect much but, I would have appreciated if they had told us the name of the disease. I don't know exactly how that would have helped, but at least it would give us some idea for our own sake.*"

Conclusion

The above discussions establish the importance of responsiveness of health services in enhancing their utilisation and effectiveness. If responsiveness has to play its role in improvement in the health services, its elements must be defined from the patient's perspective and can not be divorced from the health and treatment aspects of the health services. The WHO's prescription of responsiveness – the seven elements operating in the non-health domain may be applied to those countries where the health services are delivering their prime responsibility of treatment very effectively and equitably across social and economic classes. In those conditions it might be an interesting exercise to see if elements like dignity, autonomy and hospital amenities and food could enhance patient satisfaction and make them 'feel good', without impacting on their 'health'. But in developing countries like India, marred by a plethora of issues, where the availability and accessibility of services, quality of treatment, inequitable relationship across social and economic classes and the hindrances created thereof are all major concerns, the exercise of divorcing responsiveness from the health aspects would be futile. The elements of responsiveness as discussed above are interrelated among themselves as well. However, they may vary in importance.[145] Seen from the patient's perspective the element of treatment would be the most important part of responsiveness. Whereas, for example, access to social support networks as defined as an element under

[145] As also pointed by de Silva, that different elements of responsiveness will have different importance. The socio economic forces will determine their importance, in different countries differently. But this is remains in the non health domain according to de Silva, as stated earlier in this document. de Silva, 'A Framework for Measuring Responsiveness', p. 5

responsiveness would play a lesser role in Indian context, as in most of the cases the patient's family is there to support. A challenge for the planners and managers of the public health services would be translate the responsiveness framework into practice. For monitoring responsiveness, its measurement will be necessary. Further research is required to devise ways of measuring responsiveness in a manner so that it does not get disconnected from the patients.

There are certain aspects that will remain outside the ambit of the health services, like distance of Badi hospital from Hemlata's house, or the climb to Nazneen's home, her mother thus cannot take her to the doctor at DTC all by herself, or that Sakeena has to look after her ailing mother in law all by herself. But there are issues here that may lessen these hardships like the timings of the hospital that would have allowed Nazneen's father to take her to hospital earlier only if it didn't meant losing precious income by forgoing the peak hours of work for him. He could have taken her in late afternoon hours when he doesn't have many passengers. The questions here are; like how would it lessen Nazneen's suffering if DOTS was provided to her after school hours, or if in severely ill cases such as Ida Bano to get DOTS at her home? It will need more evidence to know the exact increase of compliance to DOTS by adopting these measures, but it certainly doesn't need any more evidence than the experience of Nazneen or Manju to know that more flexibility in the hard structured disease control programme would have made dealing with the disease a lot easier for them.

Patient interaction with the health services for these tuberculosis patients has met only the pathological aspects of the disease in alleviating their suffering to a considerable extent and is also of contention. The physical suffering and economic changes in their lives brought in by the disease are left for them to deal with. Their social relationships are also their private struggle.

A look at the barriers

The study brings up some concerns regarding the RNTCP and issues for implementation which can be highlighted as follows:

- Usage of DOTS requires more caution and sensitivity not only for the biological implications i.e. of creating MDR-TB, but also of the social aspects that instead of alleviating the suffering of the patient, many a times it aggravates it.

- Weak referrals even within the public health services are an important aspect for the point of view of the getting high rates of detection and cure with passive case finding strategy.

- Counselling is important for better coping of patients with the disease. It would also lead to increase in compliance. It would also improve reporting of side effects and help in dealing with them. "There is evidence from developed countries that satisfied patients are more likely to comply with medical treatment, provide relevant information to their health care provider and continue using medical services. In developing countries it has been observed that patient satisfaction will influence utilisation of services and compliance with practitioners' recommendations."[146] Turning a blind eye towards the absence of these side effects doesn't help the patients.

- The irrational pattern of staffing cited by Mukundlal is of paramount importance. In settings where the state coordinator of the programme puts little significance to the role of the monitoring staff like the STS, who gets paid lesser than the peon is bound to create problems. A human service organisation like the health services has to settle such issues first to draw compassions for the people who go to seek help from them as their

[146] C. Darby, N.B. Valentine, C.J.L. Murray and A. de Silva, 'Strategy on Measuring Responsiveness', GPE Discussion Paper Series No. 23, EIP/GPE/FAR Geneva: WHO.

beneficiaries. In a dissatisfying ambiance for the service providers themselves, it is unlikely that they can adequately respond to the patients.[147]

"Experiences across boundaries of time and place have shown radical differences in the ability of different populations to comply with demanding therapies, whether they may be admonitions to move away from "consumptive climes", as in the previous century, or exhortations to take a year's worth of costly drugs. Most new studies describe programme failure as alternatively patient-dependent, or drug-dependent, or project dependent. But underlying these distinctions are broader theories about the *nature* of these barriers."[148]

The above mentioned concerns of RNTCP are not apart from the issue of responsiveness itself. There is a need to bring in these changes that will deal with issues pertaining to the needs of the patients into the programme for enhancing the effectiveness of the programme to deal with the disease itself. Public health concerns and patient care are two sides of the same coin, especially in case of disease like tuberculosis, where disease control is only possible through treatment of the patients. Neglecting patient care will not improve the public health. They are not substitutable but additive and complementary. The collective public memory will feed into the larger society leading to its effects on the utilisation of the health services. It is only when these aspects of care will work in tandem as a whole that the elements of responsiveness can result and the health services can become responsive in alleviating the suffering of the patient and also achieving the goal of public health which are not mutually exclusive as evident from this study.

[147] The WHO Global TB Report, 2005 acknowledges personnel problems, understaffing and need of training, in India as an obstacle to DOTS implementation.

[148] Farmer, P: "Inequalities and Infections: Modern Plagues", University of California Press, p 227

Interviewing the Patients and the Service Providers

The study is based on qualitative research tools. Detailed interviews have been conducted with the patients for preparing their case studies. Similarly, the service providers have been interviewed to get their perspective on the public health services. Before conducting the field work, pilot testing of the tools was done at the Gulabi Bagh chest clinic in Delhi, where three tuberculosis patients, a DOTS provider and a medical officer were interviewed. This helped in refining the interview guide for the primary research.

The primary work for the study was done in Udaipur city of Rajasthan during the month of April 2005. Ten relapse patients of tuberculosis undergoing treatment were identified from the TB Register at the DTC. Apart from relapse cases, there were no other criteria for selecting the patients. The names and addresses of patients were provided by the STS. The interviews were conducted either at their residence or at their work places according to their convenience. On average, each interview was conducted in two sittings. The patients were informed about the purpose of the interview. They were also told that to give the interview or not was purely their free wish and that it would not affect their treatment in any way. All the ten patients and their family members readily agreed to cooperate with the researcher. Their treatment slips and other related papers have been taken into account for gap filling where ever possible and needed. The identities of the patients interviewed have not been shared with the service provider, so as not to affect their treatment in any way.

The families of patients' were included during interviewing as it is the family that decides at some point of time for the course of treatment and chooses the provider. Family members have also been included for their participation to get better treatment details and a collective experience of suffering and interaction with the health services. This also helped as a trust building exercise. The interviews are carried out in a discussion mode and the respondents are encouraged to speak as much as they wish to share their experiences.

The medium of the interviews with the patients was Hindi and the local dialect Mewari. The interviews were recorded with the permission of the patient and family. These were later translated in English to prepare the case studies for the research.

An interview guide with the following check list was used:

1. Patient profile: name, age, caste, religion and occupation of the patient.
2. Family profile: number of persons in the family, head of the household, occupation of the head of the house hold/ breadwinner, average monthly income of the family.

3. The Disease: time and nature of occurrence of the initial symptoms of the disease, duration of the symptoms, coping mechanism, like seeking help or home based remedies.
4. First help sought: how and why was help sought to deal with the symptoms, nature of the help sought, location of the service provider, type of care provider, diagnosis involved and outcomes of the exercise. Any other reference made or taken.
5. Duration of relief if any. Second help sought if any. Why? (Repeat of 4.)
6. Knowing tuberculosis: when and how was patients' tuberculosis detected? What were the diagnostic tests and other examinations conducted. What questions did the physician asked the patient?
7. What was the initial reaction, thought of the patient or the family members on knowing one is suffering from tuberculosis.
8. Treatment: the process of reaching the public health services (referrals, informal channels, or one's own initiative or a mix of all these). What information was shared with the patient/ family regarding the illness, causes of the disease, possibilities of getting well, precautions need to be taken, duration and nature of these precautions, length of treatment, dietary aspects, method of taking medicines and rules asked to be followed if any.
9. Direct and indirect cost of seeking help.
10. The behaviour of the health workers, availability of staff at the facility, duration of the time spent in waiting and with the doctor. Remarks on conveniences of timing and location to understand accessibility.
11. Getting ill again: when did the symptoms appearing again, what steps did the patient take this time, reasons of these steps, etc. How does the family/ patient reasons out the return of the illness? (Repeat of 3-10 in reference to the second episode of illness).
12. Impact of being ill: What are the works, activities the patient is unable to do due to illness that was a part of normal life earlier e.g. attending school for a student?
13. The social aspects: who are the people who know the nature of the patient's illness? With the view of the stigma attached to the disease, did the patient face any problems? What were the reasons in either case?
14. Burden of care: Can the patient manage his/her routine chores? Who looks after the patient? Tuberculosis requires long periods of attention from the health services and the family for recovery. How does the family cope with this?

15. Grading: to redefine the experience with objectivity and to overcome the researcher's bias if any, grading is done to gauge the overall experience of treatment for the family/ patient and reasons to qualify this grade.

Apart from the 10 patients, six doctors at different roles and two supervisory staff and one support staff were interviewed to gauge the health service providers' perspective. They were interviewed to learn their understanding of the programme, their role and obstacles that they face during the course of service delivery. There was variation from the role of one service provider to another and thus the focus of interview pertained to that. The interview guide for the service providers contained the following:

For NGO doctors;

1. Profile- name, post and location
2. Their view on NTP and RNTCP. Their view on the changes and programme impacts.
3. The successes and failures of the programme.
4. How does the programme respond to patients needs? What are the patient friendly and unfriendly factors in their view?
5. Limitations of the programme and the need to improvement.

For– public sector health services doctors: In addition to the above the interview contained the following:

1. Work profile – major responsibilities in the programme.
2. Performance issues if any.
3. Ranking/ grading of the programme in their work area.

For supervisory staff;

1. Profile- name, post and location
2. Background and experience. Training attended.
3. Their view on NTP and RNTCP. Their view on the changes and programme impacts.
4. The successes and failures of the programme. What are the pressures of performance if any? What happens in case of successes or failures?
5. How does the programme respond to patients needs? What are the patient friendly and unfriendly factors in their view?
6. Limitations of the programme and the need to improvement.
7. Ranking/ grading of the programme in their work area.

BIBLIOGRAPHY

Atre, S. R. and N. F. Mistry, 2005, 'Multi Drug Resistant Tuberculosis (MDR-TB) in India: An Attempt to Link Biosocial Determinants', *Journal of Public Health Policy*, Vol. 26, pp. 96-114.

Baily, G.V.J., 'Evolution of the National Tuberculosis Programme: An Operations Research Approach', *Health Administrator*, Vol. 15, Nos. 1-2, pp. 1-5.

Banerjee, A., Deaton, A. and Duflo, E., 2003, 'Health Care Delivery in Rural Rajasthan' (unpublished) Seva Mandir, Udaipur.

Banerji, D. and S. Anderson, 1963, 'A Sociological Study of Awareness of Symptoms among Persons with Pulmonary Tuberculosis', *Bulletin WHO. Bulletin WHO*, Vol. 29, pp. 665-683

Banerji, D., 1983, 'The Approach of Primary Health Care and India's National Tuberculosis Programme', Dr. N.L. Bordia Oration of 1983, Annual Conference of the Madhya Pradesh Tuberculosis Association, 1983, Rewa.

Banerji, D., 1998, 'Increasing the Effectiveness of the Revised National Tuberculosis Control Programme', *Indian Journal of Tuberculosis,* Vol. 45, pp. 223-226.

Baru, Rama V. and C. M. Kurian, 2002, 'Towards an Expanded Conceptualisation of Quality in Public Health Services', , Dialogues on Strategies for AIDS control in India, Workshop on Societal Concerns and Strategies for AIDS Control in India, New Delhi, CSDS and CSMCH, JNU.

Baru, Rama V., 2004, 'Abdicating Responsibility', *Seminar*, No. 537 (May), pp. 46-49.

Blendon, R. J., *et al.*, 2001, 'The Public versus the World Health Organisation on Health System Performance', *Health Affairs*, Vol. 20, No. 3. pp. 10-20.

Calnan, M.W. and Sanford, E., 2004, 'Public Trust in Health Care: The System or the Doctor?', *Quality and Safety in Health Care*, London, Vol. 13, pp. 92-97.

Chakraborty, A.K., 2001, 'Tuberculosis Program in India: Current Operational Issues', *Public Health and the Poverty of Reforms: The South Asian Predicament*, eds. Qadeer, I., Sen, K. and Nayar, K.R., New Delhi: Sage Publication, pp. 339-360.

Coalition of Health Advocates, *Tuberculosis Control Report Card*, 24 March 2005, http//:www.infochangeindia.org (Accessed on 3 July 2005).

Darby, Charles, Nicole B. Valentine, Christopher J.L. Murray, A. de Silva, 2000, 'Strategy on Measuring Responsiveness', GPE Discussion Paper Series No. 23, EIP/GPE/FAR Geneva: WHO.

de Silva, A., 2000, 'A Framework for Measuring Responsiveness', GPE Discussion Paper Series No. 32, Geneva: WHO.

Department of Health, *The New NHS: Modern, Dependable*, London, 1997.

Dubos R. and Dubos J., *White Plague: Tuberculosis, Man and Society*, first published 1952, 2nd edn.; New Brunswick, NJ: Rutgers University Press.

Entwistle, V. A., *et al.*, 2003, 'Public Opinion on Systems for Feeding Back Views to the National Health Services', *Quality and Safety in Health Care*, London, Vol. 12 No. 6, pp. 435-42.

Farmer, P., 1999, *Inequalities and Infections: The Modern Plagues*, California: University of California Press.

Gostin, L., *et al.*, 2003, 'The Domains of Health Responsiveness: A Human Rights Analysis', EIP Discussion Paper No. 53, Geneva: WHO.

Banerjee, A., *et al*, 'Health Care and Health Status: A Closer Look at Tuberculosis', unpublished paper by MIT and Vidya Bhawan Society Research Team (Udaipur).

Homedes, N. and Ugalde, A., 1993, 'Patients' Compliance with Medical Treatments in the Third World. What do We Know?', *Health Policy and Planning*, Vol. 8, No. 4, pp. 291-314.

Khatri, G. R. and Thomas R. Frieden, 2002, 'Controlling Tuberculosis in India', *NEJM*, Vol. 347, No. 18, October 31.

Kishore, J., *National Health Programmes of India*, 2001, 3rd edn., New Delhi: Century Publication,.

McKeown, T., 1972, 'An Interpretation of the Modern Rise of Population', *Population Stusies*, Vol. 26, No. 3, pp. 345-382.

Mechanic, D., 1969, 'Illness and Care', *Poverty & Health: A Sociological Analysis*, eds. Kosa, J., *et al*, Cambridge, pp. 191-214.

Medecins Sans Frontiers (MSF), 'Running Out of Breath: TB Care in the 21st Century', available at http://www.msf.org, accessed 18th March 2004.

Ministry of Health and Family Welfare, Government of India, 2003, '*Annual Report 2002-2003*', New Delhi.

Murray, C.J.L. and Frenk, J., 2000, 'A Framework for Assessing the Performance of Health Systems', *Bulletin of the World Health Organisation*, Vol. 78, No. 6, pp. 717-731.

Murray, C.J.L., Kawabata, K. and Valentine, N., 2001, 'People's Experience Versus People's Expectations', *Health Affairs,* May/June 2001, pp. 21-24.

Narayanan, P.R., Santha, T. and Paul, K.P., 'Tuberculosis Control Strategies: Challenges to Health Management Research', *Health Administrator*, Vol. 15, No. 1-2, pp. 113-117.

National Health Policy 2002, Ministry of Health and Family Welfare, Government of India, 2002.

Nayar, K. R., 2005, 'Sociology of Tuberculosis: Dissecting a Public Health Classic', *Journal of Health and Development*, Vol.1, No.1, pp. 11-14.

Nelson, K., 2004, 'Determining the Course of Tuberculosis in Patients Registered under DOTS', unpublished, Seva Mandir, Udaipur.

Park, K., *Preventive and Social Medicine*, 1997, 15th edn., Jabalpur: Banarasidas Bhanot Publishers.

Pickard, S., 2003, 'User Responsiveness in Health Care', *Quality and Safety in Health Care*, London, Vol. 12, No. 6, pp. 403-4.

Qadeer, I., 1994, 'New Strategy for TB Control: Some Issues?', Paper presented at a workshop on TB programme, CSMCH, JNU.

Qadeer, I., 1995, 'Primary Health Care-A Paradise Lost', *IASSI Quarterly*, Vol. 14, Nos. 1&2, pp. 1-20.

Rangan, S., *et al*, 'Tackling Tuberculosis in Urban Areas: Experiences from Mumbai City', *Health Administrator*, Vol. 15, Nos. 1-2, pp. 72-79.

Report of the Health Survey and Development Committee, Government of India, 1946.

Ritu Priya, 2005, 'Public Health Services in India: A Historical Perspective', *A Review of Health Care in India*, eds. Gangolli, L.V., Duggal, R., Shukla, A., Mumbai: CEHAT. pp. 41-72.

Rosen, G., *History of Public Health*, 1998, New York: MD Publications.

Szreter, S., 1999, 'Rapid Economic Growth and "the Four D's of Disruption, Deprivation, Disease and Death": Public Health Lessons from Nineteenth Century Britain for Twenty First Century China?', *Tropical Medicine and International Health*, Vol. 4, No.2, Feb., pp. 146-52.

Tuckett, D., 1976, 'Doctors and Society', *An Introduction to Medical Sociology*, ed. Tuckett, D., London: Tavistock Publication. Pp. 369-395.

Uplekar, M. and Rangan, S., 1995, 'Alternative Approaches to Improve Treatment Adherence in Tuberculosis Control Programme', *Indian Journal of Tuberculosis,* Vol. 42, pp. 67-74.

Uplekar, M. and S. Rangan, 1996, *'Tackling TB: The Search for Solutions'*, Pune: Foundation for Research in Community Health.

Valentine, Nicole B., *et al.*, 2000, 'Estimating Responsiveness Level and Distribution for 191 Countries: Methods and Results', GPE Discussion Paper Series No. 22, Geneva: WHO.

VHAI, 1994, *Report of the National Consultation on Tuberculosis*, New Delhi.

WHO Report 2005, Global Tuberculosis Control – Surveillance, Planning, Financing, World Health Organisation, 2005.

World Health Report – 2000, World Health Organisation, 2000.

URL

http://www.infochangeindia.org

http://www.msf.org

http://www.ntiindia.kar.nic.in

http://www.stoptb.org

http://www.tbcindia.org

http://www.who.int