



# Wells for India

Bringing water and dignity  
to the poorest people of rural Rajasthan

## Community Health in the Thar Desert (Gramin Vikas Vigyan Samiti)

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## 1. Introducing the Thar Desert and Gramin Vikas Vigyan Samiti

Rajasthan is India's geographically largest state, and is home to nearly 60 million people. This diverse population inhabits a land full of contrast, from the Eastern greenery to the hills of the South and the dry deserts of the North and West.

The Thar Desert extends over more than half the state, a vast arid plain sloping from the Aravalli Mountains of central Rajasthan to the North Western border with Pakistan. With a total of 23 million inhabitants residing in the state of Rajasthan, the Thar is the most densely populated arid zone in the world. Settlements are typically villages and small towns scattered across the arid region, with little nucleation and large tracts of land given over to agriculture.

The monsoon rains of July and August deliver an average of 200 mm a year, but rainfall can be as low as 100 mm. Rains are patchy, leading to severe shortages in certain areas. Agriculture and animal husbandry, the main occupations of desert villagers, are dependent on the scarce water supply. Farmers and herders are at the mercy of the environment, and in drought years shortages of water precede crises that resound through many aspects of desert life, not least public health. Drought conditions have prevailed in recent years, leading to deprivation and hardship. The wealthy may turn to alternative water sources such as tube wells and piped supplies, however, for many poor villagers pipelines are not accessible and they are left to rely on emergency tractor-pulled tanker supplies provided by the government or by NGOs.

Water is not the sole issue. The soil of the desert is sandy and saline; in places sand dunes render large areas unavailable for cultivation. The constant dry wind erodes the loose topsoil of the fields, reducing its capacity still further. Forest cover is sparse, but a range of desert trees and bushes do provide essential food, fodder, and building resource in addition to sheltering the fields.

In this harsh environment, returns are low for the majority of inhabitants, resulting in a low level of social development. This is reflected in associated development indicators such as low literacy rates, low life expectancy, and increased incidences of disease, high infant mortality and maternal mortality rates, exceeding the national average. The burden is not equally shared – the low societal status of women, discrimination against scheduled castes and tribes, and neglect of the elderly cause these sections of society to bear greater ills. All together, inequality, water shortages, crop failures, debt and sickness create a vicious circle of poverty, disease and loss of productivity.

Healthcare is a major issue in the development of the desert. Although a government health infrastructure is in place, it is crippled by lack of resources. Awareness of government health programs is low. A large number of people therefore have no access to adequate, appropriate, and affordable healthcare. Those who suffer the most are the marginalized sections of society – the poor, scheduled castes and tribes, women, girl children and the elderly.

The desert population suffers from serious infectious diseases like malaria and TB, and a full complement of intestinal and respiratory infections. Pregnant women suffer before and during delivery, and many will lose at least one child to disease. A lack of basic health and hygiene knowledge leads to late diagnosis, incomplete treatment, and further spread of a serious disease. Poverty and malnutrition both cause and compound the problems, and make it unlikely that the health concerns of the Thar desert will be solved by improved medical care alone.

Healthcare is but one area in which the gap between rich and poor is growing fast. In modern India, those who can afford it have access to the very best of medical expertise and technology. Those who cannot pay suffer from preventable and treatable illnesses. As ever, due to their situation the poor are more vulnerable to sickness than the wealthy – malnutrition, poor sanitation and lack of education contribute to the prevalence of diseases. The situation is particularly marked in remote areas like the Thar Desert. Health policy is also an issue. The 'top-down' approach of government health planning is not well suited to addressing community health in impoverished rural India.

Despite their afflictions, the people of the Thar remain spirited, dignified and resourceful, with a strong inherent sense of community. Traditional methods of water and land management, drawing on centuries of knowledge, are still used to maximize the yield from the arid soil. The rich tradition of crafts and artisanship in the region is another potential source of income. However, a decline in traditional farming practices over the years has resulted in severe deprivation and underproduction in many areas of the desert. Levels of handicraft production have also fallen, thus in times of hardship villagers rely on loans and on labour in the stone mines for income.

Gramin Vikas Vigyan Samiti, or GRAVIS, was founded in 1983 by its current Director Laxmi Chand Tyagi and his wife, GRAVIS Secretary Shashi Tyagi. PICTURE 3 – TYAGIS The Tyagis are both Gandhian activists inspired by the *Sarvodaya* (all-rising, self help) movement. The Gandhian ideals of community empowerment and self sufficiency are the guiding principles of GRAVIS. Over the past 22 years, the GRAVIS has sought to guide rural communities to *Gram Swarajya*, or village self-rule, through holistic development and reconstruction programs. By generating awareness among villagers, reviving traditional farming and water harvesting practices, motivating women, and improving health care and education services, GRAVIS promotes sustainable social development. The emphasis at every stage is the continuing involvement and empowerment of the entire local community, regardless of caste, gender or income status. In every village where GRAVIS works, a Village Development Committee (VDC) is founded comprising of representatives coming from the local community. The committee takes all the key decisions about programs such as who shall benefit from programs, what needs to be done, and when. The emphasis is laid on assistance of the marginalized or disadvantaged sections of society – women, the elderly, children, backward castes and those below the poverty line.

Health care is an important area of GRAVIS activities. GRAVIS coordinates ongoing projects for the improvement of health awareness, ante- and post natal care, nutrition, malaria control, and health care access. In addition, several collaborations with International donor agencies, Indian government and partner NGOs have arisen in the areas of eye care, care of the elderly, TB, and child development. GRAVIS' health resources include a 50-bed field hospital in Jodhpur district, and the field centres serve as training camps for village health workers. An eye care unit has recently been constructed at the hospital with the support of Sight Savers International.

It is difficult to isolate health-related activities from other areas, as all of the GRAVIS development projects have an eventual bearing on health. As a testimony to the holistic approach, this difficulty is to be expected and welcomed. However, this report focuses on describing the challenges facing Public Health in the Thar Desert, and on GRAVIS' direct efforts in meeting them. The conclusions drawn by the report will endeavour to provide a basis for future work and for the expansion of current projects.

## 2. The state of affairs: factors affecting health in the Thar Desert

Public Health is about more than merely providing doctors to treat disease. There are many factors that contribute to a community's health. These include the community's level of development, their vulnerability to diseases, awareness of health, and access to treatment. Poverty underlies many health problems. Therefore, the 'vertical' approach, where diseases or problems are specifically targeted by medical intervention, is slow and less effective. Vertical schemes are usually worked out bureaucratically, with little consideration for the practical realities of the recipients' physical and social situation. Examples of this include government health programs focused on family planning or TB treatment. Measures for sustainable improvement of Public Health need to be 'horizontal', meaning integrated or holistic. Prevention of disease through involvement of the community, raised awareness, early diagnosis and accessible treatment is the mainstay of success in Public Health. The issues giving rise to ill health must also be addressed. The provision of primary health care is undoubtedly important, but the population's well being must be understood within its own context, taking into account all factors which have a bearing on health.

This section thus describes the current public health situation in the Thar with regard to healthcare provision, environmental issues, and social factors. The term 'community health' has been coined as a more appropriate description of primary health care, as it is measurable in terms other than disease statistics. The 'public' is vast, distant, demanding and complex; a 'community' approach breaks the barriers and allows the connection to the realities of people's daily lives to be made.

### i. Healthcare provision<sup>1</sup>

The government healthcare system in the Thar is based on the proposals of the National Health Policy. This was drafted in 1982 as a response to the global 1978 Alma Ata declaration of 'Health for All' by the year 2000. The rural healthcare hierarchy is set up as follows:

For every 3000-5000 people (*panchayat*): 2 Auxiliary Nurse Midwives (**ANMs**), one male, one female, as the staff of a **sub-centre (SC)**.

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<sup>1</sup> With reference to VHAI report, 2000

For every 30,000 people: at least one doctor (**Medical Officer**), plus technical and paramedical staff, at a **Primary Health Centre (PHC)**. One PHC supports 6 SCs.

For every 80,000-120,000 people: a **community health centre** with at least four doctors, serving around 4 PHCs, as a specialist referral centre.

In the Thar, this coverage has not been achieved. Provision of higher care, in particular CHCs, is severely lacking. Less than half the requisite number of CHCs exist in the region, although coverage by sub-centres is numerically adequate. In addition, there has been a lack of interest among government health staff about motivating the rural population on health issues, and hence, there seems to be a gap between government health care providers and rural population. Thus awareness about even free health facilities provided by the government, such as immunization or TB medication, is low. The National Family Health Survey of 1993 determined that despite increases in provision and accessibility of health centres, uptake of these services was far below maximal.

The availability and quality of publicly provided health services has in fact deteriorated since the 1990s. Public sector hospitalisation dropped from 60% to 45%, the decline in infant mortality slowed, and malaria, plague and TB all staged a comeback. Maintenance of all facilities has been neglected. Run-down buildings, lack of equipment and staff, and inappropriate treatment are the current hallmarks of a failing system. The costs of treatment to the patient have also spiralled; a hospital stay today is five times as expensive as it was ten years ago.<sup>2</sup>

Part of the problem is that centralised healthcare, at the policy level, does not work well in a country with the immense regional disparities of India. Central planners are far removed from the context in which their schemes will be implemented. Combined with donation-driven projects, this has led to repeated initiatives that target specific conditions, such as TB and malaria, but little integrated development of healthcare. These 'vertical programs' are often less effective due to lack of awareness, or regional differences in the scale of the problem. Experts call for increased investment in primary health care, and a 'bottom up' approach to service provision

Like in any other part of world, finding medical professionals to staff rural outposts is an ongoing problem for the government of India. Despite the vast numbers of doctors who qualify each year in India, a large proportion of rural positions are vacant. For reasons of profit and convenience, most newly qualified doctors prefer urban practices. Secondary, tertiary and clinical care, or specialisation in a particular area, are also favoured for financial reasons, with very few opting for general practice, primary care and public health. There is also a desperate shortage of adequately trained ANMs, nurses, technical staff – laboratory, radiology and so on – and paramedics in the rural areas.

Most sub-centres in the Thar are manned by only one ANM, usually a woman. After their training, ANMs must rely on the doctor at the local PHC for support. In the Thar, the rough terrain and distances to be covered make the ANM's task extremely difficult. 'I wish I had a colleague', says one ANM, 'a man would be best. At the moment, I don't even feel safe alone – that's why I'm only at the sub-centre from 11am until 4pm.' Most ANMs live some way from their posts, and whilst many show great dedication to the job, there are others who neglect their duties. ANMs may come from outside the area and in any case have a different background to that of the villagers, making it difficult to relate to their concerns. An ANM's knowledge is also limited, and the lack of referral facilities often leads to inappropriate treatment. There have also been cases of corruption – village women report one ANM as selling tablets to pregnant women 'that would ensure a baby boy.'

Many government doctors are guilty of absenteeism from PHCs, as monitoring is virtually non-existent. Doctors usually do not live on the premises; for the villagers there is thus no 24-hour care. Some doctors refuse to treat patients at PHCs, insisting that they come to the doctor's home, where 'private' rates are charged. In any case, the standards of hygiene and treatment in PHCs often fall far short of what could be expected as the basic minimum. The lack of technical staff and equipment also hamper effective diagnosis and treatment.

There are also serious problems with drug dispensation and quality control. Out of date, illegal or adulterated medicines are distributed both knowingly and unknowingly throughout Rajasthan. This is often reflective of wider issues, such as corrupt practices by big drug companies, domestic and foreign. There are numerous examples of drugs being aggressively marketed in India whilst their use is banned or restricted elsewhere. Pressured into turning a profit for these companies, doctors may not limit themselves to prescribing only one drug. For example, vitamin pills are frequently added to a prescription. The money spent on a course of vitamin pills would often do more good, and last

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<sup>2</sup> With reference to 'Medical Nemesis'; an interview with Dr Abhay Shukla, JSA, Times of India 25<sup>th</sup> Jan 2005 pg 12.

longer, if spent on nutritious food. The extra medications also add to the confusion surrounding dosage regimes. It is very difficult for illiterate, uneducated people to remember when, and how much, of each medicine to take. Doctors are also under pressure to prescribe inappropriately, either due to constraints of time and drug cost/availability, or due to patient demands. Government doctors do not receive refresher training, nor are they encouraged to focus on awareness generation within the community, and this lack of support can also hamper their efficacy in delivering public health.

Private medical practitioners are uncommon in rural areas, although there is usually a clinic in larger villages and trading centres. They are subject to little regulation, and can charge what they wish for their services. Wealthier villagers, aware of the failings of government healthcare, go to these private practitioners or seek treatment in town. The poor, however, have no such choice. The villages have no means of seeking redress for substandard health provision, whether public or private. The elected *Gram Panchayat*, or village governing body, has no control over health issues. There is no system of monitoring or assessment of government or private doctors or ANMs, so villagers can be stuck with a bad practitioner for years.

The prevailing problem of healthcare service uptake pales in comparison to the huge gaps in service provision in the Thar. Once medical care has reached an acceptable, affordable standard, and efforts have been made to reach out to the local population, uptake will increase. Until then, the government must focus on supporting effective primary healthcare, including awareness generation, and on increasing the staff and infrastructure capacities of the system. Merely throwing money at the problem, as has been done in the anti-poverty budget of February 2005, will not help; after all, this was done in the 70s and produced a system that never fully met the needs of the people, and has steadily degenerated. Without monitoring or management systems in place, much of this funding will go to waste or be siphoned off through corruption. Decentralised planning at the state and district level, and better management of resources, will be the key to overhauling public health services.

## ii. The desert environment

Life in the desert is defined by the availability of water. Without a source of clean water for drinking and washing, people suffer from dehydration, disease and poor hygiene. Access to water also defines working life. In many families, women and girls fetch water for the family every day from a communal source. This can take hours, depriving them of profitable working time or education. Constant lifting and carrying of heavy pots of water can cause health problems, particularly for pregnant women. During times of drought, many families must make do on less than 40 litres of water a day, provided by emergency tractor-pulled tankers. This must suffice for themselves, their animals, and for cleaning. Again, getting this water may take a long time, and the tractor-tankers often run into difficulties on the sand dunes.

Desperation drives many to sources of water that are unsafe. These may be contaminated with disease-causing organisms, animal or human excrement, pesticides, or high concentrations of salts and minerals, damaging to health. Even washing in contaminated water can cause health problems, such as infection with parasites. The cleanest free source of water is rainwater, which can be harvested through traditional desert techniques (see GRAVIS publication, *Traditional Agricultural and Water Harvesting Techniques of the Thar*). However, these techniques have been declining over the years, and revival is needed. Tube wells provided by the government, NGOs, or developed by private farmers, are becoming more widespread. There are drawbacks, however, to the overuse of groundwater.

The shortage of water restricts the food available to the people of the Thar. The main crops grown are millet, *mung* beans, bulgur wheat, chilli and oilseed. These plants can tolerate dry conditions. Even so, in a bad year the yield of even these crops falls drastically. Successive years of low rainfall, as in recent times, lead to poverty and a very limited availability of food. A varied diet, including fresh fruits and vegetables, is very difficult to come by. Cereals are the staple, eaten as bread – roti - or porridge.

In addition to preventing hunger, food must also provide enough of the substances needed by the body for good health. These include protein, carbohydrates and micronutrients - the vitamins and minerals. Without these, a person becomes malnourished. For instance, iron deficiency leads to anemia, a condition causing weakness, fatigue, poor immunity and vulnerability to disease. Malnutrition can be painfully obvious, as in the case of weak and emaciated people, but can also have more subtle effects.

The low consumption of fresh fruit and vegetables, which are prime sources of micronutrients, contributes to the extent of malnutrition in the Thar. This is a direct result of the hostile environment and the poverty among the villagers. There are a few fruits that can thrive in the harsh environment, including a form of desert plum, but they are not available all

year round. Traditional methods of water harvesting can be used to grow plants that need lot of water, but these skills are not widely applied. Virtually no meat is eaten, mainly for cultural reasons, thus excluding it as a source of protein and micronutrients. It is therefore particularly important that a balanced vegetarian diet is eaten. This should include milk and pulses, such as beans or lentils, for protein. Cows and goats provide milk, butter, and yoghurt or curd, which are widely consumed. However, the animals themselves need fodder and water, and droughts see huge losses of these vital providers of sustenance.

The window of opportunity in which to grow crops is extremely limited. Hard labour is required during and following the rains to ensure a harvest. After harvesting, the fields must be prepared for the next rains, and water-harvesting structures repaired. For the majority of desert families, recent harvests were too poor to support them year round. For this reason men, women and adolescents have to seek work elsewhere. Around Jodhpur, the Thar provides red sandstone, highly regarded as a building material. The stone mines provide labour to around 2 million in Rajasthan on a permanent basis, and more on a seasonal basis. Dust and scorching temperatures make these mines unpleasant places to work. The environment demands hard work, most of the time, from its inhabitants. People may therefore be loath to seek medical care for fear of losing valuable working time. This is particularly true of chronic yet debilitating diseases such as malaria, anemia and silicosis.

The population of the Thar is high, and dense, for a desert. However, settlements are spread over vast areas, and the majority of the population has no private means of transport. Village health workers are quick to state transport as a major problem for the people. Transport to a medical practitioner for non-critical conditions can be arranged, albeit at a cost. For instance, a village, or group of villages, is usually served by a bus, or a jeep may be hired. Emergency transport to adequate medical facilities may not be readily available, for instance for a woman having difficulty in labour. In some villages, reaching a hospital may require a walk to a bus stop or jeep stand.

Local medical care may not be able to meet the needs of the patient – for instance, surgical facilities are not available in village PHCs. The journey to a distant hospital may take several hours due to the poor condition of the roads, adding to the risk to the patient. If a patient has to stay in hospital, their family face costs for visiting, or for staying in the vicinity. Treatments that require repeated visits to hospital are thus rarely completed, as transport becomes an impossible barrier.

### **iii. Society, culture and tradition**

The threats to community health arising from the environment are addressed by the communities of the Thar Desert: people's resources, habits, beliefs, and motivation all contribute to their state of health, for good or bad. Environmental factors are beyond control, but the actions of the community may be influenced and can change. An understanding of the social factors contributing to public health in the Thar Desert is thus a crucial starting point for improvements.

Rajasthan is one of India's poorest states, and the Thar Desert one of the state's worst affected areas. Poverty occurs as a direct result of the environmental problems of drought and poor agricultural yields, and there is also a high prevalence of economically and socially backward sections among rural communities including scheduled castes (SC), scheduled tribes (ST) and 'other backward castes' (OBCs). These people have been at the bottom of the Indian social pile for centuries, and thus have reduced status (in practice, although not in law), resources, education and confidence. The many health problems associated with poverty arise from an interplay of factors. For instance, malnutrition leads to decreased resistance, or immunity, to disease. Disease leads to loss of productivity and increased poverty and malnutrition. The cycle continues.

Lack of money or access precludes adequate medical treatment. The poorest 20% of the population are estimated to be six times less able to afford hospital or delivery care than the richest 20%, an enormous gap. The rising costs of medical care from public and private sectors alike have also hit the poor hard. Medical expenses are even a cause of poverty for some, who must take loans or sell assets to meet the costs of treatment.

Other contributing factors include lack of education and motivation, and poor living conditions. Education is an obvious problem in the Thar: literacy rates for Rajasthan are among the lowest in India, and school attendance among rural girls is abysmally low. Motivation is a more subtle issue. When life is a continuous grind to survive, there is not the time or energy to devote to healthcare concerns, especially when the chain of causes and effects is not fully understood, and there is much superstitious knowledge. This is reflected in attitudes and practices. There is often only a basic understanding of hygiene - although most dwellings are swept clean every day, few houses have a latrine and excrement, rubbish or waste water may accumulate nearby.

Those who suffer the most from poverty and its effects on health are women, children, and the elderly, especially those belonging to SC, ST or OBCs. Women have low status in rural Indian society, despite their legal rights. In the Thar Desert, as elsewhere, a girl usually moves to her in-laws' house when married, or old enough to live with their husband (see below). At first, she is very isolated, and may often be subject to abuse at the hands of her husband or in-laws. She is expected to work hard, obey all orders, and produce a son as quickly as possible. However, she will receive little special care or attention during pregnancy or delivery.

A woman is not generally involved in family decisions, and may feel obliged to consult her husband or father-in-law on every matter, including health. For instance, many women feel that they cannot take a child to see a doctor without their husband's permission. Purdah is also still prevalent in the region. Women are often expected to remain veiled when outdoors, in front of their parents-in-law, or when talking to strangers. This is felt to be proper by many women themselves, since it is instilled in them from childhood.

Many children, and especially girl children, receive little or no education. Female literacy in Rajasthan is low, at around 45%, officially. However, literacy rates among the poorest women of the Thar may be as low as 8-10%. Children are expected to assist with the family's work as soon as they are old enough, and a small child tending goats or cattle is a common sight in the desert. Since boys are more highly valued than girls, girl children are the first to suffer deprivation. This is reflected in the sex ratio of around 900 women to 1000 men in Jodhpur and Jaisalmer districts. Considering that women naturally live longer than men, and girl children are hardier than boys, this dismal statistic illustrates the neglect, hardship and health problems faced by women and girls in the desert. Female infanticide is an ongoing problem, but is more likely to be effected through lack of care than through direct killing. For instance, a sick girl baby may not get medical treatment as soon as a boy, if at all.

Although in practice illegal, child marriage still takes place within the Thar. In the villages, families arrange marriages. A wedding is a huge social event that must be financed by the bride's family. It thus makes economic sense to marry all the children at the same time, regardless of age. Married children do not generally live with their spouses until older. However, girls as young as 14-15 may be sent to their husbands, resulting in early pregnancy and childbirth and putting their health at risk. Adolescent girls receive little or no education on reproductive health, as the majority does not go to school. The situation is slowly improving, particularly with regard to age at marriage, but many parents still feel that child marriage is the only way they can afford to marry all their children.

Finally, the needs of the elderly of the Thar Desert are often neglected, making them an extremely vulnerable group of society. Despite the tradition of respect for the elders, when resources are scarce they are deprived and their health suffers as a result. A state pension is provided only to those with no children over 18; even then, it is a pitifully small amount. Awareness of this pension is also low. This means that impoverished elderly people have no access to medical care, or are dependant on their children for it. Elderly women in the Thar Desert have even greater difficulties. Child marriage results in many girls losing their husbands, also children, before they are adults. There may also be a large difference in age between a woman and her husband. Both considerations lead to the stigma of widowhood. Although the situation is improving gradually, widows are unable to remarry, usually treated as a burden, and even considered to bring bad luck.

Addressing the needs of the most vulnerable is a priority, but the remainder of society should not be overlooked. Adult men in the Thar have their own health and health-related problems to contend with. Farming, mining and migrant work are physically demanding, and often give pitifully low returns. Many men (and women) are also deeply in debt due to poor harvests and local loan sharks. Alcohol and opium provide a transient means of escape. They are particularly popular among mineworkers, as it gives relief from the pain induced by their backbreaking work. Opium has a long history in Rajasthan, having been used recreationally for centuries. It is usually smoked, or a brew is drunk, but intravenous use is thought to be rising. Although women work equally hard, they are to an extent culturally protected from direct exposure to drugs and alcohol – for instance, drinking takes place after work in all-male groups, and very few women pick up the habit. Tobacco smoking and chewing are also prevalent in the Thar, leading to a high rate of lung and throat cancer and chronic obstructive diseases of lungs.

Opium, alcohol and tobacco are expensive habits, and they serve to drain a man's already limited resources. An opium addict or alcoholic can easily spend the majority of their income on their habit. This leaves little remaining for the wives and children of those affected by drugs and alcohol. Their health will suffer as a result of malnutrition and poverty, as will the man's. Drug and alcohol abuse create health problems; drinking, for example, causes liver and neurological diseases. Opium and alcohol deaddiction facilities in the region are limited and under-resourced, and uptake is poor.

There is a tendency to blame the men for their irresponsible behaviour. However, considering their minimal education, lack of prospects, and life of hard, unrewarding work, the problems are at least understandable. Without addressing the concerns that drive this behaviour, no progress can be made. This is evidenced by the limited success of opium deaddiction programs in the region – once off the drug, addicts will return to it given the same social and economic circumstances.

Some Indian healthcare practitioners maintain that the health problems of the poor are largely of their own causing, through ignorance and lack of uptake of the services provided. However, most drugs are not free, doctors charge for tests and other services, and transport to a practitioner may be difficult and expensive. So even though awareness of sub-centres and PHCs is present, many do not see them as accessible or even useful. Also, as described in the sections above, the medical care offered in practice may not be as good as it sounds on paper or in policy.

Prior to the expansion of sub-centres and PHCs, access to an affordable medical doctor was very low. Indicators such as lower life expectancy and higher infant mortality rates reflected this. There was, however, a wealth of traditional knowledge used by local practitioners, some of it extremely effectively. These included the ancient systems of Ayurveda, Sunani and naturopathic medicine. Much of this knowledge has been lost due to marginalisation of these healers by government medicine, which focuses on institutional, medicalised healthcare. Some of it was and is extremely valuable, for instance awareness of the medicinal properties of local desert plants or spices. Other methods have no effect on the body, good or bad, although belief in the cure may have beneficial effects (the placebo effect). A few traditional practices are harmful. Examples include burning with red-hot irons (to drive out evil spirits), and not giving babies their mother's first milk (the colostrum, which gives the baby immunity to infections). Sadly, these are the ones that largely remain, in the hands of 'quack' doctors with more knowledge of business than of health.

Government health initiatives make no effort to retain the beneficial knowledge while reducing harmful practices, and awareness of home cures has consequently decreased. Ironically, despite the difficulties in access and the inadequacy of provision, a state of dependency on doctors, ANMs, and their drugs, is now being created in the Thar. Medication is seen by most people as the only option, and they may even react with anger if sent away empty-handed. This dependency is a threat to general health, as it exacerbates the overuse of medications or inappropriate prescription of drugs, and increases apathy. It is also a waste of resources. The money spent on vitamin pills, often prescribed by doctors in combination with antibiotics, would do more good if it were spent on food. However, the prevailing attitude amongst even the poorest appears to be that 'if you are ill, you must go to the doctor, and you must take medicine'. Few have an understanding of even the concept of preventing illness. Sickness is thus accepted as a part of life over which people themselves have no control.

This apathy is reflected in the lack of awareness of health issues and preventive measures. The expansion of PHCs and ANMs has undermined people's confidence in traditional practices, and 'medical knowledge' is thought incomprehensible to all except doctors. This 'mystification' is in part the fault of government medical practitioners, many of whom do not consider it their job to explain illnesses and treatments and prefer their patients to remain ignorant. A sense of responsibility for one's own health is also lacking. This is partly due to the dearth of formal education in the Thar Desert, but it cannot be corrected merely through disseminating factual information. If curiosity and interest are lacking, people will be unable to learn and apply healthcare information. Generating this sense of awareness and ownership remains one of the biggest challenges in sustainable public health development in the Thar Desert.

### **3. The burden of ill health in the Thar Desert**

This section discusses the diseases, difficulties and afflictions faced by the population of the Thar Desert. Medical information is briefly presented, and supports an analysis of the issue in the social and environmental context of the Thar. This information may also serve as a reference for the following section.

#### **i. Infectious diseases**

The problem of endemic infectious diseases is exacerbated by malnutrition and poverty and low awareness in the Thar Desert. Many people, especially women, children, the elderly and the very poor, are weakened by malnutrition and chronic illness. The immune system cannot then function properly to defend the body from infectious disease. This increases both the levels of infection and the mortality and morbidity rates due to the diseases discussed below.

#### **Respiratory Tract Infections**

Bronchitis, pneumonia and TB (discussed separately below) are the leading causes of death in rural Rajasthan.<sup>3</sup> Across all age groups, lack of access to affordable health care and lack of knowledge regarding the prevention and treatment of

respiratory infections allow the scourge to continue. Other respiratory afflictions such as asthma contribute to the problem.

'Respiratory tract infection' (RTI), and 'acute respiratory infection' (ARI), are general terms for bacterial infections of the lungs, bronchi or trachea. They can be caused by many species of micro organisms, and some conditions, such as pneumonia, are the result of infection with several at once. Infection can cause fever, pain, coughing, difficulty in breathing, and excessive mucus production in the lungs. Continual coughing is exhausting to the affected individual, and spews out infectious particles that allow the infection to spread from person to person. Those with impaired immunity, babies, young children and elderly people are at risk of developing life-threatening conditions and thus comprise the demographic groups with the highest mortality rates from RTI/ARI. Women are also at greater risk of infections due to malnutrition and anemia. Pneumonia is responsible for around 30% of infant (age 0-4) deaths due to illness in Rajasthan.<sup>3</sup> Respiratory infections in general are among the leading causes of death in newborns. If an infection is survived, it may nevertheless result in long-term damage to the lungs and increase the risk of future infections. Continued difficulty in breathing may impair the person's physical capabilities. Alternatively, an infection may reach chronic status, where it is not acute, but will cause problems and may flare up in an acute form if the person becomes weak.

Most chest infections are easily treatable with antibiotics. Treatment may require several different antibiotics, as individual species of micro organisms have developed resistance to particular drugs.

A number of factors specific to the living conditions and health care provision issues of people in the Thar contribute to the high level of RTIs. Firstly, high levels of malnutrition, especially among women and children, predispose the population to infection. It is observed in Rajasthan as a whole that more men actually die from RTIs than women (deaths from bronchitis and asthma women – 6.7%, population - 14.7%)<sup>1</sup>. This is due to the higher incidence of smoking, which weakens the lung's protective mechanisms, among men, and also to the larger number of male mineworkers, exposed to stone dust. Continued exposure to smoke from wood or dung-cake fires also harms the lungs, and increases the risk of RTI across all social groups. Exposure to dust from the environment is also a major risk factor. The lack of awareness regarding transmission of RTIs means that habits such as spitting and coughing without covering the mouth are accepted and widespread. This serves to propagate the infection, and puts babies and small children particularly at risk, as they have close contact with their caregivers.

Delays in diagnosis and treatment of RTIs, or lack of treatment, cost tens of thousands of lives a year in the Thar. The expense of RTI treatment arises from the costs of transport to a provider, the provider's fee, and the price of the drugs. If, as occurs in some cases, the first course of antibiotics is ineffective, continued treatment will incur additional expense. Considering the problems with staff and resources afflicting rural health outposts, access to professional assistance in the first place is minimal for many people. Finally, for the poorest, the cost of treatment is prohibitive even if the motivation and provision are there.

### **Tuberculosis (TB)**

Tuberculosis (TB) of the lungs is the second leading cause of death in the Thar Desert. TB is a bacterial infection, and causes severe damage to the lungs. TB is difficult to treat, as the bacterium responsible (*M. Tuberculosis*) can shelter in a latent form inside the body over a long period of time. This makes drug treatment a lengthy procedure. A combination of drugs is needed, as both actively growing and dormant bacteria must be targeted. The emergence of drug-resistant strains of TB is a constant threat, and has already been observed in parts of the world. Many people may be carriers of latent TB and may never develop a full-blown infection; however, weakening of the immune system through advanced age, poor health, malnutrition or HIV infection increases the risk of acute TB. Infants under 5, whose immune system is still developing, are at high risk of infection.

Pulmonary TB (TB of lungs) constitutes a major threat to public health, as it is highly communicable via the sputum coughed up by infected persons. It is estimated that each person with acute pulmonary TB infects up to 10 others every day. There are other forms of TB, where infection occurs elsewhere in the body. These forms of TB are not transmissible, but are greatly detrimental to an individual's health and may prove fatal.

PICTURE 8 – a TB patient

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<sup>3</sup> Raj HDR

TB is characteristically a 'disease of poverty.' By improving the health of the immune system through better nutrition, and HIV awareness, people are rendered less susceptible to acute TB. Many inhabitants of developed countries may have a latent TB infection, but will never develop the disease due to their relatively healthy lifestyle. There is an effective vaccine for TB, the Bacille Camille Guerin (BCG), and most of the developed world uses it. Vaccination of newborn babies with BCG is effective, but does not work well in adults or in older children. Vaccination alone has therefore not been effective, as sufficient coverage is difficult to achieve.<sup>4</sup> It is now thought that the correct diagnosis and treatment of infected persons is the best strategy for reducing TB. With appropriate treatment a complete cure is possible.

TB infection rates continue to be high amongst the people of the Thar, with the disease responsible for around 10% of non-senile deaths each year. Babies, anemic women and young children are at great risk of infection. Stone mineworkers are a second high-risk group, as continual exposure to dust weakens their resistance to TB and other chest infections (see Silicosis *not trying to say it is an infection, just a cross reference*). Cramped living conditions and lack of hygiene, particularly when coughing and spitting, contribute to the spread of TB, whilst low levels of awareness, diagnosis and treatment account for the high mortality and morbidity rates of the disease in this area.

The biggest problems facing TB control in the Thar Desert are lack of awareness, late diagnosis and low levels of patient compliance, or non-completion of treatment. Awareness of TB is necessary if people are to come forward to be tested. In fact, in many places a chronic cough and weight loss would not be considered important enough for seeking medical attention. Thus many TB patients are only recognised when advanced lung damage has occurred and they begin to cough blood. By this time, they will probably have infected many other people. Diagnosis relies on detection of bacteria in sputum, not an X-ray, as patients may not necessarily have X-ray-detectable lung damage, especially if recently infected. Three sputum examinations are necessary for a definite negative result. Finally, patients must complete drug treatment, whatever the length of time it takes. Many patients cease drug treatment when their health improves, or due to unpleasant side effects. This is known as withdrawal. Stopping treatment early results in relapse, poor health, and increased transmission of TB. It also increases the risk of developing drug-resistant strains of TB, especially if treatment is stopped and started repeatedly. Drug resistance is becoming a problem worldwide and in pockets of the Thar where TB infection is very high, such as the stone mines at Jodhpur. As yet, however, resistance to the BCG vaccine itself has not developed.

Over the last 30 years, Directly Observed Treatment Short-course Chemotherapy (DOTS chemotherapy) has proved the most effective curative treatment for TB. Much of the research and development of this treatment, including determination of the most effective drug regimen, was done in India. Following diagnosis, patients are given an intensive course of treatment with up to four anti-TB drugs. Once active TB has been eliminated, a sputum test will be negative. This usually occurs after 3 months, following which a longer course (6-12 months) of two drugs is required to completely eradicate the disease. Patients take the medication in the presence of a doctor or health worker. Taking the drugs twice or thrice weekly, rather than daily, was shown to be effective. This is an important consideration, as it makes observation easier and reduces side effects. It also allows patients to remain at home, at least for the longer course of drugs. Once completed, a DOTS chemotherapy course gives a relapse rate of just 2-3% of patients.<sup>5</sup> However, DOTS has certain limitations, including the length of treatment and the difficulty of observing patients. In addition, drug treatment is less effective when other factors such as malnutrition remain a problem. Nutritional support, rest, and improved living conditions all complement recovery.

The Thar comes under the auspices of India's Revised National Tuberculosis Control Program (RNTCP), which endeavours to identify and treat infected persons free of charge. DOTS chemotherapy has been adopted as the standard treatment, and drugs should be administered by local ANMs. However, motivation for treatment remains a major problem. Awareness of TB as a disease is very low. Perceptions are also important; if people believe that treatment is not available to them they will not even attempt to seek it. Similarly, perceptions of the drug treatment itself are often unhelpful. The side effects of TB drugs such as rifampicin and isoniazid range from the minor - commonly rashes, nausea and abdominal pain - to the major but rare, including seizures, hepatitis or renal failure. Many villagers therefore regard the drugs as poisonous and either stop or do not start taking them. It is understandably difficult to convince patients that something that causes them to feel worse is actually making them better!

The government's idealistic but overstretched resources fall short of delivering DOTS effectively. Shortages of laboratory staff mean that diagnosis is often faulty, with patients being given the 'all clear' too soon or not being detected at all (it can take up to 3 sputum cultures to ascertain a positive result). Drug provision and monitoring is often not

<sup>4</sup> Lewinsohn et al., *Semin Respir Infect.* 2003 Dec;18(4):320-38

<sup>5</sup> M S Jawahar, 'Current Trends in Chemotherapy of Tuberculosis', *Indian J Med Res.* Oct 04; 120:398

performed as required by DOTS. Instead of keeping the drugs and insisting on patients visiting, many ANMs will give an entire 9-month course to the patient at once, with instructions that can rarely be followed properly. Doses will be incorrect, or missed, and drugs incorrectly stored, or thrown away when symptoms disappear. Patients are often not followed up if they fail to attend checkups or medication appointments. Few actually complete the full course of drugs, despite assurances by ANMs and doctors alike of high compliance. The ANMs can do little else, however: their areas of coverage are often so wide that travel on a daily basis becomes a practical impossibility, for patients and providers alike.

The uptake of BCG vaccination of infants is increasing in the desert thanks to NGOs and governmental awareness projects. This positive sign is however being offset by the upward creep of HIV infection. HIV-positive patients are more susceptible to TB, and may also respond less effectively to DOTS treatment. This could cause an upsurge in TB mortality rates over the next few years. TB in the Thar is far from under control, and considerable efforts over the next decade will be necessary to stem the tide of death and debilitation.

### **Malaria**

Malaria is endemic in the Thar, due to the presence of its carrier (vector), the Anopheles mosquito. Levels of infection vary, with outbreaks usually occurring during and for some months after the rainy season of July and August. Following good rains, as in 2003, malaria outbreaks are likely to be more severe. Malaria is a debilitating disease, and mortality is particularly high among women, babies and children.

Malaria is caused by a microscopic parasite called Plasmodium. This creature has a complex life cycle involving growth stages in both human and mosquito hosts. In humans, the parasite lives inside red blood cells. It emerges periodically to reproduce, and this causes the high fever and cramps of a malarial attack. Long-term effects include enlarged spleen, liver damage, and anemia. A mosquito picks up the parasite when it feeds on the blood of an infected person. In the mosquito, Plasmodium migrates to the saliva, thus allowing its transfer to humans when bitten. There are several subspecies of Plasmodium, of which the most deadly is *P. falciparum*. Falciparum malaria is severe, and can affect the brain (cerebral malaria), leading to coma and death. Other varieties are less likely to be fatal, but the infected person's health and ability to work are still compromised. For instance, Plasmodium *vivax* malaria rarely kills, but causes debilitating fatigue, pain and fever that impair quality of life and economic productivity. Vivax malaria is the most widespread form worldwide, and one of the most difficult to treat, as it can persist in the liver for years.

As it lives inside blood cells, Plasmodium is shielded from the immune system and from drugs in the bloodstream. There are few effective treatments for the disease, and prevention is emphasised in all control strategies. Avoiding mosquito bites through use of repellents and nets, reducing the mosquito population, and taking preventative drugs are all tried-and-tested combative measures. Ideally, methods should be combined for greatest efficacy.

Malaria diagnosis requires a blood sample, a microscope and a trained technician. Without directly observing the parasite in a person's blood, it is difficult to confirm infection with malaria, as symptoms overlap with several other diseases, for instance 'flu. The limited range of drugs for malaria treatment includes chloroquine, mefloquine, artemisinin-derivatives, and sulfadoxine-purimethane. Combination strategies such as ACT have also proven effective. However, the parasite rapidly develops resistance to drug treatments, especially when used intermittently or incompletely.

The Thar Desert historically had relatively low levels of malaria, particularly of that caused by *P. falciparum*. Vivax malaria was by far the most prevalent form. However, recent years have seen increasingly severe outbreaks and a raised incidence of falciparum malaria, leading to more deaths among those infected. This rise can be largely attributed to the irrigation projects of the last 20 years, stemming from the Indhira Gandhi Canal running through the NW of the desert. The canal brings benefits, including drinking water, and allows cultivation of water-demanding crops such as rice and chilli. However, irrigation is not always well managed, and may lead to inundation of fields and large quantities of surface water. Mosquito larvae hatch and develop in any pool of standing water. The breeding potential of the Anopheles mosquito has thus increased and its area of effect spread, leading to more outbreaks of malaria. These conditions are also closer to ideal for the falciparum malaria parasite, causing previously low levels to rise.<sup>6</sup> Awareness of the disease and its prevention continues to be a major problem in tackling malaria in the Thar. In 1999, the Desert Medicine Research Centre, Jodhpur, completed a study of awareness. Among non-infected villagers of the

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<sup>6</sup> D Sharma, 'Thar desert: sitting on the tip of a malarial iceberg', THE LANCET Infectious Diseases Vol 4 June 2004 pg 322  
<http://infection.thelancet.com>

Jodhpur and Jaisalmer districts, only around 3% were aware of the mode of transmission of malaria.<sup>7</sup> This rose to 27% of infected individuals. The study also demonstrated a lack of awareness of the National Anti Malaria Program, a government initiative of the last 50 years. The minimal community involvement of the program has generated reduced acceptance and motivation regarding anti-malarial measures. Over half the population takes no anti-mosquito precautions whatsoever.

Access to diagnosis or treatment facilities is also a huge concern, and contributes to the high mortality rate of those infected. The problem is reflected nationally, with around 40-60% of rural technician posts estimated to be vacant. Long distances, costs and delays due to understaffing are also deterrents to seeking treatment. Hospitalisation is only resorted to in very severe cases, if at all. Once obtained, treatments must be used carefully and correctly to prevent recurrence and development of drug resistance. Home treatment with old or inappropriate drugs, incorrect or incomplete dosages, can prove harmful in the long-term.<sup>8</sup> The involvement of the local health infrastructure is thus crucial to malaria control.

In terms of prevention, strategies involving people at a basic level are the most likely to be accepted. Anti-malarial drugs may not be obtainable on a regular basis in the remote rural areas of the desert, thus protection from bites and mosquito eradication methods must be emphasised. For instance, simply reducing the availability of standing surface water (including pots, drains, and tanks) will bring down the mosquito population. Spraying buildings with insecticide is effective, but finds low acceptance among the community. People do not like having to leave their homes, cover food and so on whilst the toxic fumes are administered. Bed nets, an acceptable and cost-effective strategy, afford protection from bites during the night.

### Infections of the digestive tract<sup>9</sup>

The stomach and intestines are vulnerable to infection from contaminated food and water. The body's attempts to remove the infection manifest as fever, vomiting and diarrhea. Recovery is slow and fatalities higher in vulnerable people, such as those who are malnourished, the very young, or the very old. The most common mode of transmission is the fecal-oral route, where infected excrement is ingested – even in very small amounts. This is hard to avoid where sanitation is poor, and where hygiene practices are not observed. Flies are important factors too. For instance, when feces are left in the open and food is uncovered, flies can carry infection to the food.

Gastroenteritis and colitis are general terms for infection and inflammation of the gut. Cramps, fever, vomiting and diarrhea are the usual symptoms. Severe infections can cause bleeding of the stomach or gut. Serious gastroenteritis infections can be fatal, especially in vulnerable groups. Death usually results from dehydration due to severe diarrhea. This can be treated using oral rehydration therapy, ORT. ORT is simply a drink of water with added sugar and salt, which matches the body's own sugar and salt content and is rapidly absorbed (plain water may be expelled before being absorbed). Digestive tract infections have high morbidity, producing debilitating symptoms that reduce economic productivity. They are also highly contagious. Appropriate antibiotics can rapidly cure most infections, however.

A wide range of bacteria can cause infections, but the most common culprits belong to the *E. coli* and *Salmonella* families. Infection with *Salmonella typhi* subspecies gives Typhoid fever, characterised by ascending high fever, headache, cough, and diarrhea or constipation. Complications can be fatal if the disease is untreated, which include intestinal perforation, severe bleeding, kidney damage, and secondary infections such as pneumonia.

The symptoms of different infections can be very similar, as for bacterial and amebic dysentery. A major cause of death in babies and young children in rural Rajasthan, dysentery causes diarrhea and death by dehydration. Bacterial dysentery, caused by *Shigella*, is generally less severe and is treatable with antibiotics. Amebic dysentery initially appears identical, with blood and mucus often produced in the stool. However, the organisms causing the disease are not bacteria, and cannot be killed with antibiotics. Specific amebicides are needed; otherwise the disease may progress to become life threatening. ORT is also essential. The distinction between amebic and bacterial dysentery can be made by laboratory stool examination.

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<sup>7</sup>Yadav, Tyagi, Ramnath; Knowledge, attitude and practice towards malaria in rural communities of the epidemic-prone Thar Desert, northwestern India'; J Commun Dis 1999 Jun; 31(2):127-36

<sup>8</sup> V K Bhasin, L Nair; Letter in THE LANCET Infectious Diseases Vol 3 October 2003 pg 609 <http://infection.thelancet.com>

<sup>9</sup> With reference to 'Current Medical Diagnosis and Treatment (2000)' 39<sup>th</sup> Ed. Pub. Lange Medical Books

Cholera is endemic in India and generally occurs as outbreaks in a localised area. Any population with poor sanitation is at risk of an outbreak, and again, the young, old, and weak suffer the most. Cholera is unusual among gut infections in that there is rarely fever, but profuse, watery diarrhea is produced. A toxin made by the bacteria *Vibrio cholerae* causes this disease. Death can occur through dehydration if replacement fluids are not given. Like most gastrointestinal infections, Cholera is highly contagious.

In the Thar Desert, several major problems are faced regarding the prevention and control of digestive tract infections and parasites. Poor sanitation allows widespread communication of diseases. Lack of safe drinking water, shared water facilities, no latrine areas, no drainage, and poor personal hygiene contribute to the spread of infections by the fecal-oral route. In most villages, sanitary arrangements are minimal, and people defecate outside in the open. At best, waste is buried in shallow pits; in many places, it is simply left uncovered. Traditionally, the right hand is used for food preparation, cooking and serving, the left for washing after defecation. However, in practice both hands must be used for daily activities including cooking and tending children. A lack of understanding of basic hygiene can thus lead to contamination and infection, if the hands are not adequately washed before food preparation. Traditional practices of food hygiene go a long way in ensuring food safety, but unless the underlying purpose is understood their implementation can be insufficient. Another problem is that drinking water has to be brought from outside and stored in rounded clay pots. To get a drink, people dip cups – and their dirty hands – into the water. Also, hyperacidity is a common cause of stomach pain and gastrointestinal problems, although not infectious. It arises from the diet, high in chillies and spices and lacking sufficient water, and causes great discomfort to many people.

There is a lack of appropriate diagnostic and treatment facilities. Most ANMs are able to take samples for testing at the PHC, but few do so. Although prevention measures such as safe drinking water, improved sanitation and hygiene education are effective in reducing the spread of diseases, prompt treatment will reduce the amount of time for which an individual remains infectious. As evident from the above, alimentary infections can present similar symptoms whilst arising from very different causes. Therefore, almost all cases require laboratory diagnosis before the correct treatment can be given. For example, giving antibiotics to a patient with amebic dysentery will be a waste of valuable time. Additionally, rehydration therapy, the most essential and lifesaving treatment for diarrhea, is difficult where sufficient clean drinking water is not available. Availability of ORT is also low. As recently as 1999, the National Family Health Survey determined that only around 30% of children under three were given ORT for diarrhea.

The high prevalence of premature babies, and of anemic and malnourished adults and children, provides a large reservoir of susceptible hosts for all infections. The poor and disadvantaged of the Thar Desert are not only more likely to be exposed to such diseases, but are less able to fight them. Dysentery, gastroenteritis and typhoid remain leading causes of death among newborns, infants and young children. Levels of typhoid deaths alone in the Thar are much above the national average. Nutritional support and rehydration therapy can work wonders for patient recovery, either alone or in conjunction with drug treatment.

The lack of diagnosis and treatment of gastrointestinal diseases stems from the costs to the patient of drugs and transportation, and from the lack of facilities in the rural areas of the Thar Desert. This contributes to mortality rates and increased transmission of gastro-intestinal infections. The growing population of the Thar desperately needs education on the prevention of disease, in addition to improved medical care.

### **Sexually Transmitted Infections (STIs)**

With the important exception of HIV/AIDS, most STIs (or VDIs) are treatable and rarely prove fatal. However, they can produce debilitating and unpleasant symptoms with consequences for economic productivity and fertility. Chronic or recurring infections are also common. Some STIs may cause no problems directly, but can have sinister long-term effects. For instance, HPV (a type of viral warts) infection in women increases their risk of cancer of the cervix. Chlamydia, gonorrhoea and syphilis are among the many treatable STIs. Antibiotics are effective, and newborn babies may be protected from gonorrhoea infection using chloramphenicol ointment in the eyes immediately after birth. However, diagnosis and treatment are not always accessible to those infected, and reinfection is a common problem. The most significant concern is co-infection with HIV, as by contracting one STI, the person has been at risk of this one too. Many STIs also cause sores or secretions that increase the risk of HIV transmission.

It is now widely accepted that HIV (Human Immunodeficiency Virus) causes AIDS (Acquired Immune Deficiency Syndrome). HIV is transmitted through blood-blood contact, for instance through used needles, and through sexual contact. It can also be transmitted from a mother to her baby, usually during birth or breastfeeding. HIV infects cells of

the immune system, and slowly starts to kill off the body's defences from disease. Symptoms of AIDS appear once the immune system is too damaged to fight other infections. These infections cause diarrhea, pneumonia, and even some types of cancer. TB infection is also very common in HIV-positive or AIDS patients.

There is no known cure for the virus. With powerful drugs, a patient's immune system may recover to the extent that they can lead a normal life (although they can still infect others with HIV). The drugs are very expensive, and can have severe and unpleasant side effects. The only way to prevent sexual transmission of the virus is by using a male or female condom. Other preventive measures include using disposable needles and syringes, or not sharing needles when injecting drugs.

Few diseases have as many myths associated with them as HIV/AIDS. Even those who are aware of, and fear, the disease may nevertheless know nothing about its transmission, prevention or treatment. AIDS is often incorrectly believed to be transmissible by touch, sharing bedclothes or dishes, or even through the air! These misconceptions make life unbearable for those infected. In turn, this reduces the number of people willing to be tested, or even to acknowledge that they might be at risk. People prefer to believe that the disease affects only prostitutes, homosexuals or drug users. The true numbers of those infected may therefore be even higher than current estimates (5.1 million in India alone).

The scale of the problem of STIs, and particularly HIV, is as ever difficult to gauge in the Thar Desert. Poverty and crop failure due to drought often forces men to migrate in search of work – to the stone mines around Jodhpur, for instance. Unprotected sexual intercourse occurs, often fuelled by alcohol. Poverty and/or exploitation drive women into becoming sex workers, and few manage to escape the situation.

On returning home, men infect their wives. For all STIs, including HIV, women are more vulnerable to infection from men than vice versa, and condom use by married couples is very low. Many women suffer from chronic and uncomfortable STIs and urinary tract infections. Leucorrhoea is a common complaint, and can be caused by chronic infections. Being tested for these diseases is often difficult, and is hampered by lack of local female doctors or laboratory facilities. Again, treatment is hard to come by due to costs, transport problems and lack of drugs. For instance, availability of antiretroviral drugs for AIDS patients is virtually non-existent. STIs also often require lengthy treatments to completely disappear; with poor compliance common, recurrent or chronic infections are widespread. Finally, the biggest problem facing women with STIs is to persuade their husbands to be simultaneously tested and treated. Many women will not be able to do this, due to their low cultural status and timidity, and risk being constantly reinfected.

Within the rural population of the Thar Desert, levels of HIV infection are currently estimated at 1.7% and continue to rise due to extremely low awareness. Infection in some urban areas may be as high as 10%. Levels of other STIs tend to remain at consistent levels within the vulnerable population, as they have stabilised over time. Awareness campaigns and promotion of condom use by the government and NGOs are achieving only limited success. The National AIDS Policy of 1999 is not in evidence anywhere – broadcast warnings and information posters are few and far between. There appears to be reluctance even by the government to discuss the issues surrounding AIDS. Sex has long been taboo, so many HIV discussions focus primarily on the dangers of used needles – definitely a problem, but not the main problem. Unprotected sexual contact accounts for around 90% of all HIV infections in the region. Finally, posters are appearing claiming that certain yogic or meditation practices can cure AIDS, posted by unscrupulous quack healers. The medical foundations of such methods notwithstanding, the message given does not encourage caution among the general population, and will do much harm if it is not combated by appropriate information.

## **Hepatitis<sup>10</sup>**

Hepatitis is a viral infection of the liver that produces inflammation and jaundice. It can cause diarrhea, fever, anorexia and malaise, and some forms can progress to chronic status. The two most prevalent forms of the virus are known as hepatitis A (HAV) and hepatitis B (HBV).

Hepatitis A is endemic in the Thar, and so common that most children are infected, via the fecal-oral route, before age three. At this stage, symptoms are mild and the virus usually runs its course, giving lasting immunity for life. The effects

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<sup>10</sup> With reference to 'Hepatitis A' and 'Hepatitis B', informal online publications of the WHO. [www.who.int](http://www.who.int)

of the disease are more severe later in life. Adults are more likely to develop acute symptoms and die from HAV. Thus, paradoxically, as hygiene improves fewer people are exposed and develop immunity as children, and more adult fatalities occur. At present in the Thar sanitation and hygiene are at such low levels that few instances of HAV are recorded, as the disease affects mainly babies and infants and goes untested and unreported. Efforts to improve sanitation must however expect a rise in adult sickness from HAV.

Hepatitis B is transmitted by sexual or blood contact, and from mother to newborn. Adults infected with HBV can become very ill, suffering an acute form of the disease that may be fatal. However, around 90% of infants infected with HBV become chronic carriers. They can infect others via blood, body fluid or sexual contact. They are also at increased risk of liver damage (cirrhosis) later in life, and of a type of liver cancer (hepatocellular carcinoma). Immunisation against both hepatitis A and B is possible, but rarely given in India.

Testing for hepatitis viral infection requires laboratory techniques, and is rarely performed in the Thar. Only patients with life-threatening acute symptoms would even be considered for testing. There are in any case no treatments for HAV/HBV, as they are viruses. However, they do claim lives, especially HBV as a cause of liver cancer. Cancer treatment is beyond most in the Thar Desert. Prevention of infection through improved hygiene and awareness is necessary, and an improved diet containing adequate protein also helps those infected.

### **Parasites**

Whilst all disease-causing organisms can be regarded as parasites, the term generally applies to protozoans (single-cell animals like Plasmodium) and larger organisms such as worms.

Tiny, single celled organisms cause amebic dysentery. Amebas live in the gut and cause severe diarrhea and dehydration. Antibiotics are no use, and special drugs must be given following tests to identify the ameba. In the absence of adequate testing procedures or facilities, amebic dysentery is commonly mistaken for a bacterial infection and antibiotics are given. This problem is common in the Thar.

Another protozoan with a high incidence worldwide is *Giardia lamblia*. This parasite is more prevalent in children, can cause poor absorption of food in addition to diarrhea, and can become chronic, but rarely fatal. Low absorption of fat, protein and vitamin B<sub>12</sub> can cause weight loss and impaired development in children. Drug treatment is possible, but requires specific diagnosis. Giardiasis occurs sporadically in the Thar Desert, but its incidence is lower than that of bacterial infections.

The Guinea Worm, *Dracunculus medinensis*, is an endemic parasite in the Thar Desert. From 1998, a WHO eradication program was largely successful in the region, and infection rates are currently low. The worm is transmitted via a water-borne host, and has a complex life cycle. It migrates through the human body and emerges, usually in the leg, forming an open ulcer. This painful sore can prevent a person from working. Allergic reactions to the worm can make patients seriously ill, and secondary infections of the open wound can occur. Eradication of the host organism and provision of safe drinking water sources are key to defeating the parasite. Simply filtering water through fine nylon netting is sufficient to prevent infection, so education and awareness campaigns are also effective.

Several species of intestinal worm are common in Rajasthan, but usually these cause chronic rather than severe problems. Poor hygiene and poor sanitation allow worms to spread through touch and consumption. Children are more likely to be infected, as they are less aware of personal hygiene. Small children suffering from calcium deficiency have a tendency to eat sand, often leading to heavy parasite infections. For instance, hookworm eggs can enter the body from soil. These worms attach to the gut and suck blood, causing anemia. Threadworms, pinworms and roundworms all cause pain, occasional diarrhea, anal itching, and contribute to malnutrition by consuming the body's resources. Most worm infections are treatable with drugs, but care must be taken to prevent recurrence.

### **ii. Chronic conditions**

The illnesses described below arise from nutrient deficiencies or harm from the environment, and they are not infectious. However, any illness that is not immediately fatal, or that progresses over time, can become chronic. There are often no medical treatments for chronic conditions, especially if they result from exposure to damaging environmental factors. Chronic illnesses reduce the productivity of the labour force and usually result in reduced life expectancy for sufferers. Millions in the Thar suffer from such conditions, arising from malnutrition, contaminated water, dust exposure and untreated infectious diseases.

## Malnutrition<sup>9</sup>

Due to the limited possibilities of the environment, the people of the Thar face huge difficulties in achieving a nutritionally adequate diet. The better off can buy what their land fails to provide, but the poor have no alternative but to survive on what they can produce. Alternatively, when crops fail, they must labour for a pittance in order to buy food. A walk around the villages will confirm the extent of malnutrition – the majority of men, women and children are stunted and underweight, the poorest emaciated.

The staple food is bread – roti – made from millet or wheat flour. Usually, flour and water are mixed, rolled flat and cooked quickly on a skillet, sometimes with a little oil. Conventional wisdom holds that 10 roti per day is sufficient for an adult, which certainly agrees with modern nutritional guidelines. However, many of the poor must make do with less, especially the women. Roti provides the sugar-like substance carbohydrate, which is the body's major energy food. A lack of carbohydrate leads to weight loss, fatigue, weakness and difficulty in concentration. But carbohydrate alone is not enough. The body is built from protein, and needs more daily to sustain itself or grow (in children). A lack of protein leads to several diseases of malnourishment.

When protein and carbohydrate are lacking, the resulting protein-calorie malnutrition produces weakness, fatigue, weight loss and wasting, lack of attention, and decreased resistance to disease. If carbohydrates alone are consumed, as is often the case in the Thar Desert, Kwashiorkor, Marasmus and Pellagra can occur. Kwashiorkor is often seen in young children weaned onto a carbohydrate – heavy diet. Their bodies swell, filled with excess fluid, not fat. Marasmus produces a pot – bellied but otherwise very thin figure, with wasted muscles. Pellagra typically causes 'burnt' patches on the skin, which becomes dry and flaky. The legs can also swell. All of these conditions are reversible with better protein intake. In the Thar, milk, milk products, pulses (beans and lentils) and whole wheat are the best sources of protein. Groundnuts are often grown as a cash crop, especially by those who can afford irrigation systems, but these and other nuts are too expensive to be a reliable source of protein for the poorest.

The body's micronutrient needs involve minute quantities, but they are immensely important for good health. Minerals like iron and calcium, and all the vitamins, play a vital role in the body's growth and function. For instance, without any vitamins, the body could not get energy from food, and without any calcium, the bones of a growing child could not form. Iron deficiency is an extremely serious problem in the Thar – see Anemia, below.

Calcium is present in cows and goats milk, and in some green vegetables. Calcium deficiency is seen in the poorest families, who do not own milch animals or cannot buy milk, and in pregnant women, whose demand for it increases. Calcium is particularly important for adolescent girls, as without it they become vulnerable to brittle-bone disease (osteoporosis) later in life. Zinc is another mineral found in milk and some vegetables, which is important for mental development and for immunity. Milk is the major source of these minerals, as green vegetable consumption is low, especially among the poor. Iodine deficiency is less of a problem in the Thar than elsewhere in India, due to widespread use of iodised salt, and the presence of iodine in the soil.

Vitamin deficiencies can cause debilitating illness. Vitamin A is found in green vegetables like spinach, in carrots, some fruit, and in milk and eggs. Vitamin A is a crucial component of the eye's light-recognition facility, and without enough of it night-blindness can result. In addition to not being able to see in the dark, people with vitamin A deficiency can suffer sores on the eye and slow wound healing. If babies and children do not receive enough during development and childhood, they can become completely blind. Night blindness is a common problem in the Thar. It can have serious consequences – for instance, if children cannot see well in dim light, they find it difficult to study in the evenings after work. Through the Integrated Child Development Scheme (ICDS), the Government is attempting to provide doses of concentrated vitamin A syrup to young children. However, too much vitamin A can harm the liver, so the syrup should be carefully metered. Ideally, a diet containing eggs and green vegetables is best, as these provide other essential nutrients too.

Other vitamin deficiencies common in the Thar are lack of vitamins C and B<sub>12</sub>. Vitamin C is found in fresh fruit and contributes to immunity, healing and blood circulation. Low levels of vitamin C can cause sores in the mouth, reduced ability to fight infections and may contribute to anemia. The best sources of vitamin C available in the Thar Desert are oranges and papaya, although green chillies also contain some. Vitamin B<sub>12</sub> deficiency can also cause anemia, although the most common symptoms are loss of appetite, diarrhea, and dizziness. These symptoms are vague, and often go unrecognised. Milk contains B<sub>12</sub>, and is the best source as again, it provides many other nutrients too. It is

always preferable to obtain necessary vitamins through a balanced diet rather than to resort to pills and supplements. Food rich in vitamins is beneficial in other ways too, and is generally a good deal cheaper than vitamin pills and tonics.

### **Anemia:**

Anemia is a condition where the blood becomes low in hemoglobin, its oxygen-carrying substance. Symptoms range from mild to severe, depending on the level of deficiency. These include fatigue, aching, weakness, shortness of breath, and reduced resistance to infections. The membranes of the eyes and mouth, the palms and the fingertips may become pale in cases of anemia. A simple blood test measures the hemoglobin (Hb) level in the blood. Cut-off values for anemia vary, but are usually around 10mg/ml Hb. Anemia has several causes, but by far the most common is iron deficiency. Iron is an essential component of hemoglobin. To replace the body's daily turnover, around 1mg of iron should be consumed each day. For women, loss of blood during menstruation increases iron demand. During pregnancy, iron requirements also increase, to as much as 5-6mg per day. Growing children have an increased requirement too. People suffering from chronic infections, liver disease or bleeding – such as from gastroenteritis – also need more iron.

Anemia is rife among the rural population of the Thar. Currently, at least 50% of women are estimated to be suffering from moderate to severe anemia, along with around 80% of children under 3 years old. Many of the men may also be anemic, but the condition affects women and children most strongly. The limited intake of iron-rich foods - green vegetables, meat, and eggs – in the diet of the desert's poor is the prevailing reason for this situation. However, the body cannot absorb all of the iron present in food. Iron is most easily obtained from meat. A vegetarian diet should contain around 20mg of iron daily, as only 5% will be absorbed. Food rich in vitamin C promotes iron absorption, but tannins present in tea decrease absorption. In fact, tea is widely consumed in the desert, often accompanying meals, and this partly contributes to the problem of anemia. Green leafy vegetables are the best vegetarian sources of iron. Supplementary iron, in the form of ferrous sulphate tablets, is readily absorbed by the body, and is a fast and effective treatment for anemia. It can also provide the necessary boost in levels of iron needed by pregnant women.

Anemia can also result from vitamin B<sub>12</sub> and folic acid (folate) deficiencies, and will be exacerbated if these are present in addition to iron deficiency. These substances are essential for energy metabolism in the body, in addition to their other roles. Again, pregnant women have an increased demand for these substances – folate requirements increase by up to 10 times.

The combined nutrient deficiencies suffered by the desert population have a lasting impact on health and productivity. Theoretically, the Thar's provision of cereals, pulses, vegetables and milk is able to give a reasonably balanced diet, but in reality, those who are marginalized due to poverty and drought struggle to obtain the food they need. Thus, malnutrition as a matter of 'food security', or satisfying hunger, can be tackled by improving agricultural yields and reducing poverty. However, 'nutritional security', or achieving an adequately balanced diet, is a more complex matter. Income generation and the raising of awareness should go hand in hand in providing this.

### **Fluorosis<sup>11</sup>**

Water is an all-pervading issue in the life of the desert. In recent years, efforts towards drought alleviation and safe drinking water supply have led to the construction of large numbers of tube wells. These draw groundwater, often from hundreds of metres below ground. Water so far from the surface is unlikely to be contaminated with disease-causing organisms. However, high levels of dissolved salts and minerals may be present in this water, leached from the rocks over centuries. These are often harmful to those drinking the water on a regular basis. Arsenic contamination is an obvious danger. Less obviously, excess iron is also highly hazardous. This is an example of the double-edged sword of mineral micronutrients – an excess is as harmful as a lack.

Fluoride is one such substance. In Rajasthan, fluoride enters the groundwater from the geological beds of fluorine – containing minerals, fluorite, fluorapatite and cryolite. The human body absorbs fluoride from water, food or drugs. Although a necessary and essential substance, an excess of fluoride is harmful. Fluoride is important in the growth of bones, joints and teeth, and plays a role in the body's internal chemistry. However, a prolonged intake of high levels of fluoride leads to yellowing of the teeth, rigidity and pain in bones and joints, and resultant deformities such as bent backs and crooked legs. Fluorosis, as this condition is called, can also cause muscle weakness, blood related and gastrointestinal problems, and mental symptoms such as anxiety.

<sup>11</sup> With reference to 'Crippling Human Life – a study of the effects of fluorosis on people in Rajasthan', D. Malik, S. Kavoori, M. Bagoria, a HEDCON, WFI and GRAVIS collaborative study (pub. Gravis Jodhpur 2003).

Since the composition of the underlying rocks varies, so too does the severity and distribution of fluorosis in Rajasthan. Some areas remain unaffected, although there may be other problems with groundwater such as salinity. Other areas are so badly affected that there is a nickname for them in the local dialect – the 'banka patti' or 'crooked stretch'. Even within fluoride-laden blocks, there is variation between villages as individual wells may contain varying amounts of fluoride. The WHO states a safe upper limit of 1.5 ppm, but the Bureau of Indian Standards is even stricter, citing '1mg/litre (1 ppm), but the lesser the better, as fluoride is injurious to health.' In some parts of Rajasthan, tube well water can contain up to 6 ppm fluoride. As the demand for water grows, the groundwater level is falling and the water being drawn is becoming ever more concentrated.

Fluorosis has grave social and economic consequences for its sufferers. Pain and immobility can begin in children as young as five, as fluoride may be taken in via the placenta and in breast milk. This reduces the chances of their doing well in school, and may undermine their confidence from a young age. Fluorosis invariably worsens with age if the offending water is still being drunk, and so many find themselves crippled by pain and unable to work by their thirties or forties. The effects on adolescents and young people are also telling. Many girls (and boys) are embarrassed and self-conscious at the state of their teeth or their deformities, and feel that their marriage prospects decline as a result of fluorosis. Young men also report lassitude, fatigue and loss of libido in affected regions.

Ironically, awareness of fluorosis as a disease condition is low among the very people it affects most badly. Although the connection is made that salinity implies bad water, it is very difficult to convince people to stop using a well badly contaminated with fluoride. Awareness campaigns, painting the handles red, and other methods have all been tried. Typically, however, a belief in a 'family curse' will prevail. This turns many people to traditional healers for treatment, which often does actual harm – for instance, burning with hot iron to treat joint pains.

People will naturally try to treat the symptoms of a disease, even if they are unaware of its cause. For instance, many adolescents take up 'brushing with Colgate' and chewing paan or tobacco, in order to improve their teeth. The high levels of fluoride in most commercial toothpastes, and the naturally high fluoride content of tobacco, will actually make the problem worse. Many people spend large amounts on doctors, who generally prescribe palliatives such as painkillers and rarely test for fluoride poisoning. Indeed, a surprisingly low number of government and private practitioners in the area were aware of fluorosis at all.

The most obvious and direct way to alleviate fluorosis is to drink from a safe water supply. Fluoride can be removed by chemical means, but these have drawbacks and find low acceptance within the community. Rainwater harvesting, regular testing of tube wells, and dilution of contaminated water with a clean supply are all possible approaches. Finally, it is worth noting that the better-off sections of village society are rarely as badly affected by fluorosis as the very poor. This is because diet plays a large part in regulating fluoride metabolism. A diet rich in calcium and vitamin C, as enjoyed by those who can afford it, has been shown to reduce the severity and effects of fluorosis. Promoting awareness of fluorosis is essential in affected areas, and with combined efforts to improve water supply, diet and medical care, perhaps the 'panka batti' will one day become straight once more.

### **Silicosis<sup>12</sup>**

The dust generated by mining and other industries, and the dust of the desert itself, is a menace to the health of the Thar Desert's population. Constant exposure to silicate dust causes one of the world's oldest and most widespread occupational diseases, silicosis.

Silicosis results from inhalation of tiny crystals of silica. These lodge in the lungs and accumulate over the days, months and years of exposure. They initially cause irritation and inflammation. Silicosis then progresses, resulting in fibrosis of the lungs – scarring of the delicate surfaces – and emphysema – collapse of the air sacs. After a time, the disease will progress even if exposure to dust stops. The condition greatly reduces life expectancy, causing early death through respiratory failure, heart disease, and secondary infections. Symptoms are chronic cough, chest pain, weakness, increasing shortness of breath, and symptoms of infection such as fever. Tuberculosis in silicosis sufferers (silico-tuberculosis) is very common, as the ravaged lung tissue cannot resist infection.

There is no cure for silicosis; the damage done cannot be reversed. The progress and severity of the disease can be reduced by minimising additional exposure to silicate dust, but by far the best course of action is to prevent initial

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<sup>12</sup> With reference to WHO fact sheet No 238, 'Silicosis', May 2000

exposure. There are a number of methods used in developed countries for reducing dust generated in industry, and for protecting workers from its effects. Damping systems, masks, and air filters are often beyond the reach of the workers in the developing world. In addition, lax regulations regarding occupational health give employers few incentives to safeguard their workforce's health.

A vast sprawl of stone mines surrounds Jodhpur, extending into the Thar. These mines supply the local red sandstone, much sought-after as a building material. The mines are open quarries, extending over wide areas. In this desolate environment, men, women and children work with basic tools, little shelter and minimal pay. The workers are subject to extreme heat, accidents and dust. Although worker's rights are enshrined in Indian law, few of the uneducated village labourers are aware of their entitlements, a factor exploited by the mine owners. Also, the enforcement of legal standards is virtually non-existent.

Mineworkers may work seasonally or year-round. Drought, poor harvests and hardship may force rural farmers to come to the mines and earn; there are also permanent settlements of workers around the mines. The practice of dry drilling does the most damage to mineworker's health. Usually, young, strong men are put to work on the compressor drill, which releases clouds of dust. There is no protection, and it is estimated that on average, a mineworker's life is shortened by 15 years as a result of silicosis. A young man starting a working life in the mines cannot expect to live beyond 45. At any one time, an estimated 60% of mineworkers are suffering from silicosis to some degree. Dry drilling is meant to be replaced with wet drilling, where dust is damped down, but few mine owners have introduced this practice as it is costlier. There is little monitoring or enforcement, in any case.

Despite their legal rights, the workers have extremely limited access to compensation for any occupational health problems. Sick leave or maternity leave are unheard of, and medical bills are not covered. Some mineworkers estimate that they spend up to 40% of their monthly earnings on medical treatment, mainly for coughs or following injuries. Their impoverishment exacerbates their ill-health, as they can rarely afford sufficient food. The social and economic consequences of this cycle of poverty and sickness, and of the early death of so many people, are serious.

The mineworkers, with their high level of exposure to dust, are the group most vulnerable to silicosis in the Thar Desert. However, 'Desert Lung Syndrome' is noted in this and other desert areas of the world. A study found this non-occupational silicosis, caused by inhalation of environmental dust, to be quite common in desert villagers.<sup>13</sup> However, the progression and severity of this form of silicosis are far lower than that of occupational silicosis. In any case, there is little that can be done about the dust from the dunes. The mines are a different story, though, and ongoing campaigns for worker's safety and health are attempting to address the scourge of silicosis in the Thar.

### **iii. Reproductive health and child development<sup>1, 14, 15</sup>**

India has the most extensive reproductive and child health programs in the world, yet maternal and infant mortality rates are among the highest. Subsidised food and food aid projects abound, yet millions of children are malnourished. The National Population Policy and the Integrated Child Development Scheme set ambitious targets that have yet to be met. The gap between policy planning and implementation is painfully evident in the suffering endured by rural women and children.

#### **Family planning**

Across the world, those living in poverty have the largest families. For the rural poor, children mean labour now and returns in old age – at least some will make it to adulthood. Developed countries wring their hands at the expansion of populations in areas of already scant natural resources, but do not see the practicalities from the people's point of view. The desire for at least one surviving child and the need for a source of labour impel people to have many children, despite awareness of family planning. However, in many places this awareness is incomplete, and family planning is not practiced. The low social status of women is also a crucial contributing factor.

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<sup>13</sup> Mathur M.L. Choudhary R.C.; Desert Lung Syndrome in rural dwellers of the Thar Desert, India; *Journal of Arid Environments*, 1997, vol. 35, no. 3, pp. 559–562(4)

<sup>14</sup> With reference to 'Where Women Have No Doctor'

<sup>15</sup> With reference to 'SMCS guidelines'

In the Thar Desert, women bear children from their teens to the menopause. The state average is 4.5 children, one of the highest total fertility rates in the country. It is likely to be higher than this in the remote rural areas, and does not take into account children who have died. By their forties, many village women have given birth eight or nine times. This is damaging to their health, and to the health of the children. Repeated pregnancy, especially when less than 2 years elapse between births, leads to depletion of the woman's body. She loses energy, vital minerals, protein, and fat, which in the Thar are unlikely to be rapidly replaced. Each birth carries risks of complications and death. Her life expectancy is lowered, and she is made more vulnerable to osteoporosis, uterine prolapse, and incontinence in old age. The babies she carries will also suffer, as her depleted body will be unable to supply their needs. They are also more likely to be injured or die during difficult births.

Awareness of family planning methods remains low, although availability may be higher than for other forms of health care due to govt measures. Methods that rely on the cooperation of men are less likely to be used. These include use of condoms, which are also the only reliable way to protect from STIs, and male sterilization or vasectomy. Men are often wary of, or do not like, these methods.

Women in the Thar villages are brought up to be entirely submissive to their husbands, to the point of being too shy to even speak about family planning issues. They are more likely to use a method that they can access themselves, and over which they have control. The most effective methods of family planning in a rural setting are the IUD or coil, known as 'Copper T', female sterilization, or hormonal pills or injections. Other methods include the traditional prolonging of breast-feeding, and periods of abstinence at certain times of the month or after birth. These, however, are not entirely reliable means of contraception.

The Pill as used in Rajasthan is called 'Mala-D' or 'Mala-N'. A combined pill is typically taken for three weeks out of every four. This can lead to problems in remembering to restart contraception. In fact, Mala-D is taken continuously. The pills covering the 'week's break' contain only supplementary iron, and are a different colour to the others, elegantly overcoming the problems of both timing and anemia during menstruation. Women's rights advocates often criticise the use of the Pill in developing countries, stating that increased risks of stroke, heart disease and cancer are unacceptable and are not being addressed. The Pill undoubtedly has drawbacks; however, when one considers these risks in comparison to the risks of pregnancy and childbirth in rural India, the benefits are clear.

A further consideration in family planning is access to safe abortion services. Abortion is legal in India if the pregnancy endangers the mother's health. However, low awareness and unhygienic hospitals make it a risky procedure. There is a high rate of late abortions in Rajasthan, as elsewhere in India, due to prenatal gender determination. However, those who engage in this illegal practice do so at high financial cost, so this problem has less relevance for the poorest communities. For them, it is more pressing to access to abortion for mothers whose health is endangered by pregnancy, whether too-frequent, or at too young an age. *Ok, I was a bit off-topic there. Hope you approve of the edit.*

Great emphasis was placed on family planning by the government in the early days of the National Health Policy. Coercion and cash incentives for male and female sterilization were introduced, and enforced largely by bureaucratic bodies. It is felt by some that this program 'hijacked' the health services, being obsessed with meeting family planning targets but paying little attention to other problems.<sup>16</sup> Like many government health initiatives before and since, a very vertical approach was taken – single-issue healthcare, with little consideration for social context. Many tubal ligation (female sterilisation) operations are carried out every year in the Thar, mostly at PHCs. However, the emphasis placed on sterilisation suggests that the ultimate aim of this campaign was population control rather than family welfare. Rural women themselves feel threatened by controlling, coercive measures. There is now widespread suspicion of interventions - antenatal immunisations, for instance, are believed by many women to cause miscarriages in order to limit population.

Sterilisation is a permanent solution to large, unsupportable families. However, this may not be ideal for all women – for instance, a young woman with no children who wishes to wait a few years before having them. It is important to focus on giving women informed choices, so that they may delay pregnancy, recover between births, and be in control of their reproductive health. They must be able to decide how many children they want, and when to have them. It is evident from the developed world that when people's income, health care, and access to education improve, families tend to become smaller. At present in the Thar, people do not feel that they can risk having just two children, as many of their neighbours will have lost that number before.

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<sup>16</sup> HFM Pub Health article

## Pregnancy and childbirth

Pregnant women must 'eat for two', that is, they must fulfil the baby's requirements as well as their own. Malnutrition in the womb can lead to impaired development and long-term health problems for the baby. It also increases the risk of eclampsia, an illness that can kill mother and baby, premature delivery, and difficult births. Ideally, the pregnancy should be monitored by antenatal checkups every three months to assess the mother's and baby's health. The mother's body needs to be strong enough for the birth, so appropriate amounts of rest and exercise should be taken.

A pregnant woman's energy requirements rise. Increased intake of iron, folic acid, calcium, and protein are also essential. Iron is needed to prevent the mother from becoming anemic, and for the baby's own blood. Folic acid is known to be important in early pregnancy. It reduces the risk of the baby being born with spina bifida or other neurological defects. Finally, the healthier and stronger the mother, the easier childbirth will be. Childbirth is a potentially dangerous time for mother and baby. Although the majority of natural childbirths take place with no difficulty, complications can be fatal for the woman or child, or both. The most common causes of maternal mortality are infection, bleeding, anemia, obstructed labour and eclampsia – a condition causing fits in pregnant women. Serious complications of pregnancy require surgical delivery. Prolonged labour pains (>24 hours), bleeding, signs of the baby's distress such as rapid heartbeat, and retention of the placenta after birth all require medical attention. Following a delivery, postnatal care for mother and child is essential. The majority of maternal deaths worldwide occur after delivery, from infections and bleeding, but most are preventable if the problem is identified and treated in time.

India has one of the world's worst maternal mortality rates, at 540 per 100,000 births. The majority of these deaths are among rural women, and the majority are preventable. The situation is worse in the Rajasthan and in the Thar, as nutrition, care during pregnancy and delivery, and emergency care are very poor. The MMR in the Thar stands above 670. Only around 40% of women in the Thar have one antenatal check-up; even fewer have two or three. Many factors in combination make pregnancy and childbirth more risky for the desert's women.

Women's health in general suffers from the social and economic strictures under which they live. There are usually no latrines or bathrooms in villages, yet a woman must find privacy in order to defecate and bathe – exposure of any sort is completely taboo. Women cannot bathe until and unless the men have left the house, even if there is sufficient water for them to do so. During menstruation, old cloth and often earth or sand are used to absorb the flow of blood. This is unhygienic and leads to infections, worsening the widespread problem of leucorrhoea among village women. Sanitary products are available only in larger villages, but the throw-away varieties are beyond the means of most rural women. Women in the Thar lead a life of hard labour. In addition to work in the fields, cooking and cleaning, it is a woman's responsibility to fetch water for the family. Lifting and carrying heavy loads can lead to miscarriage, or premature birth in later pregnancy, and pregnant women often become physically exhausted. Early marriage and early pregnancy are common, especially among the poorest sections of society. Many girls still have their first baby well before the age of 18 (in some cases their first two or three). Girls this young often have difficulties in labour as their bodies are not strong enough and their pelvis too narrow, particularly if they are undernourished. Many women also have too many babies (more than four deliveries puts the mother's health at greater risk) and are unable to space births safely. Malnutrition and anemia also make pregnancy exhausting and birth prolonged and dangerous. Anemia is believed to affect around 85% of pregnant women in the Thar. Malnutrition is largely the result of poverty. Status also plays a part - women, even when pregnant, usually have to eat after the men. However, some women still do not eat well during pregnancy, partly due to morning sickness. There is also the belief that 'the smaller the baby, the easier the birth'.

Medical care is inadequate or inaccessible for most women in the Thar. In rural areas of India, the vast majority of births are attended by local midwives or family members (approaching 80%). The Thar is no exception. Traditional birth attendants, or *dais*, may have had considerable experience in attending deliveries, but their lack of medical knowledge puts the mother's and baby's lives at risk. For instance, untrained dais are often unaware of basic hygiene, leading to infections of mother and baby. Infections after birth are the commonest cause of maternal mortality. Some traditional methods of birth assistance may even cause problems or exacerbate existing problems. If the birth is complicated, medical help may not be sought until too late, if it is possible to reach a hospital at all. Some complications, such as placenta praevia, can cause severe internal bleeding and the rapid death of mother and baby. Even so, advanced treatment such as caesarean section is only possible in hospitals with a trained surgeon, operating theatre and a bed for recovery. Reaching an adequately equipped hospital can prove difficult, especially if transport is not readily available. Most PHCs have only limited facilities and would be unable to perform an operation safely, if at all. Antenatal checkups are valuable in this respect – if complications are detected before birth, a woman can travel to a CHC or private hospital before labour, or immediately when it begins. Finally, provision and awareness of postnatal checkups must increase if

more maternal deaths are to be prevented. Injuries to the mother following pregnancy and delivered should also be monitored and treated.

Increasing numbers of trained birth attendants are improving the maternal and neonatal mortality figures. Both government and NGOs are making efforts to reach all traditional birth attendants. A good *dai* is a valuable asset to her community, and gains great respect as a result. Awareness among women concerning pregnancy and birth is rising, but remains inadequate. Considering the difficulties in reaching medical assistance, it is important that women are supported before delivery by antenatal checkups and good nutrition. Men too can play an important role by ensuring good food for their pregnant wives, reducing their workload, and assisting with transport to antenatal checkups or hospital.

### **Neonatal health and infant mortality**

Over the past few decades, levels of newborn and infant mortality have fallen in all Indian states. This fall has slowed in recent years, however, and the target of 60 infant deaths per 1000 live births by the year 2000 was not met (IMR was 76.6 in 2000). Rajasthan lags behind the national average with around 12% of babies and children dying before their 5<sup>th</sup> birthday. This is partly a reflection of the state's comparative poverty. The infant mortality rate is accepted worldwide as a measure of development, due to the range of factors it encompasses. The survival of the newborn baby and infant child is dependent on adequate nutrition, care giving, protection from disease and medical care.

There are several conditions that disproportionately affect young babies. Birth injuries, diarrhea, chest infections, hypothermia and tetanus are responsible for 85% of all neonatal and infant deaths in Rajasthan. Neonatal tetanus is common as the umbilical cord stump provides a route of infection. TB vaccination should be done as early as possible, as newborn babies are very vulnerable. Finally, breastfeeding straight after birth is very important, as the early milk (colostrum) contains protective substances, called antibodies, from the mother's body. These give the baby some immunity to common infections, before his or her own immune system starts to function properly. Breastfeeding alone is best for babies under 4 months old. Bottle milk is usually a bad idea, as it is expensive, less nutritious, and liable to be contaminated. After the fourth month, additional appropriate food and drink should be given. During infancy, a child needs sufficient energy, as well as protein and micronutrients, to grow and develop.

Several factors again come into play in the Thar Desert regarding infant survival. The mother's nutritional status before and during pregnancy plays an important role in neonatal health. In the Thar, this may be far from ideal, with a vast majority suffering from malnutrition in some form. One thing that is fundamental to a newborn's chance of survival is the baby's birth weight. Babies who weigh less than 2.5kgs are at great risk of death, and need special care. Low birth weight can be caused by malnutrition in the womb, a malnourished mother, or by premature birth. Small babies need breastfeeding every 2 hours, must be kept warm, and protected from infections. Premature delivery is common among the poor women of the Thar. Premature labour can occur due to disease, weakness, overwork, a mother's youth, or if there have been four or more previous deliveries. A safe, hygienic delivery by a trained person is not always accessible. This increases neonatal death rates from birth injuries, infections and tetanus, which is contracted through the umbilical cord when not cut and tied correctly.

Traditional care giving practices can be very harmful to newborn babies. For instance, it is traditional to bathe a newborn in cold water after birth. However, all babies, and particularly if underweight or premature, must be kept warm for their health and survival. Another traditional belief is that the mother's first milk, colostrum, is of no use to the baby. Babies may not be breastfed until two or three days after the birth, causing extreme weakness and possible death. Again, premature or small babies are at greatest risk.

Most infants in the Thar become malnourished at an early age, before their 5<sup>th</sup> birthday. This is to some extent due to poverty and the consequent lack of food, but a dearth of awareness concerning weaning and an appropriate diet plays a part. Late weaning is a big problem in the desert; breast milk alone is insufficient after around 4 months, but many mothers continue to breastfeed exclusively in order to conserve resources. Once weaned, young children are at high risk of infections, particularly gastro-intestinal diseases. It is estimated that most children in the Thar will have diarrhea between 2-6 times a year. This can have a lasting negative impact on weight gain, development and health.

For many reasons, medical care of babies and infants is inadequate in the Thar. Firstly, there is the matter of cost and accessibility, of necessity versus practicality. Whilst most mothers say they would take a sick child to a nurse or doctor after around two days, there is no guarantee that appropriate treatment will be given. Many doctors do not bother to test for a specific infection and will generally prescribe broad-spectrum antibiotics that may do no good at all. Some may

even do harm, for instance chloramphenicol, often prescribed for diarrhea, should be reserved for serious infections as it is a dangerous drug for young children. In fact, the vast majority of children with diarrhea do not need medical treatment – they will recover on their own given ORT, rest and good food. However, knowledge of these home treatments is very low, and the prevailing practice is to give a sick child nothing to eat or drink.

A final point concerns the differential treatment of infant boys and girls. Although by all accounts things are improving, the sex ratio (of 891 female per 1000 male) is to a large extent the result of female infant deaths. Deaths are hastened through neglect - girls will be given less food, less attention, and will be sick for longer before receiving treatment. As a result, girl children are one of the most vulnerable demographic groups in the Thar.

## **Immunisation**

Across the world, millions die from or are disabled by vaccine-preventable diseases every year. Children are hit the hardest, being more vulnerable to infections such as tetanus, measles, whooping cough, and polio. The success rates of widespread vaccination campaigns are hampered by insufficient awareness, inadequate healthcare provision and mishandling of vaccines.

The purpose of vaccination, or immunisation, is to 'prime' the immune system to recognise a particular disease. Then, when encountered again, the body will be able to mount a quick, effective response and resist infection. In the developed world, all children are immunised against the following diseases:

Tetanus – caused by bacteria in the soil, tetanus is contracted through wounds, and via the umbilical cord stump. It causes muscle spasms and paralysis and is often fatal.

Polio – this viral infection can vary in its severity. It is rarely fatal but can leave lasting disabilities, such as a wasted leg.

Measles – the virus causes fever, rash, and is highly infectious. It can be fatal, and often results in lasting damage to sight and hearing.

Diphtheria – causes fever, thickening of the back of the throat and death.

Pertussis or whooping cough – characterised by the sound made by those infected, this disease can kill and may cause lasting damage to the lungs.

The BCG vaccine for Tuberculosis is also given. Diphtheria, pertussis and tetanus immunisation is given by the DPT triple vaccine. There is an effective oral vaccine for polio, requiring three doses.

The GOI has an ongoing rural vaccination campaign under the Integrated Child Development Scheme, which operates in the Thar Desert. ANMs are deputed to vaccinate all the children in their areas, and vaccinations are given free. However, awareness of the program remains low. Suspicion of vaccines also abounds; since many children develop a slight fever after immunisation, many parents do not trust the process. In any case, very few couples actively approach the ANM for vaccinations. ANMs complain that only by going house to house can they ensure all children are vaccinated. Food supplementation programs are useful in this respect, as they draw people to a centre where vaccinations can be more readily given.

There are other problems besides motivation. Most vaccines are sensitive to temperature and must be kept cold; otherwise they lose their efficacy. This can be difficult in the Thar, where extremely hot weather and an erratic electricity supply conspire to ruin vaccine stocks. Cold storage (the 'cold chain') is difficult to maintain in transit – a 'cold box' is necessary – making the ANM's task even more difficult. There are also issues regarding the delivery of vaccines. Injections should not be given when the child has signs of a cold, for instance – it may be a mild polio infection that can be aggravated by the needle.

Whilst they are some way off being eradicated, incidences of these vaccine-preventable diseases have fallen over the past decade. Vaccination campaigns are undoubtedly proving successful, but progress has been slow due to a lack of awareness generation work. Once people understand the necessity of vaccination, uptake of the free service will increase.

## **Child and adolescent health issues**

Childhood is a formative period, and deprivation can have lasting effects on physical and mental development. An adult's ability to work, think and reason are all dependent on the level of care, nutrition and education received. The global burden of poverty thus falls most heavily on the world's children, and the Thar Desert is no exception.

Life for a poor village child is hard, especially for girls. Children are more likely to be seen tending animals, carrying water, or gathering firewood than in school. They often have younger siblings in tow, adding this responsibility to their list of chores. Due to water shortages, many children have no opportunity to wash themselves or their clothes, which prevents them from attending school – teachers may punish a child who isn't clean. Boys fare somewhat better than girls, as parents will make more efforts in the direction of their feeding and education, but deprivation is nevertheless widespread.

Many children, and again girls suffer the most, are malnourished from a very young age right through to adulthood. Malnutrition in infancy has lasting effects in childhood and adolescence. There have been many studies of the effects of specific nutrient deficiencies on physical and cognitive development. However, where multiple deficiencies and environmental deprivation are prevalent, it is difficult to ascertain to what degree these effects are present. Protein-calorie malnutrition gives obvious signs of fatigue and weakness, which will compromise children's ability to learn in addition to reducing growth. The most compelling evidence for the role of micronutrients in cognitive development comes from studies of iron-deficiency. Anemic children are reported to have difficulties in concentration and reasoning, and are quieter and more wary than well-nourished children.<sup>17</sup> They are less likely to do well in school for these reasons. Zinc and vitamin B<sub>12</sub> deficiencies are also linked to the development of reasoning skills.

Malnutrition is rife among children and adolescents in the Thar, contributing to a vicious circle of underachievement in poor children. Their fatigue, timidity and lacklustre academic performance can lead to negative responses from caregivers and teachers. This hampers their development further, as a supportive environment is essential for learning. Again, poverty is the fundamental issue. Parents who struggle to provide food for the family simply have not the time or resources to devote to their children's care and education.

Regarding health and hygiene education, few parents know enough about preventive measures to pass on awareness to their children. For instance, children pick up worms by walking barefoot, stuffing dirty fingers into their mouths, and scratching. School – based hygiene education is adequate, but since many children, and the majority of girls, do not attend school it is of little practical use. Adolescent girls are left particularly isolated – very few attend school, and their knowledge of hygiene and reproductive health is extremely limited. It does not appear that much discussion goes on between female family members on this subject, at least not involving the young girls. The lack of education of boys and girls on STIs, family planning and pregnancy makes broaching these subjects more difficult later, as the 'embarrassment factor' becomes higher in adults.

There are many children in the Thar with disabilities. The problem arises mainly from the high incidence of birth trauma, due to lack of trained assistance, and of diseases of infancy such as polio and measles. It is often felt that a disabled child is a 'punishment' levied on a family for incurring the wrath of the gods, or that the child is cursed. Disabled children are often neglected, isolated and denied education. They may also suffer at the hands of their peers – children can be notoriously cruel to the disadvantaged. There are very few institutions that cater to the needs of disabled children and their families in the Thar Desert. However those that do exist in the region show that with due care and attention, a disabled child can become a productive, independent member of society.

Despite the hardships of their situation, children in the villages are still children, who run, shout, sing and play. There is a strong sense of community, tradition family and friendship that supports as much as it stymies. And there will always be that game of cricket somewhere in the sand.

#### **iv. Geriatric health**

In India, as elsewhere in the world, the population is aging. Globally, it is estimated that number of elderly people has tripled in 50 years, to 600 million; 80% of this increase took place in the developing world. At current rates, one in five people will be over 60 by 2050. In India, increasing life expectancy due to medical advances and economic growth has led to an expansion of the over-60s demographic group. However, as in many developing countries, health care and social trends have not kept pace with this sudden alteration in population structure. Governments and NGOs alike often neglect the health of the elderly, as they are overlooked in favour of child health programs, disease control, and preventive medicine. However, the elderly afflicted by both general and specific conditions. Their health issues need addressing, and in doing so awareness may be generated that will doubtless be passed on to the younger generation.

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<sup>17</sup> M M Black, 'Micronutrient deficiencies and cognitive functioning', American Society for Nutritional Science 2003.

Many conditions arise as a result of advanced age, or are worsened as one gets older. Diabetes is one such disease. Elderly people often develop this condition, where the body loses its ability to regulate the level of glucose in the blood. This can lead to kidney disease, blindness through retinopathy, and cardiovascular problems such as high blood pressure. Elderly people may suffer from reduced mobility due to arthritis or rheumatism, both more common in the over-50s. Being in pain, or being unable to live independently, can give rise to feelings of depression and worthlessness. Deterioration of sight and hearing are common and may add to feelings of isolation. Cataract is the most common cause of blindness in the elderly and is discussed in detail below. Cancer rates are also highest among the elderly, but the growth of cancer is usually slow. Most afflictions of the elderly can be managed, rather than cured completely, through diet, lifestyle and medical care.

In the Thar Desert, very few elderly people live alone. Most are part of an extended family of children and grandchildren, and many contribute fully to family life right up until their death. For those suffering from health problems, however, life can be difficult. Medical care is expensive, often remote, and in some cases completely inaccessible. For instance, cancer treatment is beyond the means of the poor. There are also no specialists in geriatric conditions outside the bigger cities. The need for continuous medication, for instance to treat arthritis, can be an unbearable financial burden. Considering that many elderly people are entirely dependant on their family, their needs may often come after those of the younger generation.

## **v. Eye Health**

Sight is essential, and its safeguarding is crucial to an individual's working life. Although the government of India and NGOs have been working actively in the sphere of eye care, there is still a great need to expand this activity in remote and rural parts of India, including the Thar Desert.

### **Cataract<sup>18</sup>**

Cataract is the world's leading cause of blindness, with an estimated 20 million afflicted. Age is the most significant factor in cataract development. As the world's population ages in the developed and developing world alike, the number of cataract sufferers looks set to double by 2020.

Cataract affects the lens of the eye, through which we see and focus. Gradually, the transparent lens becomes cloudy, thickens, and loses the flexibility that allows us to 'zoom in' and 'zoom out'. This is due to changes in the substance of the lens. The changes are not so much caused by age in itself, as by cumulative exposure to causative influences. UVB radiation, a component of sunlight, is by far the most significant. Genetic and dietary influences are important, as is general health – diabetes hastens the development of cataracts. Smoking is also a significant risk factor. Cataracts may also develop in children (congenital cataract) although this is rare and presumably governed by genetics.

Cataracts develop gradually, but may result in near-total blindness. Sufferers thus become helpless and dependent on others. Cataracts are treatable surgically, whereby the clouded lens is removed and then replaced by an artificial one (intraocular lens). Drugs and eye-drops are used to hasten recovery. The operation is quick and simple, and is usually performed under local anesthetic. It can lead to a rapid improvement in sight, allowing the affected person to regain their independence.

The global burden of cataract is not equally distributed. In India, 82% of those aged 75-85 are affected to some degree, whereas in the US the prevalence in this age range is 46%. There are numerous theories as to why this is the case. Firstly, in India, as in other developing nations, there is high incident light – the sun is stronger. People are also less aware of the dangers of strong light, and smoking, than in developed nations. You do not see many rural farmhands wearing sunglasses. Secondly, poverty is a significant factor – cataract development has been linked to protein-calorie malnutrition, vitamin and antioxidant deficiencies, and chronic diarrhea. All of these are part of life for India's rural poor.

The Thar Desert has a high prevalence of cataract cases, arising from the glaring desert sun and widespread impoverishment. For many, cataracts spell the end of independent, productive life, as facilities for diagnosis and treatment are minimal in rural areas. Traditionally, blindness is regarded as the 'will of the Gods' and is often mutely accepted as such. Even with awareness of treatment, it may be difficult to find. In India as a whole, there is just one ophthalmologist for every 400 000 people (4 lakh). This is an average; in isolated rural areas like the Thar the ratio will be even lower. This is largely because ophthalmology is a lucrative specialisation, and it is easier to make large amounts of money in an urban setting. For the rural poor, effective screening measures and prompt treatment are

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<sup>18</sup> With reference to G. Brian, H Taylor; 'Cataract Blindness – challenges for the 21<sup>st</sup> Century'; Bulletin of the WHO 2001 79:249

urgently needed. NGOs such as Sight Savers International (UK) and Vision for All (Switzerland) are endeavouring to provide affordable, accessible care for cataract sufferers, in addition to treating other disorders such as glaucoma.

### **Glaucoma<sup>19</sup>**

New statistics gathered by the WHO show that glaucoma is now second only to cataracts as the leading cause of blindness globally. This is partly a reflection of the aging populations of developing countries, as glaucoma prevalence increases with age. However, glaucoma is more likely to cause irreversible blindness than cataracts, making early diagnosis and treatment the central issues.

There are several forms of glaucoma, but they all involve the build-up of fluid in the eyeball. This increases pressure within the eye, leading to eventual blindness. The two most common forms are gradual build-up (primary open angle glaucoma), and a more acute version (angle closure glaucoma), which can cause symptoms of pain and headache. Angle closure glaucoma is the more common form in India. If detected early, glaucoma can be surgically corrected; however, current surgical techniques are far from ideal due to rapid scarring, in Indian patients especially. The patient may also be required to use medicated eye drops indefinitely.

In the Thar Desert, cases of glaucoma are seen far less frequently than cataract. However, the non-acute form of glaucoma has few symptoms and people may not seek treatment until an advanced stage. It is estimated that glaucoma prevalence is around 2%, with up to 90% of cases going undiagnosed. The shortage of ophthalmologists, lack of awareness, and differing health priorities of the government combine to make glaucoma a persistent and unmanaged problem in the Thar Desert.

### **Other eye problems**

Other conditions affecting the eyes can arise from prolonged exposure to bright light, vitamin deficiency, and dirt. These include night blindness, corneal ulcers, 'arc-eye', and inflammation and dryness. Refractive errors, or short or long sight, are also a serious problem. A simple pair of glasses would correct the sight of the nearly 2 million children in India who are effectively blind due to refractive error. In the Thar, as elsewhere, poverty renders even this inaccessible.

The sight of a child with swarms of flies attracted to the pus running from her eyes is a common one in the rural Thar. Eye infections are a widespread affliction, and can become chronic, causing pain and even blindness. Small children's eyes are very vulnerable to infections, particularly as children are unaware of the dangers. Where hygiene is poor, it is very easy for an infection, like highly contagious conjunctivitis, to spread. Flies too play a significant part in the transmission of infections. Chronic conjunctivitis can develop into trachoma, a condition affecting millions in developing countries. Trachoma causes inflammation and lumps on the inside of the eyelids. It may become difficult to fully open the eyes, or the eyelid may turn inwards so the lashes scrape painfully across the eye. Adults are also affected by trachoma and conjunctivitis.

Ointments and drops are available to treat eye infections. However, prevention is simple, and the high prevalence of eye infections in the Thar is a reflection of the widespread ignorance of basic hygiene. Simply bathing children's eyes with salt water can greatly reduce the severity of an infection, or prevent it from recurring. There is a tradition in the Thar of using *kajal*, a black powder used to line the eyes of babies and small children. This seems to have some effect on limiting infections. However, in this as in so many other cases, increased awareness, prompt treatment and improvements in hygiene are needed above all.

## **4. Gravis' work in community health development**

Over the last fifteen years, Gravis' health and health education programs have expanded greatly. Bearing in mind that community health arises from a complex interplay of factors, health programs are often integrated with other areas of development work. Since factors such as water, nutrition, social justice, and income have such a huge impact on health, all of Gravis projects are 'health projects' in the sense that community health may be improved through them.

One of the most important areas of Gravis' work is the empowerment of women. By encouraging the formation of Self-Help Groups (SHGs) at the village level, women can for the first time save money, hold bank accounts and develop

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<sup>19</sup> With reference to 'Glaucoma is second leading cause of blindness globally', S. Kingman, In Focus, Bulletin of the WHO November 2004

means of income generation. One such SHG in the Pabupura area runs a small shop, for instance. The women's confidence and status concomitantly improve, and they are able to do more for their own and their children's health. SHGs make loans from their savings, which may be used for transport and medical care.

Empowering women in agriculture, through the development of seed banks, campaigning for equal wages, and facilitating bank loans, is another key step by Gravis. Other agricultural activities, such as building *khadins*, water-harvesting bunds, improve crop yield even in dry years. Improvements in the care and quality of livestock are also being coordinated by Gravis, and many projects include the development of fruit gardens. Agricultural development boosts nutritional status and income, both of which have positive knock-on effects on health.

Water itself is of primary importance in health. Clean drinking water can reduce the impact of many diseases, and water is needed for food and livestock – for the cereals, pulses, vegetables and milk that can provide a balanced diet. Water for washing is also important. Gravis provides household rainwater harvesting *taankas*, which collect, filter and store runoff. Hygiene and health education also facilitate clean, safe water. Health education is also incorporated into all education projects for village children. Gravis runs schools for Non-Formal Education, focusing on teaching the basic skills of literacy and numeracy.

All of these measures will contribute to the sustainable improvement of community health. There remain, however, issues that can and should be addressed directly. The dangers women face in pregnancy and delivery, the high infant mortality, and the hardships endured by the elderly, the blind and the sick; all are areas of concern for Gravis. The projects described below focus on alleviating immediate suffering through providing referral and treatment services, and through building foundations for long term, sustainable improvement. The lack of awareness of health, hygiene, preventive practices, and home treatments is a major stumbling block in the development of community health in the Thar Desert. Gravis health programs therefore make awareness generation a priority. Through community based organisations, like the VDC and SHGs, and locally recruited and trained health workers, the essential information is passed on. Through the recently established Field Hospital, Gravis also endeavours to provide quality, affordable medical care to those most in need.

## CURRENT HEALTH ACTIVITIES

At the time of writing, the projects listed below constitute Gravis' health-directed activities. All projects begin on a small scale, and local involvement is emphasised throughout. Gravis implements projects developed and supported by international NGOs, with whom there is continuing partnership.

### SMCS - Safe Motherhood and Child Survival

SMCS has operated in 20 villages in Osiyan block of Jodhpur district for the last 5 years. It is now in the process of moving to Jaisalmer district, and the Osiyan villages are being covered by INHP. SMCS is aimed at pregnant women, lactating mothers and children under 2 years old. SMCS provides nutritional support, and trains village health workers (VHW) and traditional birth attendants (TBA), working to reduce maternal and infant mortality, malnutrition, and lack of health awareness. SMCS also undertakes infant growth monitoring, a service not currently provided by government health workers. Up to December 2004, SMCS was running from Gagadi and Khedapa field centres, with funding from Catholic Relief Service (CRS). The program is currently preparing to restart in Jaisalmer district. A similar program is also underway at Baap and Pabupura centres, funded by Wells for India (Wfi). Initially, potential VHWs are approached – usually, the first women recruited are the *dais*, or traditional midwives. They are confident and respected in their communities, and already possess valuable experience. These women then assist in a baseline survey of the health situation, and the first beneficiaries are identified. Beneficiaries are pregnant women, and children under 3 years old. Poverty is the main determining factor, and caste is also taken into account.

Beneficiaries are provided with antenatal checkups, supplementary iron and folic acid, child growth monitoring, and a food ration. This is partly provided as an incentive to participation. The nutritional support is provided by USAID, via CRS and Gravis. Every month, each child under two years old is entitled to 1 litre vitamin-A enriched refined cooking oil and 1.5 kg vitamin-A and calcium enriched bulgur. Mothers are supplied with a card for receipt of the food supplement, which is provided for Rs 20. This card also documents the child's weight-for-age and immunisations. The monthly distribution meetings allow children to be weighed regularly, and ANM vaccination visits may be arranged.

VHWs are the mainstay of village health. Their initial training lasts three days, and is carried out by a resource team. A VHW's training encompasses basic first aid, signs of illnesses such as TB, anemia, and malaria and judgment of when referral to a doctor is necessary. Basic skills such as making home rehydration solution are also covered. TBAs and

VHWs are trained in a hygienic method of delivery - the 'five cleans': using new, clean blades for cord cutting, clean cotton for tying, clean hands, clean surface, and clean clothing for the baby. And, as they are happy to demonstrate, bangles must be removed, or cleaned well and pushed back from the hands. They are also taught to recognise early danger signs and arrange hospital transport. The TBA or VHW will also weigh the baby, knowing that a birth weight below 2.5 kg requires a trip to hospital. The unhelpful traditional practices of bathing the baby in cold water, and of not breastfeeding for 2-3 days after birth, are being overturned by highly motivated TBAs and VHWs. Finally, all VHWs and TBAs keep records of deliveries, written for them by the local teacher, a child, or in some cases, by their own husbands. Meetings are held monthly in which the VHWs/dais receive a stipend of Rs 290. Disposable midwife kits, contraceptives, and IFA tablets are also distributed (although all are able to obtain supplies independently). They are encouraged to report progress and problems. They also have the opportunity to discuss their work with each other. Some points of practice and theory may also be covered, especially if a visitor is present. VHWs are encouraged to hold village-level health discussions, particularly relating to nutrition during pregnancy. Pregnant women are encouraged to eat well. At present, 2-3 such meetings occur each month in target villages. The VHWs are also trained in promotion of hygiene awareness and vaccinations. Most of a VHW's work is with women and children. Some issues, such as TB and sanitation, are discussed with men as well in the health meetings. However, there is reluctance on both sides to discussions of family planning and pregnancy. The ideal scenario would be a flow of information from VHWs to village women to their husbands, but many women lack the confidence to discuss their health issues with their husbands.

### **Catholic Relief Services – CRS**

Founded in 1943 by the Catholic Bishops of the United States, CRS is one of the largest humanitarian NGOs in the world. India is one of the 99 countries in which CRS operates. Work began here in 1946. CRS places emphasis on providing direct assistance where necessary, and on encouraging sustainable, community based development everywhere.

' Catholic Relief Services work is founded on the belief that each person possesses a basic dignity that comes directly from God. Because of this belief, we advance the intrinsic value and equality of all human beings, and strive for systems and procedures that demonstrate fair and equitable treatment of all people.'

- [www.crs.org](http://www.crs.org)

Operating through 63 partner organisations like Gravis, CRS projects in India encompass health, education, agriculture and social development. Mother and child health is promoted through education and awareness generation, and through the provision of supporting services and VHWs. CRS also supports organisations involved in HIV/AIDS prevention, the eradication of child labour, emergency response measures and economic independence generation or microfinance.

After a birth, the parents are encouraged to have their newborn baby vaccinated. Many parents are reluctant about the process. Few parents actively approach the ANM for the free injections, so TBAs and VHWs have a range of strategies for motivating people. Few parents actively approach the ANM for the free injections. Village health worker's tactics vary. Here are a few examples:

'If they won't listen, sometimes I just take the children anyway!' I talk to the *Dada* and *Dadi* [grandparents] as they can influence the parents.' I show them other healthy children who are vaccinated, and explain that they'll be protected from five diseases.' Other examples of motivation work include encouraging men to save a few rupees a day for good food for their pregnant wives. Some dais and VHWs encourage an expectant mother's family to save a little money in case emergency transport is needed – 'We tell parents to put by as much as they can, and to warn the local jeep driver so he's not away when the birth is due'. And if a family is too poor to afford health care, many VHWs will organise a contribution from village funds or from women's groups. Since SMCS health workers understand their communities' attitudes, its strengths and weaknesses, they are best placed to deliver effective care.

SMCS workers have good relationships with their local ANMs. In Cherai village, the ANM is very happy with the collaboration – 'My work has been made easier as motivation and awareness have increased. Now people are starting to come to me for vaccinations. Before, I had to go to their houses.' Bringing mothers and children together in meetings

also makes group vaccinations possible. The record-keeping SMCS card also provides valuable information for a visiting ANM.

On the whole, VHWs are positive about their work and feel that much progress has been made over the course of the SMCS program. However, all agree that lack of awareness remains a big problem in their villages. As one VHW complained, 'Sometimes it seems like people just come for the food, and they aren't so interested in knowing about health.' This situation is changing slowly. The implementation of the next phase of SMCS will address these problems in a new area. In the meantime, VHWs in the Osiyan block villages are determined to continue their good work, and will do their best to safeguard their community's health.

### **INHP – Integrated Nutrition and Health Project**

This project began in 1998 and is carried out in Osiyan and Phalodi blocks in collaboration with CARE (Cooperative for Assistance and Relief Everywhere) as a supporting program to the GOI's Integrated Child Development Scheme (ICDS). ICDS aimed to deliver vaccinations and nutritional support to all rural children, via special centres known as Anganwadis. The full course of Polio, Tetanus, DPT, and measles vaccination is given, in addition to supplementary doses of vitamin A. The nutritional support rations are provided by USAID in conjunction with CARE, and are similar to those provided through CRS under SMCS (see above).

The initial response to ICDS was very low, particularly in the poorest areas. As in many other instances, the government had provided services without concurrent motivation or awareness generation efforts, and there was a gap between the service providers and beneficiaries. INHP was instigated in part to bridge the gap between the people and the government's health workers. INHP also works towards raising general health awareness through community based organisations. Community based 'Change Agents' are the key players of the program, and distribute information and advice on the Anganwadi's services. Anganwadi workers also raise awareness of immunisation, medical care and reproductive health. Gravis workers encourage monthly meetings at the Anganwadi centres, at which the entire community can discuss health issues. Both INHP and Chayan (see below) projects are branches of CARE's RACHNA mission, aimed at sustainable, widespread improvement in nutrition and health, particularly reproductive health.

### **Case Study – Santora village – Rukma Devi – Dai and VHW**

Before being recruited as a VHW, Rukma Devi occupied a special position in the village of Santora. She is the 'dai', the village midwife. With the nearest doctor 30km away over an unmade road, her skills are enormously valuable to the community. Four years ago, Rukma Devi chose to undergo training to become a village health worker (VHW) and to refine her skills as a midwife.

'The training is good, and I learn a lot from our monthly meetings' says Rukma Devi, 'And I enjoy discussing my work with women from other villages.'

'The biggest problems in my village are sore throats, coughs, malaria, diarrhea, and stomach aches, but knowledge is an even bigger problem', she replies when asked about the health situation in Santora, 'I'd say only half the people here have any idea about health. And they only go to a doctor if they are very ill.'

Rukma Devi's day-to-day work includes holding meetings and liaising with the local government health worker, the ANM – known as 'nurse behn-ji' (sister).

'I hold meetings two or three times a month, men and women come and I tell them about good food, water, and cleaning. I tell parents to get their children vaccinated by the ANM.'

When asked about her dealings with the ANM, Rukma Devi smiles broadly and says 'we have a very good relationship, and we support each other's work.'

Rukma Devi is called for deliveries 5-10 times every month, and keeps a record of all the babies born, which the local schoolteacher writes for her. She has found the training very helpful, and can now recognise early danger signs. Not one mother has died in labour in her village since the project started.

Finally, although Rukma Devi is very happy with the support she receives from SMCS, she would like GRAVIS staff to come to more of her village health meetings. 'A visit from a doctor would be nice,' she says, 'as people would listen and learn. Increasing knowledge is the most important thing.'

## Chayan

Reproductive health is the major focus of this initiative. In the first phase, reproductive health change agents (RHCA) are recruited from the community to act as advisors on family planning, pregnancy, childbirth, infant health, and STIs, including HIV/AIDS. They meet with newly married couples, for instance, to discuss family planning and pregnancy. Women who have just given birth are also offered advice on family planning, and are given information on vaccinating their babies. Agents are trained to recognise possible STIs, and to encourage those infected to seek treatment – from a medical doctor, as many prefer local practitioners for these complaints. RHCAs also hold awareness meetings in their villages.

RHCAs undergo three rounds of training, at six-month intervals, and meet with Gravis staff monthly to discuss problems and developments. These meetings are often held at the local Anganwadis, providing extensive cross-over between Chayan and INHP. Anganwadis also provide a convenient venue for RHCA training. Training takes place over two days, and is structured according to CARE's guidelines. The staff who teach RHCAs are themselves given training by CARE shortly before the RHCA event. An RHCA's training is modular, with emphasis first being placed on family planning and the reproductive cycle. The RHCA's advisory role is also explained, and some counselling skills are discussed. The later training sessions cover STIs, including HIV/AIDS, and social marketing concepts. The step by step process is designed to overcome difficulties in discussing certain topics, like STIs, with RHCAs.

### **CARE – Cooperative for Assistance and Relief Everywhere**

The US-based aid organisation CARE has worked in India since 1950. One of the largest private NGOs, CARE is committed to development projects across the world.

'In some of the poorest communities in the world, CARE and our partners are working to create meaningful and significant change in people's lives. Every day, our innovative projects help communities in more than 60 countries address their most threatening problems and create lasting solutions to poverty.'

- [www.care.org](http://www.care.org)

In India, CARE is currently supporting the Government of India's Integrated Child Development Scheme, and is implementing its own health, nutrition and family planning campaigns through the RACHNA project in eight Indian states. CARE emphasises the welfare of women and girls by providing nutritional support to pregnant and nursing mothers.

Recent initiatives include drives to promote HIV/AIDS awareness and safe sexual practices, working within the Government framework of the National Aids Policy. CARE aims to provide integrated services at a community level, and recruits community based workers.

## GRAVIS Hospital

In the Thar Desert, hospitals are lacking both in quantity and quality. The need was thus felt for an affordable, efficient and fully equipped rural hospital. In 2001, Gravis Hospital was set up in Tinwari village, Jodhpur district. Tinwari is a large village, a hub of trade and transport for around 50 outlying settlements, and was chosen as the most accessible location in the region. The 30-bed hospital was built with funds from the Japanese Embassy (Japan sponsors development work in Rajasthan), the Worthington Foundation (US), IDEX (US), PPI (US), and from Gravis' resources. In 2005, accommodation for 20 more beds and an eye care complex have been constructed.

The main hospital is a two-storey building, situated by the main road through Tinwari (Ghewda road). On entering, the reception desk, waiting hall diagnostic facilities (X-ray, Sonography, ECG) and doctors' consulting rooms are on the ground floor. The labour room and maternity ward, the small triage/first aid room, nurses' room, laboratory, and hospital administration are also housed on this floor. The first floor is accessible by stairs or by a winding ramp. It includes the operating theatre and associated area, male and female wards, private wards (rooms for those prepared to pay extra for privacy) and a waiting area. There is also access to the roof terrace; the staff quarters at the rear of the hospital can be seen from here. At the time of writing, construction of the new Eye Unit at the rear of the hospital was also underway. The pharmacy/dispensary is located outside the hospital, facing a small but pleasant garden. The hospital's design provides a nice example of effective use of space; some of the nearby PHCs/CHCs may be bigger in terms of floor area, but contain many unused rooms.

The hospital is staffed by a team of doctors and paramedical personnel, including a full-time lab technician and an ambulance driver. Several members of staff including a doctor live on the hospital premises, providing 24-hour care. Gravis hospital has working arrangements with three Jodhpur based surgeons, who perform general, orthopedic and plastic surgery respectively. They are called to the hospital as required, which involves a drive of around one and a half hours. Each Thursday, an ophthalmic surgeon also visits to diagnose and treat eye patients.

Between its construction and the end of 2004, the hospital has treated 19,494 patients. Records show a total of 232 general surgeries, including assisted deliveries, and 918 eye surgeries. A typical day at the hospital sees the arrival of anywhere between 20 and 50 patients, depending partly on the time of year. Patients come from remote areas and from closer by. Their problems vary, from a woman having difficulty in labour to a local drunk who's fallen off the bus and smashed his face. After seeing the doctor, patients take their prescriptions to be filled at the pharmacy. Alternatively, if a test is required a form is passed to the lab technician. The results come through rapidly; the doctor delivers their verdict. The doctor does not charge for his or her services, and medicines are provided on a cost-recovery basis. The patient's circumstances will be taken into account and drugs may be subsidised.

The hospital is not without problems and challenges. As relative newcomers to the area, Gravis' medical team must win the trust of the local population by outshining the incumbent small-scale practitioners and quacks. The steady increase in patient numbers shows that this aim is being achieved. Also, despite the emphatic notice at reception, Gravis Hospital's doctors are frequently asked to perform prenatal gender-determination scans. It is generally the more affluent local residents who make such requests. Despite the offers of thousands of rupees (the price for a medically indicated scan is fixed at Rs 250), Gravis doctors remain adamant. This abhorrent and illegal practice will never occur at Gravis hospital.

### TB control

Gravis is a registered partner organisation under the GOI's Revised National Tuberculosis Control Program - RNTCP. Whilst TB patients are treated at Gravis hospital, the most significant areas of work are awareness generation, screening and monitoring of TB patients. During health camps, particularly in mineworker's settlements, many cases of suspected or recurrent TB are encountered. Sputum samples are taken and tested. Patients are advised to go to their local PHC for testing and treatment, as Gravis hospital cannot provide TB drugs free of charge.

Awareness generation takes place through village health workers; those working under various projects (Khoj, SMCS and others) are all conscious of the threat of TB. They advise anyone with a chronic cough, weight loss and other signs of TB to be tested. One of the biggest challenges of TB control is early withdrawal from treatment; many patients do not complete the DOTS chemotherapy course resulting in recurrent and resistant infections. To address this challenge, Gravis has recruited 20 DOTS workers from affected communities. Having received training from the Government TB Control Dept., they are responsible for the identification, referral and monitoring of TB patients in their area.

### Case study – RHCAs

Ketu village Anganwadi is hosting an RHCA training today. Dhardas and Mira both used to work for the Anganwadi before becoming RHCAs. Adjusting his carefully tied red turban, Dhardas says, 'There was no information in the village on these things. I decided to be an RHCA to give this health information to my village.' Mira smiles, her veil half-covering her face, and agrees. 'I wanted to learn so that I could give this knowledge back to the village.'

'People take our advice,' says Mira, 'there haven't been many problems.' Her main area of work concerns advice on family planning, mainly to village women. 'I give women information about *nasbandi* [sterilisation], and last year 200 women from my area had the operation. Some had only two children, but some had seven, eight... .' 'Men don't do *nasbandi*,' Dhardas adds, 'they're afraid it will make them weak. I tell them it won't, but still they're afraid.' 'Even women don't like it,' Mira laughs, 'they think it will make their husbands visit other women.'

In a typical month, Dhardas and Mira hold several meetings in their villages. 'Sometimes the *samuh* [women's SHG] and *panchayat* [village government] come,' Dhardas explains, 'and there's always men and women present.' As well as the meetings, the RHCAs make door-to-door calls. 'We work with the ANM, too,' says Mira, 'especially regarding family planning and vaccinations.'

What are their hopes for this training, and for the next year? 'I'm looking forward to finding out more about AIDS,' Mira muses. 'So am I,' says Dhardas, adding: 'I'd like to know more about TB. And cancer. What are they, and how are they treated?' For him, at least, Reproductive Health is just the beginning.'

### Case Study – A mineworker's health camp

Among their houses of red stone blocks, the stone that they labour over each day, the people of X village gather for a mobile medical camp. Everyone, from adolescent girls to middle aged men (there are few old men), works in the mines, whose desolate pits form a backdrop to the dusty settlement by the main road.

Among the patients is Raman, 51, who complains of pains in his joints. The backbreaking work in the mines has caused deformative osteoarthritis. Raman is currently being treated for TB, he tells us. 'I've taken the drugs for two months. Now I go for injections every other day.' The injections are streptomycin, which should clear up the infection after the two month intensive course has killed most of it. It will be a long haul. 'I have to keep going for 6 months,' says Raman, 'and I will. I had this problem two years ago, but back then I stopped taking the medicine too soon. Now I realise I must take it all.'

This early withdrawal from treatment is causing big problems. In the next village, Madhu Ram waves a tattered medical card. 'This is from 1986, when I was first told I had TB,' he relates, 'since then I've been treated twice – once I took medicine for 6 months, then for 18 months.' But the treatments didn't work. Madhu Ram, wiry and imposing in his faded military-style jacket, still has TB. It is likely to be a form resistant to modern drugs, untreatable with current medical knowledge. His wife and children are also being treated for TB, having contracted it from him. 'It's difficult to get treatment as the PHC is 12km away,' says Madhu Ram, 'and for me it hasn't worked. I've had TB for eighteen years. All I can do now is make sure I cough into cloths so no one else gets it.'

Despite the GOI's drive to control TB in rural areas, the shortcomings of government healthcare are evident in the Thar. At Gravis hospital, the requisite three sputum tests are always performed before a patient is given the 'all clear'. At PHCs this may not be done; patients have frequently arrived at Gravis hospital with acute TB having been told by the PHC that they were cured. Such patients are either referred back to the PHC, with their test results, or offered the drugs at cost-price from Gravis Hospital. It is also important to generate awareness within the patient's family – they should be encouraged to be tested and must be made aware of the risks of infection. In addition, the patient should receive adequate care and nutrition to support recovery.

Over the course of Gravis health activities, a total of 190 medical camps have resulted in the identification and direct treatment of 120 TB patients. More may have been referred to PHCs. In the period 2003-2004, village health workers identified 16 TB patients who later began treatment. In addition, immunisation campaigns have led to increased uptake of the BCG vaccine, which protects newborn babies from TB. All this is very promising; however, there is the constant threat of resistant strains of TB emerging. This has begun to happen, due to the high prevalence of TB in the region and the inappropriate or incomplete use of TB medication. In future, even greater vigilance will be necessary to control TB in the Thar.

### Eye Care

This program has proved a huge success since its inception in 2003. Funding comes from Sight Savers International (SSI), and Gravis' partner organisation JGVKS assists implementation. To date, over 7,000 eye patients have been treated and around 2,000 eye surgeries have been conducted through the project. Around 80% of patients are over 60 years of age; the remainder are cases of congenital cataract in children and young people.

The program is staffed by 10 field workers, 2 field supervisors, 1 outreach paramedic, 3 itinerant teachers, 1 project coordinator, 3 ophthalmic assistants, an ophthalmologist and a project director. The field workers hold meetings in the villages and go door to door raising awareness of eye problems. They publicise the regular screening camps and encourage people with eye problems to go for testing. *Quote from fieldworker.* Some ophthalmic assistants were trained outside, but many received training through SSI support via a 6-month crash course. They are able to recognise the signs of cataract, glaucoma and infections.

Screening camps are run from JGVKS Lawan centre, in Jaisalmer district. So far, over 100 camps have occurred. Ophthalmic assistants hold these camps in the villages, and refer those requiring treatment to the Gravis Hospital. Eye testing and surgery days are held every Monday and Thursday at the hospital. Patients come both from screening camps and independently. Patients arrive in the morning, and are examined by the visiting ophthalmologist. Surgery is then scheduled for the afternoon, and usually begins around 4pm. Operations may continue into the night. Gravis Hospital is busy on Mondays and Thursdays, especially as patients are usually accompanied by one or more relatives.

The young wander in and out while the elderly patients wait quietly on mats upstairs, their turbans, veils and jewellery contrasting with the piece of surgical tape marking the affected eye.

Cataract surgery is by far the most common treatment. In the procedure followed by Gravis' visiting ophthalmologist, the opacified lens (cataract) is removed via a small incision, enlarged with a 'tunnelling tool'. The cataract is freed and rinsed out with sterile saline, and then an artificial Intraocular Lens is inserted. The incision is closed with a cauteriser (heat probe), so no stitches are needed. Patients are prescribed medication, eye drops and dark glasses (aphakic spectacles) to ensure swift recovery. Patients are advised to return for a check-up after one week. The surgery is known as Short Incision Cataract Surgery - SICS.

The cost of the operation is covered by SSI; however, patients must pay for their medication and transport costs. Gravis suggests a small donation to cover hospital fees - prior to the operation all patients are given a blood pressure check, and eye wash and local anesthetic are administered by hospital staff.

### **Sight Savers International - SSI**

Since its initiation in the UK 50 years ago, Sight Savers International has helped treat 75 million people for blindness or potentially blinding conditions. Working in 26 countries, SSI supports the education, counselling and training of the incurably blind in addition to providing treatment for reversible conditions.

In India, SSI aims to treat those suffering from cataract, glaucoma and refractive errors. There is also a focus on tackling visual impairment and blindness in children. Children who are irreversibly blind are educated and trained, to give them independence later in life.

[www.sightsavers.org](http://www.sightsavers.org)

The field worker's job of awareness generation and motivation is essential. It seems that only around 50% of those diagnosed in screening camps actually seek treatment at the hospital. There are several reasons for this, the most pressing being transportation problems, as the hospital is some 150km from the screening locations. A survey revealed that around 55% of patients felt that transport should be provided free of charge. However, Gravis and SSI both feel that such a provision would lead to dependency and a fall in the perceived value of the services provided. Since the free operation actually costs SSI around 800 Rs, it does not seem unreasonable to expect the patients to contribute within their means.

Transport issues also render postoperative checkups a problem. Most patients return within a month, rather than the 7 days recommended. Due to difficulties in understanding the drug and drop dosage regimens, some patients' vision does not progress well postoperatively. A check-up is therefore essential. The incidence of postoperative eye infections among Gravis Hospital patients is very low, however.

Gravis is currently extending the Hospital to include a specialist Eye Unit. Eye care activities will then take place independently of the main hospital. The Unit will include diagnostic facilities, an operating theatre, waiting rooms, and a specialist dispensary. An effort is also underway to recruit another ophthalmologist, although finding one prepared to work for the rates offered by Gravis is proving difficult.

### **Health Camps**

Every month, Gravis organises several medical outreach camps in the remote villages of the Thar Desert. These provide medical care to people whose access to GOI healthcare facilities is extremely limited. Camps are often organised through existing projects, or may be supported by one-off or regular donations from organisations or individuals. Camps provide treatment for common problems and refer more serious cases to the hospital. The most frequent health problems include deficiencies such as anaemia and malnutrition, hyperacidity, respiratory infections, worms in children, malaria, gynaecological problems and skin complaints.

At the time of writing, the most recent camps were held on 19<sup>th</sup> and 25<sup>th</sup> January 2005, at Ekal Khori and Minnon ki Dhani villages, respectively. The location of the camps, as always, was chosen by the beneficiaries in a previous consultation. The camps were held in isolated areas with minimal access to healthcare. From 10am, a medical doctor

and paramedical staff from Gravis hospital attended to patients. In both camps, over half the patients were women, and around 15% were children. Respiratory infections, skin infections and malarial symptoms were the most common ailments, with women additionally complaining of genito-urinary tract infections. Anemia was also widespread in village women. In each location, the doctor visited bedridden patients at the villager's request.

Medicines are distributed free of charge, although a token registration fee of 5 Rs is levied. This is done at all Gravis camps to minimise the risk of fraudulent 'patients' turning up for free medicine that they can then sell. The medicines most commonly given out are antibiotics, vitamins, de worming tablets, ORS, antimalarials and painkillers. Courses of medication of one week, or more for the weakest patients, are usually prescribed and patients are asked to come to the Gravis hospital for follow up. In general, around half (according to Manish) of those medicated at camps attend follow-up sessions. This turnout reflects the difficulties in transport and costs facing many patients. Advice on preventing future illness is not generally given.

More specialised health camps aimed at the elderly, mineworkers, and eye patients, and held on a regular basis. A recent series of health camps in mineworkers' villages is funded by Misereor, Germany; and by IDEX, US. In these settlements, there is a high prevalence of TB, and sputum is collected for testing if the disease is suspected. Patients are then advised to come to the Gravis Hospital for further tests. Injuries resulting from accidents are also more common, from stones dropped on feet to pieces of metal from machinery embedded in one man's leg.

There are several problems arising from holding one-off medical camps, although with careful management most may be circumvented. Firstly, as mentioned above, there are always those who try to take advantage of the free drugs for personal gain. Secondly, the camps cannot cover a very wide area in one day, as transport in the remote villages is so difficult. However, camps are rarely held in the same location more than once, giving greater coverage to the area as a whole. Finally, there are the issues of dependency and awareness. Whilst medical camps provide essential drugs to patients with life-threatening infections, there is always a danger that people will become ever-more reliant on camps, drugs and doctors and will take even fewer initiatives to safeguard their health in their daily lives. That said, it is difficult to refuse drugs to the people who come to the camps. Having paid 5 Rs, everyone expects something more than advice! Vitamin pills and the virtually useless co-trimoxazole do sterling work as placatory medications in this respect. However, antibiotics are not prescribed when inappropriate – for instance, a child with diarrhea will be given only ORS and vitamins.

Gravis medical camps are certainly well-received by the population of remote areas. However, the limitations are realised – for instance, no mobile testing for malaria, parasites or TB can be done. The responsibility rests on the patient to take the doctor's advice. Many are content to take the drugs for a brief period and forget to go for further tests. Holding awareness generation events simultaneously with medical camps may go some way towards overcoming these problems.

### Case Study – Emi

Emi's eyes are bright in her worn, furrowed face, that tells of her harsh life in the desert village of Cherai. Emi is 65, or rather, that's her best guess, as she doesn't know her exact age. She is here for a checkup following her second cataract operation.

'I'm very happy with the operation. Before, I couldn't see at all. I couldn't do anything. But now, I don't even need help in my daily activities any more. I can move around alone.'

And how was the operation itself? 'It was fine. And the dark glasses were very cool and comfortable,' laughs Emi.

The operation has had a positive effect on the whole family. 'I didn't do much work because of my age,' says Emi, 'but now I can look after my grandchildren and do housework. Apart from my eyes, I've always been healthy.' Emi has three sons and thirteen grandchildren. 'When I went blind I couldn't even recognise my sons, or my grandchildren' she recalls. 'It happened gradually. There wasn't any pain, just water and itching.'

Emi's youngest son brought her to the hospital. 'I heard about it from other people in the village,' he says, 'their relatives had the same problem. The operation cured them, so I took my mother to the hospital.'

Will he tell other people about the success of the operation? 'At the moment I don't know of anyone who has a problem. But when I do, then I'll certainly tell them to come here.'

## Malaria control

A year of good rains brings untold benefits in terms of harvest and drinking water, but also has a down side – outbreaks of malaria will be more widespread and more severe. In years where malaria incidence is set to rise, Gravis organises awareness and screening camps in affected areas. One such epidemic occurred in 2003, although the distribution of rainfall was patchy. Gravis ran 39 medical camps, which provided treatment to over 1500 people. Treatment was either given directly, in evident cases of malaria, or following testing in suspected cases. This relief effort was supported by Wells for India, UK.

Gravis is also involved in a collaborative malaria control project with the Rajasthan Voluntary Health Association (RVHA). Under the program, 4 field workers and 4 lab technicians operate from Baap and Pabupura field centres. The lab technicians were government trained; the health workers were recruited and trained by Gravis. In the villages, the health workers raise malaria awareness, promote preventive measures, and collect blood samples on slides from suspected cases. The slides are taken to the technician for rapid confirmation of malaria. In addition, some of the health workers are able to diagnose malaria using a microscope.

## ADOPT – Assimilated Development of Older People in the Thar

The ADOPT project is a collaborative activity with Help Age International (HAI) and European Union. After exhaustive research, the project began in earnest in 2003. The necessary research included a baseline survey of elderly people in the target region, which identified the beneficiaries of the project. In total, 2514 beneficiaries were selected, using criteria based on age, poverty, caste, and sex. Over the last year, some 90% of beneficiaries were elderly women, illustrating the greater plight of this group.

ADOPT focuses on providing sustainable means of income generation, or economic development. The aim is to restore the elderly person's independence and dignity, and to allow them to contribute to the family and the community. Water harvesting structures, fruit gardens and cows are provided to beneficiaries, and training is given. ADOPT also tackles the health problems of the elderly directly through organizing health awareness camps. The incidence of mental health problems among the target population is very low. 'If we knew of anyone suffering from dementia or Alzheimer's, then we would take steps to assist them and their family,' says Mahipal Singh, ADOPT's field supervisor at Kalron, 'but so far, we haven't encountered these conditions.'

### Help Age International – HAI

HAI was established in 1983 through a merging of Help Age India, Help the Aged (Canada), HelpAge Kenya, Pro Vida Colombia and Help the Aged (UK). The NGO works both in emergency situations and long term development projects. HAI also advocates policy change in the 80 countries in which they work.

'Both the needs of older people and their contributions to society deserve a much higher place on the policy agenda. We need to see a changed mindset that welcomes the participation of older people in decision making and takes a fresh view of the relationship between the generations.'

- [www.helpage.org](http://www.helpage.org)

A global network of some 70 partner NGOs assists and implements HAI projects. In India, around 50% of HAI's resources are dedicated to health, social care and training; the remainder is divided between income generation, emergency relief, advocacy and organisational development endeavours.

ADOPT's effects on health are not limited to the elderly themselves. For instance, the cows provided under ADOPT give milk for the whole family, improving nutrition all round. 'My grandchildren's health has certainly improved since the cow arrived' says one beneficiary. In her particular village, medical care is difficult to come by. An ANM visits occasionally, but her time is usually taken up with immunizations. Therefore, a journey to Phalodi, the nearest town, is necessary. This costs 40 rupees, approximately one day's wages for an unskilled labourer. For the elderly, then, providing a means

of income generation also provides access to healthcare. ADOPT and Gravis are also lobbying the local government for the reinstatement of reduced bus and rail fares for the elderly, which ceased 10 years ago.

Health awareness camps take place every 2 months, at a location decided by ADOPT's Village Old People's Association. Elderly people also benefit from Gravis' occasional healthcare provision camps in the area, and from the eye care program.

## PAST HEALTH ACTIVITIES

All good things must come to an end. The projects discussed below have all completed their sphere of activities in the field. However, there are several instances of new projects following on from a previous endeavour. The people involved at the village level are the key to sustainability, and in many instances they are continuing the work begun by Gravis and its partners.

### Sustainable Health Care Project for villagers of the Thar Desert – PPI DELETE

People for Progress in India (PPI) sponsored a small-scale community health project in 25 villages of Jodhpur district from 2001-2004. PPI is based in Seattle, USA, and since its foundation in 1978 has sponsored projects in nine Indian states. PPI projects include agricultural and horticultural development work, microfinance schemes, education and training. In the area of healthcare, PPI has sponsored eye care initiatives and sustainable health development projects, and is currently supporting several projects for the training and empowerment of disabled people.

The project villages are near to the Gravis Hospital, to which PPI also donated funds. The hospital staff were therefore responsible for carrying out the project. Initially, Village Health Committees (VHCs) were formed in each of the project villages. Committees were representative of the community, with women taking a leading role in many instances. Members were given training in the roles of the VHC, prevention of disease, and community action. The VHC also assisted in the selection of health workers (VHWs), who were then trained by Gravis. Their training was similar to that of SMCS and Khoj health workers, covering immunisation, preventive healthcare, pregnancy and nutrition, and basic awareness of TB. Some of the VHWs had also been working under Khoj.

One of the roles of the VHC was to liaise with Gravis staff in the organisation and implementation of medical camps and awareness generation events. A mobile medical camp took place every month from 2002, where villagers in remote areas were seen by a doctor and referred or given medication. A similar number of awareness generation camps also took place, on topics ranging from adolescent girl's health to hygiene and nutrition and social problems relating to health (such as alcohol and discrimination).

#### Case study – Ghewda Village Health Committee

The Village Health Committee still meets once a month in Ghewda village. They also hold general health meetings around the village several times in a month. 'We plan a meeting on a certain topic, like family planning or vaccination, and then hold the same meeting in three or four different places,' explains Shankar Ram. 'Sometimes the Samuh [women's SHG] also come.'

Through their patient efforts, the committee have achieved a great deal. 'People listen to our advice. Now everyone digs pits for waste – 2½ feet deep! They filter water, and use long-handled cups to take it out of the *matka* [water pot].' And as a female VHW says, 'around a quarter of babies used to die. Now this is less, and girls are treated equally.' The VHC is dedicated to improving health awareness. Much progress has been made. For instance, 'people with TB aren't isolated any more, they get treatment.' But Shankar Ram feels that the government could do more to assist them in this area. 'There are a many bad habits here, like drinking too much tea [which exacerbates anemia and hyperacidity], smoking and alcohol. The government doesn't do anything to educate people.'

The committee's work is not limited to healthcare alone. 'Together we've improved a lot of things. It's easier to teach as a group. We can motivate people and collect money. We built a school, and now it's run by the government. And we pressured the government to fix our tube well when it broke down.'

The sustainable health care project was a success in that it encouraged community involvement in health and managed to promote preventive measures. Awareness generation was also fruitful in the project villages. The health committees

still meet, there is widespread belief in community action in all areas, and the participants are determined to continue their good work.

## KHOJ

Gravis was involved in the Voluntary Health Association of India's nationwide Khoj program for ten years. 'Khoj' literally means 'search' in Hindi, which reflects the objective of the project: 'to search for innovative methods and strategies to combat community health related problems in remote areas.' VHAI aims to tackle the problem of inadequate, centralised health provision by focussing on small, community based health projects. Khoj also addresses the social and economic factors affecting health, and aims to provide sustainable solutions within the context of the community. Gravis was one of the first partner NGOs under Khoj, and Khoj was Gravis' first major health initiative. Gravis targeted

### Case study – Khoj health workers – Ghewda village.

Govardhan Ram, local farmer and father of four, has been a health worker under KHOJ for many years. 'In the beginning, there were a lot of problems', he says, 'I had to keep on telling people about immunisations. No one knew.' But now things are different. 'People come to me, men and women, to ask my advice,' he says, 'they take the initiative and have their children vaccinated themselves.'

What sort of advice does Govardhan Ram give? 'If it's a small child with a fever for four or five days, I tell them it could be pneumonia and they need to see a doctor,' he replies, 'and if I suspect TB in an adult, I tell them to get tested.' He adds, 'I explain about TB testing and treatment. A lot of people are still too scared of TB to get checked. But I tell them it's treatable.'

Pregnant women receive advice on vaccinations, but their needs fall mostly within the province of Teepu Bai, Govardhan Ram's fellow VHW and the local Dai. 'In the beginning it was very hard,' she relates, 'everyone was against me going [to join KHOJ], but I was determined. I thought I'd learn something to give back to the village.' Early efforts included giving out iron tablets and *laddoos*, nutritious sweet pastries, to pregnant women. 'At first they thought we were trying to poison them! But I ate the *laddoos* first, and I said, 'if I don't die, you won't,'" laughs Teepu Bai. Also, according to Teepu Bai, girl children receive better treatment now than when she began her work.

Both health workers are highly motivated and look set to continue their work in future. 'I've always felt comfortable,' says Govardhan Ram, 'there's never been a time when I haven't been able to give advice, at least.' And the job gets easier. 'Now people know more, my workload's reduced,' he laughs, 'it's all about knowledge, in the end.'

20 villages over an area of 12000 square kilometres, benefiting some 50000 people. The program began with a focus on safe motherhood and opium deaddiction, which were identified as major concerns in an initial survey. Antenatal care was introduced for the first time in the area, and coverage has now reached 70%. Traditional birth attendants or dais were targeted and trained in safe delivery methods. Village level health workers were also recruited. TBAs and VHWs were later integrated into other programs such as SMCS and INHP.

## VHAI

The Voluntary Health Association of India was formed in 1970, and today links more than 4000 health care institutions and grass-roots community health programs. VHAI is a federation of 24 state-level Voluntary Health Associations, and is coordinated from New Delhi.

'VHAI's primary objective is to make health a reality for the people of India by promoting community health, social justice and human rights related to the provision and distribution of health services in India.'

- [www.vhai.org](http://www.vhai.org)

VHAI's work includes policy and advocacy campaigns, media sensitisation, and parliamentary lobbying, in addition to grass-roots level training and community health support. VHAI believes in creating a sustainable health movement in conjunction with Indian cultural heritage by addressing both health and development issues.

Over the course of a decade, much has changed in Khoj villages under Gravis. Social concerns such as caste discrimination were also addressed, and now there is much less division between higher and lower caste villagers. Education too is an important part of Khoj; schoolchildren and adolescent girls received health education. On seeing the improvements brought by Khoj, other villages asked to join the program and it was duly expanded.

The strategies and methods developed during Khoj play a major part in other health activities. Health workers recruited under Khoj have remained and joined other programs, giving extensive crossover and collaboration between Khoj and other projects. Khoj itself came to an end in 2003; however, the 'search' goes on and sustainable community health development continues to be a priority.

### **Bhalu Watershed Development Project–Wells for India**

For five years from 1997, Wells for India (Wfi) supported an integrated development project in Bhalu village. Although initially funded entirely by Wfi, resources were later obtained from the UK Department for International Development (DfID) and the EC. Beginning with a focus on water harvesting and agricultural support, 'Project Bhalu' branched out into aspects of community health. Many of the methods applied in health and other areas were new to Wells for India and Gravis. The project therefore functioned additionally as an experimental and learning exercise.

The building of field bunds, anicuts, fruit gardens, *khadin* and *taanka* all had indirect health benefits, through improving water security, agricultural yields and nutrition. Concerning health directly, the most pressing need was to improve women's health. Women's latrines and washrooms were built, and training given as to their maintenance. Five health workers were trained in techniques of safe delivery, treatment of minor illnesses and first aid, herbal medicine and awareness generation. Medical kits were given to these VHVs. Washable cotton sanitary pads were also distributed to women and adolescent girls.

The health workers succeeded in reducing delivery complications and maternal mortality, building links with the local ANM and raising awareness of immunisations. Antenatal checkups have also increased, and more pregnant women are aware of good nutrition. Hygiene and health awareness generally improved, and in conjunction with the water development work this led to a fall in water-borne infections. There has also been an increased interest in herbal medicine among villagers. Mixed results were achieved with latrines; out of the 46 provided only half were maintained in a hygienic condition and regularly used. Private women's washrooms, however, met with much approval from village women. Many women also began to use the cotton sanitary pads on a regular basis.

#### **Wells for India -Wfi**

Wells for India has worked in Rajasthan since 1987, in close partnership with NGOs, the local government and the villagers themselves. The small charity focuses on sustainable solutions to water shortages in the region, in addition to supporting emergency relief measures when needed.

Health and the empowerment of women have become important aspects of Wfi's work. In the words of Professor Mary Grey, co-founder and ? of Wfi:

'Water is always the focus, but water has a social context: this involves community relations, the desperate situation of women in Rajasthan, how people use water, who has access (caste issues), and how it used to address the serious health problems that block the achievement of well-being across the community.'

Past health projects include health worker training in Dudu block, work with prostitutes and their children, including HIV-AIDs awareness development, and projects focusing on nutritional improvements. Women gain confidence and esteem through the projects. Wells for India are continuing with health intervention in partnership with Gravis in Chopra Dhora, where a water development project is currently in operation. For more information see [www.wellsforindia.org](http://www.wellsforindia.org)

A village development committee (VDC) was set up to involve the community in the project decision-making process. As part of the health efforts of Project Bhalu, the VDC were given monthly health awareness training sessions by Gravis medical staff. These proved popular and attendance was high, although it is difficult to ascertain the level of knowledge that was retained. Gravis staff were also responsible for village health worker refresher training. Each month, a specific set of topics was discussed, such as infectious diseases, women's complaints and their treatment, infant care and preventive health care.

It is to be hoped that the progress made in the five years of Project Bhalu will be sustained by the efforts of the villagers. The high level of motivation among VDC and VHWs and the overall level community approval are promising. Bhalu project also provided valuable insights into health development that may now be applied elsewhere.

### **A survey of health awareness**

Gravis gathers data as per the monitoring requirements of its partner organisations. However, the data generally focus on the numbers of beneficiaries attending distributions or antenatal classes, how much the children weigh, how many packets of iron tablets were given out, and so on. This is necessary and helpful, but does not directly illustrate the effects of the health programs on the people, their attitudes, and behaviour. A snapshot survey of beneficiaries was therefore undertaken in six villages under the SMCS program. The survey took place during December 2004. The survey used a questionnaire designed to probe women's awareness of health issues, ranging from infectious diseases to reproductive health, and also to test how their actions related to their knowledge.

In total, 40 women were surveyed; this is sufficient to allow a statistically valid analysis. Their ages ranged from 16 to 65 years, mean age 32.9 years. It must be noted, however, that many women do not know their exact age. They had from 0 to 9 children, with an average of 4.1 (surviving) children. Around 90% of the women surveyed were from scheduled castes, scheduled tribes, or other backward castes. The number of self-help group (SHG) members questioned in the survey was limited to around 25% to ensure a representative survey. It was found that only 10% of the women were literate; one or two more could sign their name.

There is a definite difference between knowledge and practice. For instance, the majority of respondents (70%) were aware that malaria is transmitted by mosquitoes, but only half knew of an effective preventive measure. There was one woman who didn't know about mosquitoes, but nevertheless used insecticide –'powder' – in her home to prevent malaria. Another is that of the 63% of women who know that they should wait 2-3 years between births, 40% of these (or 25% of total respondents) had not done so themselves – as evidenced from a comparison of their age with their number of children.

Around 75% of women claim to go to the doctor when they or their children are unwell. No respondents claimed to ask the advice of the VHW. A few women stated that they were unable to take any decisions regarding medical treatment without the advice of their husband or father-in-law.

Most women knew that one should take the full course of medicine prescribed by the doctor. However, awareness of home remedies was extremely low, with only 10% of women demonstrating knowledge of any form of home rehydration therapy for a child with diarrhea. Only a further 15% were aware of commercial ORS. A few other, non-rehydration based remedies were described, such as giving a child curd, seed pastes, and even opium.

The survey revealed excellent awareness of immunisation at 93%. The majority of births were attended by dais (who are trained, in SMCS villages), and the uptake of antenatal checkups was also high at 68%. A question on contraception produced mixed results. Twice as many women knew of tubal ligation (sterilisation) alone as were aware of a non-permanent method of contraception. Only a third of women claimed to be aware of the Pill, condoms or the IUD. In addition to the qualitative data gleaned from the survey, a scoring system was devised to allow statistical comparisons (see Appendix X). This revealed several interesting points. There was no significant difference in awareness (by score) between age groups 18-30 and 30+; and although it appears that women in their late 20s-early 30s score the highest, the difference with regard to age is minimal. Literacy, however, was important – women who had completed Class 5 scored significantly higher than their illiterate companions. However, only four literate women were questioned in the survey, limiting the validity of the analysis. Perhaps most surprisingly, SHG members showed no significant increase in score over other women.

It could be imagined that women with more children may be more aware of health issues, but the data indicated no link between number of children and awareness. There was however a strong negative correlation between awareness and

the distance to the nearest doctor (PHC); that is, the further a village from a doctor, the lower the average score. This may be coincidental as those living in the larger villages where PHCs are located may have other advantages over women from more remote areas.

The limitations of the survey became evident during its course. The questions, whilst designed to be simple and direct, were not readily comprehensible to many women. This was particularly so for questions regarding the prevention of illnesses. When asked 'how would you *prevent* stomach upsets?' most women would first reply 'go to the doctor', or 'medicine' and an exhaustive explanation of the question was necessary. This illustrates two points. Firstly, there is extensive dependence on doctors in the region. Secondly, although some women did do things to prevent stomach ache, such as not eating leftover food, they had only a vague idea of why they did them. The *concept* of preventive healthcare is very alien to them.

There is also the concern that out of fear or embarrassment, women gave untrue answers. Before the questions began, it was explained to the women that this was not an exam, there were no 'right' answers, it didn't matter if they didn't know, and that they should say what they thought. However, being given the answers one 'wanted to hear' is always a consideration. For instance, despite implicit dependence on doctors, the proportion of women seeking 'immediate medical assistance' for a sick child seems suspiciously high. Embarrassment is another factor, especially surrounding questions on family planning. However, even the shy, younger women were willing to whisper their answers to a female interviewer, so this does not seem to have been a huge problem. Following the survey, all women were invited to ask questions of their own.

### **Other work**

In addition to health education and awareness generation through the main projects, Gravis has published several booklets and training manuals in Hindi relevant to health concerns. 'Bacchon ki das Beemariyan' describes the commonest illnesses in children, and what to do. 'Vridh Swasthya Rog Nidan' covers geriatric health. Guides to reproductive and child health - 'Matra Evam Shishu Suraksha' – and several on drinking water are also in circulation. Another book, 'Nai Disha' encourages equal treatment of girl children, which includes seeking medical care. All the books are fully illustrated.

Until 1999, Gravis ran a school for disabled children. All the pupils were mentally disadvantaged. Later, the school was handed over to another organisation called Navjyoti that runs the school now. The aim was and is to help the children to develop skills, allowing them a degree of independence and reducing their perceived status as an economic burden.

## **5. Facing the challenges of Community Health**

Community health is an integral part of any development program. Since poor health arises from poverty to a large extent, any improvement in a community's level of development will have beneficial effects on health. However, it is important to focus on health as a distinct set of issues. Gravis is addressing these issues through the projects described in the last section, and in doing so is attempting to overcome the specific difficulties and challenges of community health development.

One of the main problems faced by community health programs is the lack of obvious and immediate results. Improvements in crops and water supply are measurable benefits, and are felt by the community as soon as they happen. However, whilst people notice ill health, they generally take longer to notice its absence. Therefore, it can be difficult to get across to people the direct benefits of preventive measures. They themselves are more concerned with curative health, an area with visible and immediate results, and acceptance of other interventions may be low. In time, the realisation will dawn that fewer mothers and children are dying, or that fewer cases of diarrhea and other sicknesses are occurring. Thus most successful community health programs will gather momentum as they progress; this is seen in many of Gravis past and current projects.

Health is also a very personal issue. In the Thar, many people have strongly held beliefs with regard to health, such as the existence of 'heating' and 'cooling' foods, and a host of superstitions and suspicions with regard to medical treatment. In addition, certain areas such as reproductive health, are less open to discussion than others due to cultural reservations or taboos. Women in the Thar are often unwilling to discuss their intimate health issues with men, for instance. Applying health projects in these circumstances requires discretion, sensitivity and the building of trust between Gravis and its recipients. By training volunteers from the villages, Gravis endeavours to address health issues

through the community itself. Trained VHWs and RHCAs understand the social and cultural barriers to health awareness far better than any outsider.

The Thar Desert itself throw up considerable challenges to NGOs working in the region. Vast distances, fierce heat, rough terrain and water shortages, combined with poor communications, infrastructure, power cuts (in those areas that have power) and regular increases in the price of fuel make the task of grass-roots development a demanding one. In many areas, even navigating between villages requires a certain expertise as there are no roads, and tracks or landmarks can shift or disappear with the next sandstorm. The costs of running the necessary fleet of jeeps, motorbikes and 4x4s also mounts up. Where possible, field staff travel by means of local buses to reduce costs. These are reliable and provide an adequate, if uncomfortable, service in many regions, but in the most remote and underdeveloped areas there are no buses.

Through its network of field centres, Gravis maintains a presence within the communities it serves. Maintaining communication and organisation between Jodhpur and the field can present difficulties, but the centres are able to function autonomously to a large extent. Centre staff meet regularly with project coordinators and other project staff, and progress is continuously monitored through reports.

### **Working for Health through Social Change**

The harsh conditions of the Thar, the unpleasant endemic diseases and the relative poverty of the region are all detrimental to community health. The situation is even worse for the victims of discrimination and social injustices, namely, women, girl children and scheduled castes or tribes (SC/ST). Low status, lack of economic or decision making power, and discrimination with regard to loans, wages, and access to resources continue to oppress women, and their health suffers as a result. There are tales of men who refuse to pay for their wife's medical treatment, such as assistance in delivery, because they can easily marry again (and gain a dowry into the bargain) – why waste money? This attitude, at its most extreme, stifles the wellbeing of the entire community. Girl children remain uneducated and trapped in the same cycle of subjection as their mothers. Members of lower castes may even now also endure discrimination, especially concerning access to resources such as land and precious water. This condemns them to grinding poverty, with all the associated evils of ill health and hardship.

Both 'casteism' and discrimination against women are scorned by the upper echelons of Indian society, and laws are in place that ostensibly protect these vulnerable members of the state. Dowry demands have long been illegal, for instance, and a beaten wife is entitled to demand the arrest of her spouse. But in the villages, in the remote rural areas of the Thar Desert, nobody enforces these laws, and tradition governs people's behaviour. Just as public health cannot be addressed successfully through a 'top down' approach, so social change cannot be effected merely by passing legislation. Behaviour change at the grass-roots level is necessary if progress is to be made.

Gravis is facilitating social change through all its projects. Women must constitute half of a VDC, and are usually the named beneficiaries of a *taanka* or a fruit garden. SHGs allow women to achieve a degree of financial independence, which in turn generates status and confidence. The economic aspect of SHGs is also a persuasive factor in gaining support from husbands and in-laws, although many women are still discouraged or prevented from joining groups. SHG members draw support from each other and from their regular meetings with Gravis staff. Gravis has also made efforts to improve the status of women in agriculture through women's seed banks, loan facilitation and animal husbandry projects (see pub).

Gradually, perceptions are changing. When women are regarded as productive, empowered members of a community, discrimination will reduce and their wives' health and welfare will become a prime concern for village men. Girl children will also benefit, as they will be awarded an education and treated on a level with boys. Through village level workers like VHWs, Gravis endeavours to promote fair treatment of girl children. This includes equality in seeking medical treatment, and an end to child marriage. Improvements have been marked, and more girls are attending school (government or Gravis schools) in Gravis project villages than elsewhere. Through their education, girls learn how to safeguard their own and their family's health. Village health workers also deliver penetrating lectures to parents on setting a good example to their sons, as when all boys are brought up to treat women as equals discrimination will be a thing of the past.

One challenge that has yet to be successfully addressed is the involvement of young married women in village activities. New brides are often subject to extreme restriction by their husbands and in-laws, and the relative confidence showed by unmarried adolescent girls vanishes. Some are able to attend VDC meetings and join SHGs, but in general

they suffer in silence. VHWs are usually older women, and those who are also *dais* are already strident, powerful figures in their village. There is a keenly felt need, within Gravis and among the VHWs themselves, to recruit young women and train them as health workers, as the 'next generation'. Interest among young women is low, they do not feel that they will command respect, and are deterred by the demands of home and family. Only a few feel prepared to learn from Gravis and the health workers. It is hoped Gravis' work with adolescent girls in the area of health awareness may in time spark the necessary interest and confidence among young women.

Caste barriers are addressed by Gravis through meetings and discussions, again largely implemented by workers from the community. Through their belief and affirmative action, discrimination has reduced in project areas. Gravis has recruited several high-caste women health workers, who have rejected the system and are prepared to help any member of their community, regardless of caste and economic status. VDCs must be representative of all castes; in fact the majority of VDC members are often SC/ST. Lower castes are also given precedence as project beneficiaries, which confers both status and greater economic empowerment.

Any society faced with a harsh existence will tend to be conservative in its behaviour and unwilling to elicit change merely for the sake of experiment. The people of the Thar are in this way naturally and reasonably wary of new ideas, especially those relating to behaviour change in their daily activities. Preventive health and hygiene measures, however, have to be sustained at this level if they are to be effective. Community acceptance of health development projects, from long-handled cup to latrines, is a crucial turning point for progress. Gravis therefore places emphasis on blending traditional knowledge with new technologies, although this is more difficult in health than in other areas. Techniques are kept simple, and are introduced through community based workers and organisations. Community approval limits the application of development ideas. There are numerous methods that could vastly improve community wellbeing in the Thar, such as the Nalgonda technique – community based chemical defluoridation of water – but this and other schemes prove too complex and detached for widespread acceptance. Simplicity and comprehensibility are essential to success.

Finally, development is becoming a leading political issue at the village and *panchayat* levels due to the expansion of VDCs and health committees. Health has never been a major issue at elections, but has achieved greater prominence in recent years. Community based organisations are developing considerable lobbying power at a local level. The challenge now is to sustain this over the years, in time allowing the people of the Thar to voice their complaints at district and state levels. Major health provision issues such as local control and accountability may eventually be addressed in this way.

### **Training for sustainable improvements**

Delivering successful health-related training can be far more difficult than education in other areas. This problem arises in part from the perceptions of the non-medical person, and partly from a lack of appropriate resource material. Health is seen by persons across the world as a complex, impenetrable subject, understood only by those with some special aptitude, who become doctors and nurses. In the Thar Desert, where the education gap between doctors and their patients is immeasurably vast, this situation is very pronounced. A doctor's knowledge achieves almost mystical dimensions in the minds of the population; a misconception that many doctors do little to dispel. People do not consider themselves able to access the information a doctor knows, and are incredulous at the suggestion that they too could learn to give out medicines and treat the sick. Incredulous, that is, until they discover that they are far more capable of understanding the subject than they realised – take the VHWs, whose healthy confidence in their abilities is testament to this.

Health worker training presents significant challenges in the Thar Desert. Perhaps the greatest potential setback is that virtually all *dais* are illiterate, being older women; even then, only 10% of younger women are able to read and write. Although it is observed that illiterate persons often have extremely good memories, the information must be presented in an accessible way. Learning lists of facts as for an exam does not suit those who never went to school, nor does a 'classroom style' learning environment. Sadly, the Indian education system favours a didactic, lecture-based approach; it is therefore often difficult for Gravis staff, who have known nothing different, to adapt their teaching style to the needs of their students. The people of the Thar are used to learning from experience, observation, discussion and gossip. Learning methods that focus on these strengths are far more successful than simple feeding of facts.

The culture of respect and deference to a teacher-figure means that feedback on teaching is invariably polite and positive. Nobody will be prepared to speak out in a training session if they do not understand something. It is therefore essential to focus on delivering appropriate information, explained in an accessible style. For instance, an RHCA gains

nothing by knowing what the letters 'HIV' stand for, but instead needs to know what 'HIV-positive' actually means, the signs of AIDS, and how the disease is passed on. Rough and ready practical knowledge –what to do when a certain situation presents itself – is of far more use than accurate but distanced theoretical information. A VHW is better off knowing how to make ORS than understanding the anatomy of the digestive tract.

In general, people understand a new piece of information much more fully if they have reasoned it through for themselves; this is particularly evident in health. Health workers have difficulty in remembering a series of instructions or facts that seem counterintuitive, so generating a full understanding of causes and effects is important. A working medical knowledge of this sort need not be complicated. For instance, a simple, illustrative description can convey the idea of a disease from the chest being coughed out into the air, inhaled by another person, and so passed on. A particularly nice example from 'Helping Health Workers Learn', by, concerns flies and the spread of gastrointestinal infections, a significant concern in the Thar. Workers are encouraged to reason from the premise that as flies have feet, what happens when they stand on waste and then on food? This process connects facts that health workers already know into a coherent series, enabling them to retain and apply the information, and even to explain it effectively to others.

Training health workers and generating health awareness in village meetings is often best left to non-medical staff. They may be able to explain matters in more accessible language and with less concern for medical accuracy than many doctors. Gravis' doctors do run training and awareness meetings, but are always responsive to context and to the requirements of the audience. However, in order to generate analogies, demonstrations and discussion-based learning, even non-medical staff need a good working knowledge of the subject. Gravis staff are mostly from a humanities or social studies background, and may have the usual reservations about medical information. It is relatively easy to learn the facts from guidelines or textbooks; much more difficult to understand them in such a way as to explain them simply to others. (Many doctors in developed countries cannot do this, in fact!)

With these points in mind, Gravis hosted a 'Learning Conversation Workshop' offered by staff from CRS, in February 2004. Applicable to all fields of training, the 'learning conversation' method is designed to generate informative discussions from the starting point of two contrasting stories or case studies. Around 30 field staff attended. During the workshop, staff took part in group activities, wrote their own stories and case studies and learned to analyse the material with respect to what could be learnt. They also developed learning conversation role-plays. The straightforward, relaxed style of the workshop, and the ease with which the new method was picked up, should lead to learning conversations becoming an integral part of Gravis field training activities. Staff training exercises of this kind are essential to Gravis commitment to building capacity within its workforce.

Once basic knowledge is secure, more advanced information can be given, to VHWs, for instance. Several TBAs and VHWs have been working for nearly ten years, and have developed an excellent understanding of their area. They are motivated and able to continue their work independently. They provide vital care to their community and are instrumental in bringing about behaviour change and social change. The purpose of training village volunteers is to give the community confidence in itself, to generate critical awareness of their situation, and to empower them to change it.

### **The Gravis approach**

Gandhi was suspicious of modern (allopathic) medicine, believing instead in the attainment of good health through good food, careful hygiene and appropriate home treatments or traditional remedies. In following Gandhian idealism, Gravis wishes to promote these principles in its health development work. They have especial value in an area where allopathic treatment is often inadequate and inaccessible. At the same time, efforts are being made to deliver appropriate and accessible medical care where necessary, and to raise awareness among the population of diseases that require treatment. However, Gravis believes that prevention of disease remains the key to success in all health projects. Again in deference to Gandhi's views, and in accordance with the practical realities of the situation, Gravis begins all health projects on a small, manageable, community based scale.

Gravis shuns the 'vertical approach' in health and all other areas. Most health projects are components of integrated schemes that address the social and economic aspects of community health. The primary aim of all health efforts is to increase community wellbeing, through those methods that are most appropriate and sustainable. Centralised planning is not emphasised, but becomes necessary at times, for instance when implementing the projects of large international NGOs. Program structure is necessary as a means to achieving sustainable development, but does not become so restrictive as to preclude expansion and innovation. Gravis also tries to avoid excessive designation of funding towards particular features of a program, and values flexibility within all projects.

In any field of development work, it is frighteningly easy to generate dependency whilst attempting to assist a community. For instance, free food distribution, or free healthcare via medical camps are non-sustainable, and may cause reversion to a worse state when they end (as they must). People lose their traditional knowledge and self reliance, and more significantly, lose faith in their own ability and judgement. This can be seen in the Thar – people have become overly dependent on modern medicine without questioning its quality, efficacy or appropriateness, and silently accepting the difficulties surrounding access and affordability. There is also the subtle consideration portrayed by 'what we obtain too cheap we esteem too lightly' (Thomas Payne). That is, by providing services free of cost or effort they become devalued also in the minds of the people, can increase apathy and indifference, and do not encourage initiative and sustainable development.

Free services generally address the felt needs of the community, such as immediate relief from hunger, sickness, and drought. Community acceptance of such methods is high, but the real needs of sustainable agriculture, healthcare provision and water harvesting may not be met. However, real needs may not be as visible or comprehensible to the community as their felt needs. Addressing felt needs, then, provides a means of gaining trust and acceptance, which can then be directed towards tackling real needs. Gravis attempts to listen to and draw on the felt needs of the community, whilst ensuring that long term real needs are being met.

Whilst Gravis endeavours to use subsidised or cost-recovery schemes, it is careful never to generate the expectation that free handouts will forever be available. No person is expected to contribute beyond their means, and communities are encouraged to band together in support of the poorest. For instance, women's SHGs, VDCs, and VHCs generate funds through individual contributions, which may then be used to help those who cannot afford healthcare. An emphasis on education and training also encourages responsibility within the community. Trained health workers are often provided with an incentive payment. This allows them to perceive the value of their services and encourages the participation of those who are dedicated and committed to their work, as opposed to people with nothing better to do. Maintaining this incentive system in the long term will be challenging. Potential solutions will arise through community savings schemes, such as a health insurance fund.

Ultimately, community health can only be sustained at a high level when the prevailing social and economic situation is supportive and progressive. Gravis endeavours to address both issues through integrated community development. Economic development is progressing steadily. Socially, working at the grass-roots level to remove injustices, and to deliver the health of the community back into their own hands, is achieving good results. Sustainability is always the aim, and is promoted by the involvement of the community in health programs. This is best expressed by the communities themselves. Progress is being made, in the words of a village health worker and committee member – 'We've achieved a lot together and we'll go on working. We're doing this for ourselves. Ourselves, our children and our grandchildren.'

## **6. Future directions**

The efforts of Thar Desert communities towards achieving sustainable health and well-being have made great progress over the last twenty years, with the guidance and support of Gravis and its partner organisations. There remains much to be done, however. The health projects undertaken to date provide an excellent basis on which to move forward, both by expanding to new regions and building capacity in existing project areas. New issues such as HIV-AIDS have come to the fore since Gravis began its operations. These will be addressed in future projects, always with sustainable, community-based solutions in mind. Over the next five years, Gravis hopes to intensify the focus on health, increasing the roles of awareness generation, preventive and curative medicine, and community wellbeing in all projects. It will aim on setting up a health network in the region combining health providers, government departments and NGOs in order to expand and strengthen community health development in the Thar.

### **i. New Projects for 2005**

Improving Women and Children's Health Conditions in Thar Desert -

Gravis has a long-standing collaboration with the Student Union of the University of Tampere, Finland (TAMY). The current program addresses aspects of reproductive health, adolescent girl's health, preventive medicine and awareness generation, and will strengthen the existing village health network in Gagadi area. Funding was additionally obtained from the Finnish Government.

## SMCS – Safe Motherhood and Child Survival

GRAVIS is expanding this project in a new area with the support of CRS, in Jaisalmer district. At the time of writing, a baseline survey and the identification of TBAs and potential VHWs was taking place.

## SPAAC - Short Phase AIDS awareness campaign

Funded by HSBC, this low-cost short-term project is designed to provide vital and accessible information on HIV-AIDS via pamphlets, posters, calendars and field staff discussions held with schools and community based organisations. The project emphasises practical information and is also intended as a capacity-building exercise for field staff.

## ii. Gravis health priorities for the next five years

### Community Based Organisations and Health workers

- Build capacity of trained VHWs, TBAs and RHCAs by expanding skills base through training.
- Encouraging CBOs to generate funds for health activities – such as for VHW payment.
- Reach out to untrained TBAs and recruit VHWs in new project areas.

### HIV-AIDS

- Begin flexible, community level awareness generation projects in neglected areas.
- Liaise with government AIDS initiatives.

### Eye Care

- Expand its eye care project in new areas and develop capacities of eye care unit and its staff further

### Gravis Hospital

- Increases its coverage, strengthen staff and facilities and develop it as a training centre on community health development in coming future.

### Geriatric health

- Make continuous efforts on awareness generation and education on geriatric health issues and develop a resource centre

### Gravis staff and structure

- Build health care training capacity of Gravis staff by increasing knowledge and confidence.
- Focus on staff awareness of appropriate teaching methods.
- Design small scale, modular projects that can be implemented with minimal funding, and that can be scaled up or combined to create larger programs where funding is available.