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Barriers to Health – A perspective from the lives of marginalized citizens in India

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Barriers to Health – A perspective from the lives of marginalized citizens in India

Abstract

What circumstances prevent or hinder people in Himachal Pradesh, India from getting the health care they need? This question framed a summer research project in India in 2011. The project focused on qualitative personal interviews to collect stories and perceptions of the health care system. The gathered stories bring to life the health statistics found in public health journals. While health care officials presented a version of the health care system that spoke of all its strengths, the stories from the people living in poor regions of Dharamshala, India uncovered flaws in the health system. A recurrent theme among the locals was the inability to afford even the most basic health services. While hospital visits are free, patients must pay for all physical supplies used in the health service. Additionally, unforeseen circumstances sometimes prevent people from getting the care they need. Among other stories, this paper includes the story of Viki who lived in the ‘tent houses’ in Dharamshala who could not afford to get surgery for his eye.
Barriers to Health – A perspective from the lives of marginalized citizens in India

Introduction

“The health care here is near flawless,” the district malaria officer, Jeewan, told me. “Himachal Pradesh has some of the best indicators in India and has won several awards for its health implementation.” These words began my investigation into the health care system in India. This was far from the story I had uncovered from my background research. According to the World Health Organization (WHO), India falls behind developed countries in nearly all measures of health. The life expectancy for females in 2009 was 66 years, while the life expectancy for females in the U.S. was 81. The probability of dying under five years of age in India was 66 per 1000 births while in the U.S. it was 8 per 1000 births (see Figure 1). Additionally, India spends only 6.1% of its GDP on health care while the U.S. spends 17%¹. In virtually all areas in health, India is underperforming. To hear that the Indian health care system was “near flawless” made me think that I wasn’t hearing the full story. A medical student shared with me the following story of one flaw in the medical system.

A woman went to a local hospital with a pain in her lower abdomen. The hospital was unable to figure out what the issue was and kept her there for four days. On the fourth day, her appendix ruptured and they were forced to send her to Tanda for more specialized treatment. It took eight hours to travel to Tanda, with every second inching her closer to death. Appendicitis is fatal if left untreated, and often people whose appendix ruptures have no chance of recovery. Fortunately, the doctors at Tanda were able to treat her and she made a full recovery.

¹ World Bank. 2010. World Development Indicators 2010. CD-ROM. Washington, DC
After hearing the woman’s story, I realized that I could not get the full picture of health care in India by talking to government officials. I wanted to collect additional stories from people who have felt the impact of India’s health system personally. Back in McLeod Ganj I came across a 17 year old Rajasthani boy named Viki. Viki helped me organize interviews, took me to hospitals, and served as my ‘key informant’ for the project. The first portion of this paper provides stories from marginalized citizens of India who struggled to access or pay for health care. The second portion of the paper discusses the changes made to the Indian health care system in 2005 through the National Rural Health Mission.

Meeting the ‘key informant’

I first met Viki when I returned to McLeod Ganj. While walking through the streets this skinny Indian boy started walking in stride and talking with me. He asked me where I was from,

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as most Indians do, and made small talk. Soon, he asked me if I could buy him food. I agreed, preferring to buy food for people rather than give them money. He promptly took me to a shop where he pulled a few bags of powdered milk off the shelf. The same thing had happened to me two weeks prior. A woman carrying a baby stopped me and said “No money, milk for baby.” That time I had tried to buy the powdered milk for her, but the shop owner refused, saying it’s a “bad habit.” He told me that they get foreigners to buy them these packages, then they sell them back to the shop. These packages are expensive on Indian standards, and I have no doubt that the ladies that pull this scam do quite well for themselves. Viki was now attempting the same trick, but I knew better and refused. After a little arguing I brought him to a restaurant and had lunch with him.

We chatted a while and I told Viki of my research and that I wanted to see the hospitals in the area. Viki lived in the slums in lower Dharamshala, which he termed the “tent houses.” Every day he takes a shared jeep up the hill to McLeod Ganj where all the western tourists visit. He walks up and down the two streets in McLeod Ganj offering to fix travelers backpacks and shoes. In one day he makes at the most 100 rupees ($2). Viki originally came from Rajasthan, so his skin was darker than most of the local Indians. His brother and cousins were also in the shoe-repairing business, and it seemed like there was an army of boys trying to fix shoes. Whenever it rained Viki skipped work, since fewer tourists walk the streets when it is wet. Every now and then he couldn’t come to McLeod Ganj because he didn’t have 10 rupees (20 cents) for the bus ride.

After lunch Viki escorted me to Delek hospital, which was a 20 minute walk down the hill. After we toured the building he invited me back to his home. He called ahead and asked his mother to prepare a meal for me. The locals in the slum build the frames of their houses with
thick bamboo poles and drape tarps over the frames. In spite of the heat of the place, the packed dirt floor, and the wide beds, the inside of the tent houses is surprisingly comfortable. Viki’s family had two of these houses, one for sleeping, and one for cooking and relaxing, but each one was no more than 20X20 feet. I think perhaps six people lived in those two houses, but other houses are much more crowded. The first night I went to the tent houses, Viki’s mother prepared mutter paneer (peas and cheese) and served me chai. It was the best chai I’ve had in all of India.

Since then, I’ve gone back to the tent houses three times, the last two times I’ve conducted short interviews with a few people there. It is hard to describe, but the tent houses are the place in India I have felt most at home. Perhaps it is in part the number of children running around. As soon as you set foot in the perimeter you have children calling to you saying “hallo!” and “how are you.” Little toddlers run up next to you, grab your hand and walk with you wherever you go. If you sit in someone’s house long enough, inevitably someone will hand you a baby, usually only wearing a shirt. You just kind of hold the baby, look into its big brown eyes and say “hello baby.” And then you coddle it and hug it close to you, and it will close its eyes and hold onto your finger like you are the most trustworthy person in the entire world.

Life in the tent houses is slow, and fairly comfortable. Although some material needs are unmet, people eat enough and have a safe place to sleep. The density of people forces the family to stay close. While I was interviewing one man, there were probably 12 people within a 15 foot radius of us, most were part of the family. People would lounge on the bed listening, teenagers would hold and play with the babies, and two women would squat next to the wood-burning stoves and make chapattis. Everyone is there, everyone hears what you are saying, and everyone shows interest in you. You get the sense that there is no fear in the area. People trust each other and let their 3 year olds run around the village unattended. And people have enough to eat. Yet
through all of this, Viki’s mother’s warm smile seems to hide tiredness in her core. She will stop you in the street, hold your hand and look at you unspeaking with her warm smile. She has no facility with English. She works many hours a day picking up plastic bottles from the street that the tourists leave behind. She bags them up and brings them to a store in Dharamshala which gives her 20 rupees per kilo of plastic she finds. In one day she might earn 100 rupees, the equivalent of two dollars. Even though she has so little, when foreign visitors spend an afternoon at her house she will cook a special meal of cheese and peas just for them while the rest of the family has a simpler meal of rice and curry.

The case of the untreatable eyes

Viki’s eyes struck me from the moment I met him. A scar divided the skin to the right of his right eye. Running directly under his iris grew a skinny red vein-like protrusion. At first I couldn’t look him in the eyes, his disfigurement making me feel uncomfortable. After several days of talking to him I became accustomed to his appearance and afterwards I barely noticed his eye. About a year earlier, Viki fell and hit his head on a rock. The rock split the skin next to his eye open and damaged his eyeball. Fortunately, a tourist from Australia managed to sew the skin together and prevent additional damage. His eye healed and he never lost his eyesight, but the injury left him with a permanent disfigurement. Viki told me, regarding his eye, that he “wanted to be beautiful.” I asked him why he couldn’t get surgery for his eye to remove the red growth. He replied that even though the procedure itself would not cost much, he needed to go to the super-specialty hospital in Chandigarh and his family could not afford the trip. Bus fare and hotel accommodations were outside of his family’s means.
This story illustrates hidden costs associated with the health care system. Even though
the care itself was close to free, the distance to the hospital turned out to be an insurmountable
barrier. This also shows the problem with India’s tiered system. The Indian government in
Himachal Pradesh succeeded in providing primary care to the vast majority of the population,
but specialty care continues to be an issue. An article in a local paper pointed out the shortage of
specialty doctors. Waiting times for certain specialties extended to an impossible time. Beyond
that, only two super-specialty hospitals existed in the entire state caring for nearly 7 million
people. Traveling to the hospitals proved to be too difficult for many Indians.

After hearing Viki’s story, I offered to help him treat his eyes. He told me that the only
way to treat his eyes would be to take a 6 hour bus ride to Chandigarh, stay there overnight and
go to the hospital. I asked him how much it would cost and he said no more than 3000 rupees
($65). The price seemed reasonable so I agreed to take Viki to the hospital. The next weekend
Viki and I took a quick detour to Amritsar to see the Golden Temple and the festival at the Waga
border. As soon as we left the altitude of McLeod Ganj and entered the heat and humidity of the
Punjab valley I started sweating and didn’t stop for the rest of the trip. The festival at the Waga
border lasted until seven pm. I recommended that we sleep at the Temple since it’s free, but Viki
seemed in a hurry to get to Chandigarh. We took a late bus from Amritsar and arrived in
Chandigarh around midnight. Viki found a taxi and haggled a price to find us a hotel. The taxi
driver took us by three different hotels, but each time the hotel employees told us they were full.
Finally we found a hotel that had a room, but they wanted an exorbitant amount for the room.
We haggled, drove away, and came back, and agreed on a slightly lower price. At this point it
was nearly 1 am and I was exhausted from traveling. All I wanted was to get into a nice clean
bed and fall asleep. We walked up to the hotel room and found that it had no air conditioning
and no window. The room was over 80 degrees, and the single bed looked as if the blankets had never been washed. I decided this was the best it was going to get, I handed my passport to the hotel worker and sat down. As soon as Viki handed his ID to the worker the worker, flustered, asked Viki something in Hindi and waved the frayed and damaged paper ID in front of Viki’s face. Viki and the worker argued in Hindi for a few minutes, then Viki told me to get up and we left. I asked Viki what happened, and he said that the worker couldn’t accept Viki’s ID, and that the hotel needed to have all of our documents or else we couldn’t book a room.

We returned to the same taxi and asked if there was another hotel. The taxi driver complained that he had done all he could so he brought us back to the bus station. Viki told me to get some sleep and that he would be walking around a little bit. At two in the morning, a dozen Indians had stretched out under the open roof of the bus station and were dozing lightly. I pulled out my sleeping bag and stretched out in my own little patch of concrete by one of the giant pillars holding up the roof. I closed my eyes thinking “well, this is India” and went to sleep. A couple hours later I woke up and saw Viki, who had been sleeping next to me, arguing with two Indian soldiers. The soldiers, seeing me awake came over and stood by my feet and asked me what I was doing here. I rubbed my eyes and told them I was traveling with Viki and planned to take him to the hospital. After making some small talk and acting as friendly as a person can be who has a machine gun strapped to one side, they told me that I shouldn’t be sleeping here. It was dangerous out in the open and I should find a hotel. They told me that I wouldn’t sleep at the bus stand in my own country, so I shouldn’t do so here either. I looked around at the other Indians who were scattered around the bus stand sleeping in chairs and on the floor and I wondered to myself why they thought the Indians could sleep here, but a white
foreigner could not. I politely nodded and told them that I would look for a hotel tomorrow, and they walked away.

The next morning we took a bicycle rickshaw to find a hotel. As had happened the night before, several hotels told Viki and me that there were no rooms available. Finally Viki told me to wait at the rickshaw while he asked the hotel by himself. When he came back he shook his head and said that the room “wasn’t possible.” He told me that when he first asked for a room, the hotel worker said that they had a room for 700 rupees. Then Viki told them that he had a foreigner with him. The hotel worker promptly replied that the room wasn’t available. Neither Viki nor I understood this phenomenon. Later, when I told the owner of my guest house in McLeod Ganj about it he said that it was probably about money. The hotels wanted to charge the foreigner more than the local price and so refused the room at the lower rate. I think, though, that there was something else going on. That for some reason the Indians didn’t like the fact that a poor slum boy and a ‘rich’ foreigner were staying together.

Viki and I finally made our way to the Chandigarh super-specialty hospital, our final destination. Upon arrival, we quickly learned that all the offices except emergency care are closed on Sunday. We stopped a doctor who was passing by in the emergency room and asked him if they could treat the eye at the hospital. The doctor briefly examined the eye and told him that the surgery was most likely possible and that Viki would have to come back the following day to get it properly examined. The doctor would then set a date for the surgery probably a few days out. Viki seemed very uncomfortable in the hospital environment. He seemed very hesitant to approach or talk to the doctors. Staying another night in Chandigarh was the last thing Viki or I wanted, let alone staying four nights. The heat made my head foggy, and for an
unknown reason, Viki and I could not book a hotel room. We both agreed to go back to McLeod Ganj and forgo the surgery.

This story illustrates the difficulty distance creates in health care. If a trip to the hospital takes more than a day, all kinds of unforeseen circumstances can prevent someone from getting the care they need. By himself, Viki would not have been able to afford a bus ticket or the cost of a hotel. Traveling with a westerner we could not book a hotel. Getting the surgery, because of these circumstantial reasons, was not possible.

*Interviewing the Slum Dwellers*

One man from Rajasthan, for the purpose of this essay called Manu, shared the following story. Five or six years ago in Rajasthan, a truck rolled off the road and fell on Manu breaking his arm. He went to the free “checkup” (primary) doctor, but the doctor told him the surgery was not possible there. Manu had no choice but to go to an expensive private hospital because the injury was so severe. The surgeons there set the bone and inserted metal plates for support. Looking at his arm, I saw large scars where the surgery took place. The surgery was a success, but the hospital charged Manu 180,000 rupees ($4000). For a day laborer who makes at most $4 a day, it would take him three years of solid work to earn this amount. Manu sold his wife’s and daughter’s gold jewelry for 70,000 rupees and had to take out a loan for 80,000 rupees to pay the doctor’s fee. To this day he has only been able to pay off the interest on the loan and still owes far more than he can earn.

From an American standpoint, medical care in India is cheap. An identical surgery might cost ten times less in India as in America. However, on Indian standards, health care is often unaffordable. The National Rural Health Mission states that 40% of Indians who are
hospitalized must take out loans or sell their valuables to pay for the visit. Manu’s story shows this well. Surgeries and hospitalizations can cost many times someone’s yearly income. To put it in perspective take the following scenario. Manu earns an income of roughly $4 a day, or $1400 a year. This means that his surgery cost him nearly three times his annual income. Say an American earns $40,000 a year at a decent job. In equivalent terms, Manu’s surgery would then cost three times this income, or $120,000, a completely unaffordable amount.

Finance

The thing to understand about money in India is that many people live on only a few dollars a day. While it seems to a westerner like a $50 trip to the neighboring district to attend the hospital is not much, $50 is a severe financial burden for many people in India. Even a twenty cent bus fare is sometimes unaffordable. One day I called Viki and asked him to meet me in McLeod Ganj, and he replied that he didn’t have the 20 rupees for the trip there and back. If he couldn’t afford 20 rupees for the bus it is no wonder he cannot afford to go to Chandigarh to fix his eye. When doctors talk about the costs of surgery, they mention numbers like 100 rupees to buy sutures. Initially I thought $2, that is nothing, but sometimes that is equivalent to a person’s entire day’s earnings. Likewise, hospital visits are extremely cheap in comparison to the U.S. system, but like the NRHM stated, 40% of Indians who are hospitalized must take out loans or sell their valuables to pay for the visit. You cannot understand the financial barriers in the health care system until you are aware of what a rupee is worth in the lives of the villagers.

National Rural Health Mission

In 2005 the Indian government recognized that its health system fell below the level it should given its development status. To help improve the infrastructure and the health of its citizens, the government instigated the National Rural Health Mission (NRHM). In the mission document the government outlined the most pressing challenges the system faces.\(^4\) According to the document, India spent only 0.9% of its GDP on health in 1999, down from 1.3% in 1990. Part of the mission of the program was to increase the spending in the health system to 2-3% of its GDP. The system lacked an emphasis on preventive care including hygiene, safe drinking water, and nutrition. Inequalities across income and class were apparent. Over 40% of hospitalized Indians borrow heavily or sell assets to cover expenses. The following table outlines the current state of the Indian health care system and the goals the National Rural Health Mission listed.

**Figure 2. The National Rural Health Mission.**

<table>
<thead>
<tr>
<th>Current State of Health Care System</th>
<th>Mission</th>
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</thead>
<tbody>
<tr>
<td>• Public health expenditure in India has declined from 1.3% of GDP in 1990 to 0.9% of GDP in 1999. The Union Budgetary allocation for health is 1.3% while the State’s Budgetary allocation is 5.5%.</td>
<td>• The National Rural Health Mission (2005-12) seeks to provide effective healthcare to rural population throughout the country with special focus on 18 states, which have weak public health indicators and/or weak infrastructure.</td>
</tr>
<tr>
<td>• Union Government contribution to public health expenditure is 15% while States contribution about 85%</td>
<td>• The Mission is an articulation of the commitment of the Government to raise public spending on Health from 0.9% of GDP to 2-3% of GDP.</td>
</tr>
<tr>
<td>• Vertical Health and Family Welfare Programmes have limited synergisation at operational levels.</td>
<td>• It aims to undertake architectural correction of the health system to enable it to effectively handle increased allocations as promised under the National Common Minimum Programme and promote policies that strengthen public health management and service delivery in the country.</td>
</tr>
<tr>
<td>• Lack of community ownership of public health programmes impacts levels of efficiency, accountability and effectiveness.</td>
<td>• It has as its key components provision of a female health activist in each village; a village health</td>
</tr>
<tr>
<td>• Lack of integration of sanitation, hygiene, nutrition and drinking water issues.</td>
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</tbody>
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\(^4\) Ibid.
• There are striking regional inequalities.
• Population Stabilization is still a challenge, especially in States with weak demographic indicators.
• Curative services favour the non-poor: for every Re.1 spent on the poorest 20% population, Rs.3 is spent on the richest quintile.
• Only 10% Indians have some form of health insurance, mostly inadequate
• Hospitalized Indians spend on an average 58% of their total annual expenditure
• Over 40% of hospitalized Indians borrow heavily or sell assets to cover expenses
• Over 25% of hospitalized Indians fall below poverty line because of hospital expenses

Out of the listed flaws of the system, the government places great emphasis on the financial burden of the health system. The government also recognizes inequalities in the system between class and income. Public health expenditures and preventive care are also important to the government. These four areas are the primary aim of the program.

India’s goal in 2005 was to create a system in which every citizen could obtain affordable health care. The structure of the Indian health care system is quite brilliant and other countries could learn something. The chief characteristic that differentiates the Indian system from the American system is that the Indian system has central leadership while the U.S. system relies on
the scattered private sector to provide care. The National Rural Health Mission, instigated in April 2005 created the framework for a comprehensive health system\(^1\). As of yet each state has made advances creating the desired infrastructure, but many states still fall below the guidelines. Himachal Pradesh, however, has won awards for its health system.

The National Rural Health Mission aims to improve health outcomes by facilitating the creation of health infrastructure and improving sanitation and nutrition. The NRHM has a progressive view of health. The integration of health services surpasses the U.S. in foresight and its comprehensive view of issues. Stated in the Mission is a comprehensive understanding of the issues Indian’s face. The U.S. relies on the private sector to deliver most health services. This leads to fragmented care and a shocking inability to target large health issues. The recent national campaign against childhood obesity is proving difficult to carry out because the system is not set up to promote national agendas. India, however, owns nearly half of the health sector and has been able to set up a system where it can instigate national health missions.

The goals of the National Rural Health Mission include reducing infant and maternal mortality, universal access to public health services, controlling communicable diseases, access to primary health care, population stabilization including gender balance, promoting health lifestyles, and revitalizing local health traditions.\(^5\) It is clear from this list of goals that the health of the population is the center of this mission. In contrast, in its recent health reform, the U.S. placed its efforts to strengthen the private sector but seemed to forego comprehensive health initiatives. As a result, numerous health issues in the U.S. remain off the national agenda. India acknowledges the importance of primary care in its health system and sought to expand access for all of its citizens.

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The Indian health infrastructure as outlined by the National Rural Health Mission creates a tiered system offering primary and preventive medicine at its lowest tier. The higher the tier, the more specialized the care. Primary Health centers provide services to approximately 30,000 people. The Primary health tier includes community health centers, primary health centers, civil dispensaries, and sub-centers. At the bottom tier lies the sub-center which should provide services to between 3000 and 5000 people. The sub-centers staff two multi-purpose care givers, one male and one female, to provide frontline health care. The female care giver is called an Auxiliary Nurse Midwife (ANM). The care givers are salaried by the state government. The sub-centers provide a means to deliver immunizations, iron supplements for pregnant women and other national health initiatives to the local population. They also provide basic drugs for common tropical diseases such as diarrhea, fever, and worm infestation.

Secondary health centers provide specialty services to districts. However, only basic specialties are available. The highest level of health care is the tertiary hospitals, which offer all the super-specialties. These hospitals, which include teaching hospitals, are well equipped and can provide most of the health services available in the west. However, the distance separating the tertiary hospitals causes many people to be unable to get to them. In the example above, Viki could not get treatment for his eye, because he had to travel five hours to another state to get to the nearest super-specialty hospital. Specialty care continues to be an issue the Indian health system faces.

While the National Rural Health Mission outlines a plan to provide access to quality care to virtually the entire population, the results of the system fall short of its goals. The Indian health system faces shortages in human and physical capital. As outlined by one author,

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"public health system in India suffers from shortages, imbalances, maldistribution, poor work environments, low productivity of personnel, vacant posts, high staff turnover, loss of personnel to private sector, and migration of health personnel to urban areas or overseas. Information on health workforce is sparse, available data are fragmentary and the research is limited."7

A recent article in the local paper in Dharamshala depicted a long queue at a hospital and showed the shortage of specialty physicians. Many specialty doctors in India transition to the private sector where pay and working conditions are better. As a result, the public health system in India lacks specialty doctors and other personnel.

**Conclusion**

When judging India’s health system, things look different depending on what perspective you take. When I went to the slum I saw people living in shacks with no real walls. I saw people washing their clothes and themselves in the river, and I saw the lack of electricity or running water. To my American eyes I saw poverty. However, to the couple of army doctors, the slum in Dharamshala was not a real slum at all. “The poor are pretty well off here” they told me. I took that phrase to mean that the poor don’t face threats of physical violence, they eat three meals a day, and have an actual bed to sleep in. I imagine that the slums in Delhi and Bombay make the slum in Dharamshala look like a vacation resort in comparison. Likewise, when I saw the health conditions, and the health infrastructure in the hospitals, to my American

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eyes I saw a backwards society. Imagine a care giver whose career consists of collecting and condensing instances of infectious diseases who does not have a computer. From the American perspective this looks extremely inefficient. From the Indian perspective this is the way it has always been.

When dealing with development, historical context is just as important as global context. Yes, the Indian health system has a long way to go to catch up to the Western models, but India has made significant advancements in their health care delivery. Over the past ten years, per capita expenditures on health have doubled. Recent government legislature has created several programs to expand the government’s role in health care. Even just this year Himachal Pradesh enacted a program that offers ambulance services. Many problems still exist, but continued efforts make the future of health care in India look positive.
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