Health Access for Informal Workers in Rajiv Nagar, India

Ushaben's Story

Ushaben was wearing a nightgown as she walked in to meet us. “We want to take half an hour of your time to talk about your recent surgery”.

“Half an hour? I don’t have that kind of time – 10 minutes is all I can spare. I was just about to go for a bath when Madhuben came to call me. I have a small shop at my house and I need to be there to attend to customers.”

All right, we said, we’ll make it short.

So we started talking.
Ushaben and her husband run a small shop in the front of their house. Her day begins at 5 a.m., and it is close to midnight by the time she calls it a day. She has two sons, 24 and 20 years of age, who live with her and her husband. Her 22-year-old daughter married a year ago and has gone to live with her husband and his family.

A few months ago she had an operation to remove a growth in her thyroid gland – an ailment that started five years ago. From the time the problem first started, in 2008, up until she had her surgery in a private hospital, she had made repeated visits to three different hospitals and various private physicians.

She first noticed she had a problem in 2008, when she started losing weight and began to have severe hair loss. After a few months of seeing her suffer, Ushaben’s mother suggested she go to a doctor. Ushaben went to a local private doctor who said she needed to get some reports done and referred her to a charitable hospital in the city.

At the charitable hospital, she was diagnosed as having a growth in her thyroid. She went there two or three times over the course of a year to receive treatment and periodic reports, but her condition did not improve. She admits she was not consistent when it came to taking her medication or making follow-up visits to the doctor. “I did not have the time to go to the doctor. Between my shop and other house work, I could not attend to my illness properly”.

In 2010, since her condition was not improving, Ushaben decided to go to Vadilal General Hospital, a large and well-reputed hospital in the city. They did some investigations and made the same diagnosis. They prescribed medications which cost Ushaben about Rs.100 (1.57 USD) a week. She continued that treatment for two years, hoping to cure her ailment.

However, paying for the medicine was becoming burdensome for her, and the growth was, in fact, getting worse. One of her neighbours advised her to go to the Civil Hospital, the largest government hospital in the state of Gujarat. She went to the Civil Hospital in mid-2012 - by which time she had had her illness for over four years. Someone had told her that if the growth became too large even a surgery would not be possible. The doctor again did some investigations for which she was required to pay Rs. 250 (3.93 USD). She was prescribed some medication and, because she could get it there for free, Ushaben made a point of going back.
After some time the doctor told her that she needed to have the growth removed surgically. She agreed, and was admitted by the hospital authorities. For four days, family members took turns staying with her day and night as the hospital required that at least one relative be there to attend to her. At the end of four days, Ushaben was told that the surgery could not be performed because her thyroid was not stabilizing. She was asked to go back home with no resolution to her problem. She and her family had been inconvenienced in vain.

She recalls, "I had a really difficult time at there. Each time I would go, a doctor would see me and then they would give me a date to come and get some tests done. When I would go on that date for the tests, there would be a different doctor, and he would start the process all over again, and I would be given another date to get the tests. I made so many fruitless trips to the hospital."

Finally, her condition was getting so severe that a local doctor told her that surgery was the only option. By this time her husband was disillusioned with the quality of service in the government hospital and did not want to spend several days there. However, her husband’s brother-in-law knew of a private hospital where she could get the surgery done. So in mid-2014, she went to the private hospital and got her operation. "The operation cost Rs. 20,000 (314.21 USD), and we had to borrow from relatives and friends to pay the amount to the hospital. I was discharged on the third day."

She is now free of the growth but her health problems have not come to an end. In August this year, she suffered from nosebleeds and went to the local doctor. He conducted various tests, including a blood test and an x-ray, but they did not show anything. The doctor told her that her nosebleed was due to a blood pressure problem and gave her an injection. He also gave her medication for a week and she says her blood pressure is now under control.

She had a repeat episode of bleeding from the nose and mouth recently. She had been visiting her injured brother-in-law in Vadilal Hospital, and her husband suggested that she should see a doctor during her next visit. Once again they did blood and urine tests and an x-ray, but all her reports were clear. “Before I went for the tests they told me it could be tuberculosis,” she said, almost indignantly.

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Ushaben asked that her photo not be shown, but allowed us to take a picture of the shop where she works with her husband.
She felt healthy for a couple of months after her surgery, but for the last three months she has been feeling very weak and is losing a lot of hair. “It looks like I am going bald – I had such thick hair! I hope it is not cancer.” She thinks about going back to the private doctor who did her surgery to get this new problem investigated. The finances are a concern though. The consultation alone would cost Rs. 100 (1.57 USD), and each trip there and back costs her about Rs. 50 (0.79 USD). She would need to take an auto-rickshaw because the bus route is very circuitous.

During her latest visit to a local private doctor she was told that the problem was due to an issue with her heart. “He told me that your blood is flowing in reverse – you tell me; can that happen? Can blood flow in reverse? He told me I need to have an eco-cardiogram.” She laughed lightly and continued, “The doctor has recently bought a new eco-cardiogram machine – maybe that’s why he wanted me to get one.”