

Letter from Ganiyari

JAN SWASTHYA SAHYOG (JSS) DIARIES

The forest is called Achanakmar. For non-Hindi-speaking friends, this would roughly translate into 'being struck, suddenly'. Can you think of a name more theatrical, formidable? I am not sure how many in or around the forest have been 'struck' by animals from this wildlife sanctuary. Close by, in the gentler surrounds of Ganiyari, Chhattisgarh; the tribal Baigas, Gond, Abhuj Maria and many others are being struck with far more regularity and finality by something else. We would like to believe that what is striking them is disease; in some ways it is. Yet, what is truly striking them, I believe, is poverty. And apathy. This is a remote, rural, neglected region of India, which is difficult to reach and impossible to remember once one arrives in New Delhi and gets consumed by the more important and urgent calls of life.

The local population is chronically malnourished. Life is hard and regular employment difficult to come by. Many families carry the toll of alcoholism. The favoured spirits are derived locally from the Mahua tree. Men and women are equally afflicted. Families often tend to be large with five or more children not being unusual. If under such circumstances, disease strikes, the blow can be fatal. Diseases are rampant. Tuberculosis and diabetes may be the star attractions but anaemia, infections, infestations, deficiency syndromes, sickle cell disease, bites, stings and every other disease one can think of, jostle for attention.

If one looks around for the available public healthcare for the indigenous population, one is not surprised. There is almost nothing. These people do not matter and we are too busy and important to be bothered about them. So people continue to fall sick, suffer and die. God forbid, they show a little spunk and try getting treatment in one of the private clinics or hospitals at the nearby Bilaspur or the slightly further Raipur. There is a high likelihood of them then falling into an endless spiral of debt from which they might never recover.

Enter Jan Swasthya Sahyog or JSS (Fig. 1). Each word in this name is meaningful. A few bold, committed and extremely unusual doctors initiated the project more than a decade ago. Spend a few days at JSS and what impresses you is how rooted the idea is in the local community and how organically the community connects with it. Each one is an equal stakeholder. Taking one person's name here would mean disrespecting the hundreds of others. The founder doctors had the audacity to not only conceive such a project but have also dedicated their lives bringing their vision to fruition. The community in its response surpasses my

expectations. Every time I visit JSS, I wonder why we do not engage more often with the communities that we work in?

JSS is not only a hospital. It is people working for themselves facilitated by the guidance and mentoring of committed doctors. Attention is crucially being paid not only to the cure of disease but also to its prevention in the community. People are being educated and made aware of sickness and health. Treatments are being re-thought and re-designed in accordance with local needs and within the framework of available logistics. Role of the generalist, which has long lost any shine in the medical profession, is being explored, even celebrated.

One often gets to see miracles of the generalist at JSS. While I am there, a 60-year-old farmer walks in with recently appeared symptoms of difficulty in using language. His brain imaging is urgently arranged from Bilaspur and it looks far worse than the patient. (I wish someone would donate JSS a CT scan device; an EEG machine would be a welcome addition too.) We discuss this patient around 4 p.m. and I am worried about where we are going to find a neurosurgeon. This seems to be a brain abscess and surgery is needed both for confirmation of the infectious nature of the lesion as well as for treatment. There is not much time to fret over it and I get busy with patients with epilepsy. Later in the evening I discover that the quiet, unassuming, soft-spoken person trained to be a paediatric surgeon has gone rogue and performed neurosurgery! It is a success. I would consider this otherwise modest surgery life-saving over here. I did not hear any applause anywhere or even much surprise. This is what everyone at JSS does regularly. They challenge themselves and break boundaries.

Over the past 10 years, I have travelled a lot and been to scores of small towns and villages and met hundreds of healthcare professionals. Many of them come across as being committed and caring. Yet I have never seen a patient being brought for a consultation not by his family but by a health worker! At JSS I was surprised to see that this happens regularly. I am told that 13-year-old Birju's parents have recently migrated to Allahabad in search of a livelihood. He and two of his siblings are staying with grandparents. The village health worker has brought Birju to the epilepsy clinic. Another young patient's parents are erratic in getting her to the epilepsy clinic. I am informed that they are Mahua addicts too. The village health worker who has brought her knows all the details that I need and does not seem judgemental or annoyed. I feel guilty because I am feeling both these emotions very intensely. I have so much to learn from these villagers.



Fig. 1. Views of the outpatient at Jan Swasthya Sahyog, Ganiyari

People can be very, very poor. They can be so poor that they are unable to afford medicines that they desperately need to remain seizure-free and that cost as little as ₹100 per month. I met a few patients who told me that they knew that their medicines should not be missed. Yet, every once in a while, they just do not have the money to refill their prescription. My long held dream of setting up an 'epilepsy drug bank' reappears. When will I be able to get this done?

The guiding light and driving force at JSS is empathy and concern for the community. Cost of care is designed thoughtfully and not set in stone. Individual patient circumstances are kept in

mind while handing over bills. Patients open up and talk. They do not appear overwhelmed, as they seem to be in the tall steel and glass structures called 'hospitals' in big cities. I wonder why we do not have more JSSs. The model not only works but it has profound lessons especially for doctors, health planners and governments. Or are we just not ready to listen, yet?

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