

FEATURE

SPOTLIGHT: PATIENT CENTRED CARE

Patient communities reform healthcare in India

Public disillusionment with health service provision has led patient advocates in India to mobilise and push for change, **Anita Jain** reports

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India presents a classic paradox. At one end patients receive the best of advanced medical care, and at the other millions lack access to basic services. The public health sector is neglected, and patients have to rely on a private sector that is commercialised and unregulated (box). Corruption is pervasive, resulting in exploitation of patients and irrational care.¹ Yogesh Jain, a public health advocate, puts it plainly, “With the discourse on primary healthcare hovering around access, cost, and sometimes quality, patient centred care seems like a futuristic thing in this country.”

Disillusionment with the status quo has given rise to vibrant examples of patients mobilising to safeguard their right to health. A vision for a better future is driving communities to organise so that they can collectively influence health outcomes, as the following examples show.

Action by people with HIV

Recounting her experience living with HIV, Kousalya Periasamy, founder and president of the Positive Women Network in India, says, “I was able to buy the medicines because I was well-off. Rather than shout for changes in the system, I could have sat back. But I saw people around me dying without medicines. Our friends are no more.”

At the 14th World AIDS conference in 2002, Periasamy and other HIV/AIDS activists demanded that the Indian government provide free antiretroviral drugs. Their persistent efforts were successful, and free access through the national HIV programme was established in 2004.

“You have to make a noise, else you will not get anything,” says Periasamy. Information about treatment options and solidarity among patients are vital to the movement, she says. Advocacy organisations such as Lawyers Collective have had a key role in educating the community on their rights to consent for testing, treatment, and confidentiality; the social and legal implications of stigma and discrimination; and intellectual property provisions that limit access to medicines.

Last year, HIV activists from across the country staged a protest outside the Ministry of Commerce against intellectual property provisions being negotiated in a regional free trade agreement.² A similar movement in 2011-12 resulted in the Indian government rejecting provisions in the EU-India free trade agreement that might have restricted production of affordable generic medicines.³ The HIV community has also challenged proposed patents on antiretroviral drugs such as tenofovir that could prevent production of affordable generic versions until 2018.⁴

“The HIV movement in India is premised on the right to health approach, which promotes participation of affected populations in all levels of health related decision making,” says Lorraine Misquith, senior research officer at Lawyers Collective. “This is an exemplary model for a community led and driven campaign, where the community is empowered to respond to actions, laws, and policies that negatively impact their right to health.”

Patient groups improve care for chronic illnesses

A transformative approach to empower and support patients with long term conditions to manage their illness⁵ has been pioneered by Jan Swasthya Sahyog (www.jssbilaspur.org/), a non-profit organisation providing health services to rural and tribal communities in central India.

Jain, one of the founding doctors of JSS explains, “Treatment continuation rates for most chronic conditions were poor even if the drugs were free. Hospital centred care just does not work in these illnesses. Not enough time can be spent with each patient to ensure good follow-up care. A platform was needed where patients with the same illness and their families could get together and discuss the disease and its treatment.”

JSS has established patient support groups for chronic conditions, including sickle cell disease, epilepsy, type 1 diabetes, and alcohol dependence. Currently, 13 patient groups

Healthcare in India: a snapshot

Financing—Public expenditure on health is 1.2% of GDP, which is among the lowest in the world. Costs are largely borne by patients through out of pocket payments, making it a major cause of household debt and impoverishment

Privatisation—93% of all hospitals and 80-85% of all doctors are in the private sector, which provides for 80% of outpatient care episodes and 60% of inpatient care. The sector is largely exempt from regulatory oversight

Access to medicines—Often called the developing world's pharmacy, India is the world's third largest producer of drugs and exports medicines to over 200 countries. Yet, over half of its population lacks access to medicines they need; 74% of out of pocket expenditure is on drugs

Workforce—India has the largest number of medical colleges in the world yet faces a workforce crisis. India has seven doctors and 17 nursing and midwifery staff per 10 000 population. The global averages are 14 and 29 respectively. Urban density of health workers is four times that in rural areas

Infrastructure—The third national District Level Household and Facility Survey in 2007-08 showed that out of 4535 community health centres, only 754 are functional as per the Indian Public Health Standards

Sources: *High level expert group report on universal health coverage for India*, November 2011; *World health statistics 2014*; and Sengupta A. *Universal health care in India. Making it public, making it a reality*. Municipal Services Project. Occasional Paper No 19. 2013.

have been set up with over 300 patients from 85 villages. They meet regularly, with the venue rotating between villages so members have to travel equal distances.

Community health workers trained in disease management and group facilitation skills steer the meetings. Information on the disease and its treatment is shared with participants. The health workers encourage discussion of challenges and concerns and identify topics of common interest. "Topics like drawing a family tree to understand the inheritance pattern of sickle cell disease, and managing pain were discussed more than once in the sickle cell disease groups. Among epilepsy patients, topics like structure and function of the brain, mechanism of seizures, and pregnancy and anti-epileptic drugs evoked lively discussions," shares Jain.

"We were sceptical whether people would join because of the little time they can afford given the sheer burden of eking a livelihood in rural areas. But the idea has been a runaway success," says Jain. Mutual motivation has resulted in greater adherence to recommended treatment. "From a dismal compliance rate of 40% in epilepsy and sickle cell disease, it has reached high 90s. Alcohol abstinence rates are well over 70%. People can see the effect of compliance with treatment in terms of freedom from seizures and being able to return to school in epilepsy, and fewer crises in sickle cell disease. Many patients feel this is the only support they are receiving. Family members are encouraged to participate and are trained to provide care. Some groups have initiated monthly savings by members to help out with small and urgent needs."

The team is working towards patient groups for conditions like tuberculosis, mental health problems, hypertension, and air borne contact dermatitis.

People in rural areas often follow traditional beliefs or visit unqualified healers rather than seeking appropriate medical care. Sharing information with many people at a time helps spread knowledge. "We have observed a sisterhood of people with a common illness in rural areas. People with an illness often know a few others with the same illness. We have used this technique to identify and reach more patients with care," says Jain.

Public hearings hold health officials to account

Self reliance and self determination of people in planning health services is a fundamental tenet of the international conference on primary care's Alma-Ata declaration of 1978.⁶ Jan Sunwais or public hearings, also referred to as mass social accountability events, put this into practice.

Traditionally, most people in India have not been empowered to voice their opinions and concerns with the health system. Channels to facilitate their participation and address grievances have been nearly non-existent. The Right to Healthcare campaign by Jan Swasthya Abhiyan, the Indian arm of the People's Health Movement (www.phmovement.org/), devised a framework for community based monitoring and planning of health services that was incorporated in the National Rural Health Mission in 2007.

The process has flourished in Maharashtra, where around 1000 villages across 13 districts participate.^{7 8} "Regulation of health services is a public function, the responsibility for which cannot be limited to a distant bureaucracy," says Abhay Shukla, a physician and health activist from SATHI-CEHAT, a non-governmental organisation that steers the programme in Maharashtra (www.cbmpmaharashtra.org/). "Even so, having these provisions on paper is a first step. Community engagement with health services needs to be actively facilitated by community based organisations through a series of interlinked processes and mechanisms from villages to the state level."

The process starts with community meetings to make people aware of their rights and entitlements. SATHI-CEHAT has set up a system where people in each village get together annually to rate provision of services at the local government health centre. The ratings are collated on a report card that is displayed at the health centre.

The process culminates in public hearings where the findings from the report cards are shared. People also voice their experience of the health services and instances where they have been denied care. Government health officials attend the hearings and are expected to respond to the concerns raised. An independent panel of judges, which includes professionals such as teachers, doctors and lawyers, mediates the dialogue.^{7 8}

"Over 2-3 years, most issues that can be resolved locally such as staff absenteeism, overcharging, rude behaviour, and non-provision of essential services, are addressed through public hearings. An improvement is observed in the functioning of primary health centres. Some issues related to inadequate staffing, infrastructure needs, and shortage of drugs require approval at the next level of administration, and are taken for discussion in a public forum there," says Shukla.

Over 450 public hearings have been held so far across the state, and they have proved popular and successful in fostering accountability and transparency in public health services. A qualitative evaluation of these hearings documents improved community engagement and greater health awareness and use of services.⁷ Hearings in some areas have evolved from a fault finding exercise to a participatory dialogue between

communities and health officials to plan health services in line with their needs.

“Making the public health system responsive is a huge challenge,” says Shukla. “Resistance from bureaucracy and inadequate funding has stalled the process in several states.” Community monitoring of the availability and quality of health services should be a non-negotiable and mandatory component of the health programme, Shukla suggests.

People’s participation in regulation of the private sector is equally, if not more, critical.⁹ The Jan Swasthya Abhiyan in Maharashtra is pushing for a formal charter of patients’ rights to hold private healthcare providers accountable for emergency services, quality of care, information provision, privacy, and autonomy for patients.

These glimpses into patient participation in healthcare in India highlight the crucial role of informed and empowered citizens. When access to basic care is uncertain, the discourse on patient centred care shifts from individual doctor-patient interaction to collective engagement and advocacy by communities to make the health system function and deliver their needs. The new national health policy in India proposes making health a fundamental right with the promise of improved access to treatment.¹⁰ This vision can be achieved only through active engagement and participation of people.

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