

COPASAH SOCIAL ACCOUNTABILITY

THEME: PATIENT'S RIGHTS -FULCRUM FOR ACCOUNTABILITY OF PRIVATE MEDICAL SECTOR

(Speakers Dr. Abhay Shukla & Dr. Abhijit More)

April 3, 2018; 3.30 pm - 5:00pm IST

Background- In many low and middle income countries especially in South Asia and Africa, the private healthcare sector is playing a major role in providing healthcare. With advance of medical technology and commercialization of healthcare, the healthcare landscape is rapidly changing in low and middle income countries. This poses significant challenges for access to quality and affordable care by patients. Hence there is a growing discourse around the need to protect patient's rights, which can be a key platform for ensuring greater accountability of private healthcare providers.

This webinar will describe in detail the current discourse on patient's rights, both in terms of existing legal and formal provisions such as charters for patient's rights, as well as common violations of these rights. A few existing mechanisms for protecting patients rights will be presented as examples. We will discuss how mechanisms to ensure Patients rights need to be built into any regulatory mechanism for the health sector, with corresponding grievance redressal systems, to ensure that patient's rights do not remain on paper, but are made real entitlements for ordinary people.

Main points discussed in the Accountability Dialogue:

1) Why the concept of patient's rights emerged at global level?

- There is an inherent power hierarchy between doctors and patients because of information asymmetry between doctor and patients.
- Patients are in a vulnerable position, both physically and mentally
- Patients have to share personal health information with doctors, thus exposed to potential misuse.
- So effectively, doctors have upper hand in decision making for patients!
- Growing consensus at international level that all patients must enjoy certain basic rights irrespective of nature of healthcare providers, whether public or private!
- The patient is entitled to certain protection to be ensured by physicians, hospitals and the State, which have been codified in various countries in form of Charters of Patient's Rights.

2) Why should Patients have rights related to Private medical providers?

There are four rationales for demanding patient's rights in private health sector-

- A. The Human rights rationale: Patients rights are Human rights – state obligation to protect dignity of all human beings according to Universal Declaration of Human Rights.

- B. The Market failure rationale: Without regulation and rights, market failure will adversely impact on patients
- C. The Health systems rationale: The Private medical sector has grown through major public subsidies, it needs to be accountable
- D. The Ethical imperative – ethical duties of doctors translate into basic rights of patients

3) What are common violations suffered by patients?

- Hospital not giving proper information about diagnosis, proposed treatment, estimated expenditure
- Not giving details of treating physician(s)
- Denial to share medical records of the patient
- Denial to give itemized bill, lack of transparency in rates
- Refusal to share documents for second opinion
- Denial of basic emergency care to accident victims
- Compulsion by hospital to buy medicines / undergo tests from particular outlet linked to hospital
- Violating human dignity, privacy and confidentiality of patients
- Discrimination regarding HIV positive patients
- Detaining patient or dead body of deceased patient as a hostage, for settlement of bills

4) Can you tell example of patient's rights violation in the form of any case story?

- This is case documented for public hearing on Right to Healthcare organised by National Human Rights Commission and Jan Swasthya Abhiyan in Mumbai in 2016.
- Mrs A was registered at B Hospital under observation of Dr C for pregnancy check-ups. Dr C had assured that she will be available for delivery.
- When patient was admitted with labour pains, at 10.30 am, Dr C was not available.
- However, hospital administration and other junior doctors in hospital gave false assurance that Dr C will come and do the delivery.
- Repeated requests by the husband that they want Dr C to conduct the delivery or else they will shift the patient were not heeded.
- Each time given false assurance that Dr C will come in an hour. She did not come till 8.45 pm.
- Meanwhile junior, incompetent doctors handled the case through the day and took her to operation theatre at 5 pm.
- Delivery was prolonged due to inept management and new born delivered finally at 9 pm was asphyxiated, referred to NICU in other hospital and kept for 19 days.
- Family had to spend a huge amount.
- Now the baby is physically handicapped and case of mental retardation. The boy can't sit, talk, walk, or eat on his own.
- Mrs A had to leave job to take care of this son. Family is suffering daily.
- Patient could not get any bills, discharge card or receipts from Dr C immediately. Patient got discharge card, bills after 1 month of follow up.
- Family is still waiting for justice.

5) What are the factors that are driving patient's rights violations in private hospitals?

- Dr Gadre and Dr Shukla authored a widely read book 'Dissenting Diagnosis' with interviews of doctors exposing malpractices related to private healthcare which are driving factors for patient's rights violations in private hospitals-
 - Unnecessary treatments and interventions
 - Irrational care driven by profit seeking by large hospitals
 - Pharma industry–doctor nexus
 - Institutionalized system of kickbacks
 - Inflated, arbitrary costs of care
 - Revenue targets given to doctors in corporate hospitals
- Growing malpractices, irrational care and unnecessary procedures in LMICs are inevitable products of large scale commercialisation of health care, which lacks effective regulation or accountability
- Medical councils have dismally failed in promoting self regulation for medical ethics, almost never act on erring doctors
- To ensure rational health care and minimise patients rights violations, society must ensure appropriate regulatory systems whereby 'market failure' is minimised
- Health care must be made socially accountable and should increasingly become a public good accessible to all

6) What are commonly accepted Patients Rights?

Patient's Rights can be broadly classified into four categories-

- Individual human rights – Privacy, confidentiality, access to records, non-discrimination
- Public health / Social rights – Access to health care, charges according to standard rates
- Consumer rights – choice of medical store, second opinion, transparency of rates and billing
- Accountability related rights – right to complain, redressal system

There is no uniform template for charter of patient's rights. However, some of the commonly accepted patient's rights can be summarized as follows-

1. Right to Emergency Medical Care
2. Right to information, including info about rates of services
3. Right to patient records and reports
4. Right to choice of medical store or diagnostic centre
5. Right to transparent and affordable rates of care
6. Right to confidentiality and privacy
7. Right to informed consent
8. Right to second opinion
9. Right to take discharge of patient, or receive body of deceased from hospital, without preconditions
10. Right to protection as per guidelines, during participation in clinical trials and biomedical research
11. Right to grievance redressal and feedback

7) What are mechanisms for enforcement of patient's rights?

- Internal grievance redressal mechanism with apology and / or correction of mistake
- Monitoring bodies linked with Clinical establishment regulation
- Professional Bodies like Medical councils
- Formal court mechanisms- Criminal Law and Civil law of Tort
- Ombudsmen (both general ombudsmen and healthcare specific ombudsmen)
- Mediation councils
- Patients' rights advocates

Legal representation by patient associations can help individual patients and families to claim their rights

Some noteworthy examples of institutionalised mechanisms of enforcement of patient's rights-

1. **United Kingdom- NHS Constitution** empowers the public, patients and staff by setting out existing legal rights and pledges in one place and in clear and simple language.
2. **Punjab (Pakistan) Healthcare Commission-** Directorate of Patient Rights and Complaints is constituted to hear complaints regarding-
 - a) Adherence to service delivery standards and standard protocols
 - b) Violation of charter of patient's rights
 - c) Malpractice and medical negligence
 - d) Harassment of medical professionals/staff
 - e) Violence in hospitals
3. **'No Fault Compensation' system in Austria and Thailand-** Separating professional liability from compensation; the patient has only to prove that there have been negative implications from receiving health services. There is no need to prove who is wrong. Technical team will make the final decision on no fault compensation within the determined rates or refusing the appeal.

Some possible outcomes of Grievance Redressal for patients-

- Mediation leads to clarification of misunderstanding or information gap
- Professional disciplinary action (removal or suspension of doctor's license to practice)
- Financial compensation (either based on a fault system or a no-fault system)
- Criminal (imprisonment and fines)
- 'Specific performance' (e.g. rectification of records, corrective therapy)
- Apology (with or without admission of liability) and explanation
- Any other administratively effective measure

8) How to strengthen Patients Rights?

- Promoting widespread literacy among citizens regarding patient's rights and awareness about malpractices
- Developing a framework for accountable, social regulation which includes Patients rights charter
- Promoting forums for dialogue and collaboration among active citizens and ethical doctors

- Designing standard treatment guidelines by groups of rational doctors
- Moving towards a system of Universal Health Care which makes available free, quality healthcare for all

Speakers- Dr Abhay Shukla and Dr. Abhijit More

1) Dr Abhay Shukla is a public health physician who has been working on health issues in collaboration with people's movements and grassroots NGOs as part of SATHI, a Health sector civil society organization in India. He is a member of advisory bodies for the National Health Mission as well as the National Human Rights Commission of India. He is a national convener of People's Health Movement-India and has facilitated public hearings on right to healthcare across the country. Dr Shukla has authored and edited several books on health system issues including co-authoring the widely read book 'Dissenting Diagnosis', which exposes malpractices in the private medical sector. He is involved in action and research for the promotion of patient's rights, social regulation of the private medical sector, and developing a system for universal healthcare.

2) Dr Abhijit More, a medical doctor and health activist. He is working as a Senior Project Officer in SATHI, a Pune based NGO in India working on health issues. He is also a co-convener of Jan Arogya Abhiyan (Maharashtra State Chapter of People's Health Movement-India) which is a network of civil society organizations working on health rights. He is involved in advocacy and campaigns for patient's rights, improving public healthcare system, regulation of private healthcare sector and Universal Health Care in Maharashtra. He has written many newspaper articles on various issues of public health importance.