

Patient rights implementation in health facilities in Karnataka, India

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Impact

This dissertation on the governance for patient rights implementation has been impactful in many ways.

Impact on society

Several allegations of patient rights violations in health facilities are often reported in the media in India. Patient rights movements involving NGOs, individual activists, researchers, ordinary citizens in India pressurize the central and the state governments through public interest litigations in the courts, protests and direct policy advocacy at all levels. Yet, there is hardly any empirical work from India that sheds light on the systemic issues that affect the implementation of patient rights in health facilities. This dissertation is first of its kind in India, that explores the governance aspect of implementing patient rights that too using critical paradigmatic research approaches. The explicit focus on power relations to study the governance for patient rights implementation was helpful to identify the pathologies in the existing policy and practice frameworks for patient rights implementation in India. The study identified the problems with the framing of patient rights in formal policies at the subnational levels. It also demonstrated the discrepancies between the policy intentions for patient rights protection and actual practices at the health facility level. The findings of the research were shared with the Department of Health and Family Welfare, Government of Karnataka in the form of a report. The framework on multilevel governance on grievance redressal for patient rights violations and other findings reported in chapter three and four could support the policy community in Karnataka and in India and similar other settings to decide on effective policy options to respect, protect and fulfill the patient rights. Next to the framework, the PhD research also offers explanations on the status of patient rights policy initiatives. This could provide critical lessons for future policy reforms in India pertaining to patient rights.

The findings of this dissertation also caught the attention of print media in Karnataka. The publication of the research paper in the International Journal for Equity in Health exploring the various discourses on patient rights in Karnataka was picked up by a regional English newspaper, Deccan Herald as a news story. The news article highlighted the perceptions of health care providers and practices in health care facilities concerning the implementation of patient rights norms and policies.

The other important impact of this research was the research partnerships it developed with the grassroot level social movements for patient rights protection. Such partnerships will bridge gaps in theory and practice. This also helped to develop empirical work on

patient rights that is more relevant and useful to both academic and non-academic world. For the grassroots level social movements, this dissertation especially chapter three offered critical insights on the strategies adopted by various stakeholders to influence grievance redressal processes for patient rights violations in health facilities. The research publication in BMJ Global Health titled “Crying baby gets the milk? The governmentality of grievance redressal for patient rights violations in Karnataka, India” is a potential tool for evidence-based policy advocacy that can be used by the grass root social movement in their struggle for justice. As a policy advocacy tool, this publication provides a vivid chronological documentation of the issue and the cause taken up by the grassroots social movement, their strategies for policy action, successes/failures, their strengths and weakness. This research offered an opportunity to grassroots social movement in Karnataka to critically introspect their thinking and practices and plan the next course of action in their journey seeking justice from the formal governance system in Karnataka for redressing the grievances on patient rights violations. This is one of the direct impacts of this dissertation. The findings of this particular research paper were also disseminated in a webinar organised by the Health Equity Network of India (HENI)- a forum that have membership from both academic and practice arena. Publications in journals and presentation in forums such as HENI also helped to gain visibility for the work done by the grassroots social movement.

I collected data on the governance for patient rights from ten health facilities (both public and private) in Mysuru district in Karnataka. At the end of data collection in each of these facilities, I instantly shared the initial findings on the perceptions and practices concerning patient rights to the facility administrators of each of the hospitals involved in this study. This interaction with the health facility administrators was a perfect opportunity to sensitize on the importance of patient rights and apprise them of the challenges to promote patient rights in health facilities. The health facility administrators expressed that this immediate feedback was useful to think and act about patient rights at their health care organizational level.

The participants of the study included care-seeking individuals from all walks of life, various cadres of health care providers, health facility administrators, public health officials, non-health sector officials, NGO representatives, health activists, representatives from medical professional associations and hospital associations. The data collection methods used in this study such as in-depth interviews, focus group discussions, participant observations created spaces for dialogue on patient rights with critical actors in the system. During data collection, several participants expressed to me that this research provided an excellent opportunity for critical reflection on the current thinking and practice of patient rights in health facilities. Many care-seeking individuals

from the health facilities who engaged in this study, reported that they heard about the term patient rights for the first time in their lives. That way, this research made efforts to bring out the voices of the care-seeking individuals especially the socially disadvantaged concerning their rights which many a times remain unheard/not adequately heard in the policy circles.

This PhD dissertation helped to explore the pathologies within the governance arrangements for patient rights implementation in health facilities in Karnataka specifically. As a next logical step, further research should focus on the interventions to address the governance challenges associated with implementing patient rights in health facilities. The experience in PhD laid the foundation for my post-doctoral work. I secured a competitive grant namely the “Department of Biotechnology (GoI)/Wellcome Trust India Alliance Early Career Fellowship in Public Health” for the next five years i.e from 2024-2029. Through this fellowship I aim to empower and engage with select indigenous tribal communities of Chamarajanagar district of Karnataka state in India in the governance processes for protecting and promoting their rights to achieve wellbeing.

Impact on science

This PhD contributes to build the knowledge base and theory building on the very less researched domain- patient rights in India. Though scholars recognise the need for power analysis in the field of health policy and systems research, empirical work applying the notions of power and power relations in health governance especially from Lower-middle-income settings are few. This PhD dissertation uses power as the central analytical lens to explore the governance for patient rights implementation in health facilities. The use of theories and methodologies inspired from critical research paradigm such as multilevel governance framework, governmentality, critical interpretive synthesis and critical discourse analysis enable analytical transferability of the findings of this PhD on patient rights to other settings similar to Karnataka/India. I also demonstrated the use of some of the innovative data sources such as litigations on patient rights violations from the Supreme Court of India in critical interpretive synthesis methodology. I also illustrated the research utility of diverse and enriching data maintained by grassroot social movements working on patient rights. In this way, this PhD work advanced regional understanding, collaboration and policy/practice relevant knowledge production on the governance for patient rights protection in health facilities.

To improve the research uptake, the findings of this PhD were disseminated in the scientific sessions at the international conferences such as the Seventh Global Symposium on Health System Research, Bogota, Colombia, 2022, 6th and also in the 7th edition of the International Conference on Public Policy, Toronto, Canada. The 6th edition was held in Spain, but I gave a virtual presentation. I also regularly shared my

PhD work at various stages of the research process with peers at the Institute of Public Health, Bengaluru, Maastricht University, Netherlands, and at the Institute of Tropical Medicine, Belgium. It was also possible to publish four research papers from this PhD work in reputed scientific journals such as Health Policy and Planning, BMJ Global Health, BMJ Open and in the International Journal for Equity in Health.

The research papers of this PhD work, served as a learning resource materials for the undergraduate and post graduate students in public health in India and abroad. For instance, the research paper in chapter three was used for the undergraduate students in Global Health, University of British Columbia to teach the role of power in health governance. I used my PhD research papers to teach the Health and human rights module for the final year MPH students of Rajiv Gandhi Institute of Public Health and the Centre for Disease Control, Bengaluru, India.

Initiating empirical work to explore the governance for patient rights implementation through this PhD also enabled critical reflection on the future possible research topics for the scientific community in the area of patient rights. Some of the candidate research areas include internal power dynamics of social movements working on patient rights, patient rights governance in systems of medicine other than western medicine and governance processes in the redressal of patient rights violations involving cadres of health care workers other than doctors.