

Patient rights implementation in health facilities in Karnataka, India

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Summary

Title of the thesis: Patient rights implementation in health facilities in Karnataka, India: a critical perspective on governance

Patient rights are human rights attributed to health care-seeking individuals. Instances of patient rights violations are reported (almost daily) in India. Patient rights violations such as denial of health care, discrimination, disrespectful care, and poor quality of care instances are rampant in India. Yet, India does not have a law uniquely dedicated to patient rights. Despite the growing problem of patient rights violations in health facilities, scholarly work on patient rights is scarce in India. The available empirical literature on patient rights in India heavily focuses on whether health care workers and patients are aware about patient rights. Excessive focus on awareness levels on patient rights detracts from the core issues of how the Indian State governs patient rights implementation and what it does to promote patient rights and prevent patient rights violations in health facilities. Constitutionally held human rights principles should be reflected in all settings (including patient care) and at all levels (from national to subnational). It then becomes pertinent to examine how the institutions, rules, regulations, norms, and everyday practices of actors (in a nutshell- governance) at various levels of system espouse human rights vis-à-vis patient rights.

In this thesis, I analysed the formal and informal rules, institutions, norms, and beliefs that govern how care-seeking individuals, health care providers and other stakeholders perceive and practice patient rights in health facilities. This analysis of “governance” for patient rights implementation allows capturing structural issues at the policy and organizational level, as well as diverse forms of power asymmetries that are often at the heart of advancing patient rights in health facilities. In this thesis, I aim to explore and explain the power dynamics that emerge in the governance processes for implementing patient rights in health facilities in India. To this end, I used a power-centred approach to governance to understand the structures, institutional arrangements and social interactions concerning patient rights implementation at subnational levels and in health facilities. Thus, in my research patient rights and power dynamics in governance for patient rights implementation were the key conceptual foci.

The study was primarily qualitative in nature and was conducted in two phases: In phase one, to get a global perspective, I started with a critical examination of available scholarship on patient rights implementation. In this critical review, I used grievance redressal systems and mechanisms for care-seeking individuals as entry point to understand patient rights implementation. In the initial systematic scoping review using a critical interpretive synthesis (CIS) approach, a multilevel governance framework on the grievance redressal for patient rights violations in health facilities was developed. The relevance of this framework to the Indian context was validated through the analysis of Supreme Court of India cases on patient rights violations. In phase two, to understand the governance for patient rights implementation at subnational levels, I chose Karnataka, a southern state in India as the research site. Phase two included two research studies. In the first research study, I studied the influence of power dynamics on patient grievance redressal system. I used a critical case of alleged patient rights violations by a medical professional in a government health facility in Karnataka. I collected data through in-depth key informant interviews (6), media reports (35), and other legal and non-legal documents pertaining to the case. Michel Foucault’s

governmentality theory guided the thematic analysis of the qualitative data. Apart from patient grievance redressal system, discourse (i.e., text and talk around patient rights) is also a useful entry point to understand the power dynamics in the governance for patient rights implementation. Therefore, in the second research study of phase two, I conducted a critical discourse analysis (CDA) of the subnational policies on patient rights, everyday language and (subtle) social practices on patient rights in health facilities. There were four main data sources for CDA: i) in-depth interviews with various stakeholders concerning patient rights at state, district, subdistrict, and health facility level, ii) focus group discussions with care-seeking individuals and health care providers, iii) participant observations in selected health facilities, and iv) document reviews.

Three findings are critical in this dissertation on the governance for patient rights implementation in health facilities. Firstly, the PhD study illustrated the role of power relationships in the construction of governance processes for patient rights implementation in health facilities. The care-seeking individuals and their family members were rendered powerless and made dependent on health care providers to learn and exercise patient rights. Care-seeking individuals attempted collective efforts to counter the medical and bureaucratic power especially within the domain of grievance redressal for patient rights violations. Yet, often to no avail, my research showed how medical power along with bureaucratic power took control of the governance processes and outcomes of grievance redressal for patient rights violations. The dominance of medical and bureaucratic power made justice elusive for care-seeking individuals. Secondly, my research showed that the understanding of patient rights by various stakeholders such as care-seeking individuals, their family members, health care providers, and public health authorities differs from human rights perspectives. It also showed that their understanding on patient rights is largely embedded within the logic of health care consumerism and quality of care. Thirdly, it brought to light that the implementation of patient rights was for the most part limited to grievance redressal for patient rights violations. Formal governance arrangements and practices at the subnational levels were inadequate and tokenistic for promoting patient rights in health facilities.

Seemingly, the formal governance practices to promote patient rights knowledge among care-seeking individuals or redress grievances on patient rights violations uphold and assert patient rights. Paradoxically, the formal governance practices made only a symbolic or a perfunctory effort, ignored human rights-based discourses, problematically exacerbated unequal power positions in health care provider-patient relationships, undermined patient rights and therefore, rendered care-seeking individuals powerless. This research makes two important contributions to understanding the implementation of patient rights in health facilities i) it demonstrates the complexities of power asymmetries ingrained in governance processes for patient rights implementation ii) it explains how governance regimes are politically constructed (not) to promote patient rights and redress grievances on patient rights violations. Achieving the effectiveness of the governance for patient rights implementation involves power sharing with care-seeking individuals as well as alignment of various actors with human rights, justice, and ethics perspectives of patient rights. Reimagining effective governance for patient rights implementation demands a new politics that shifts power decisively towards care-seeking individuals - the right holders.