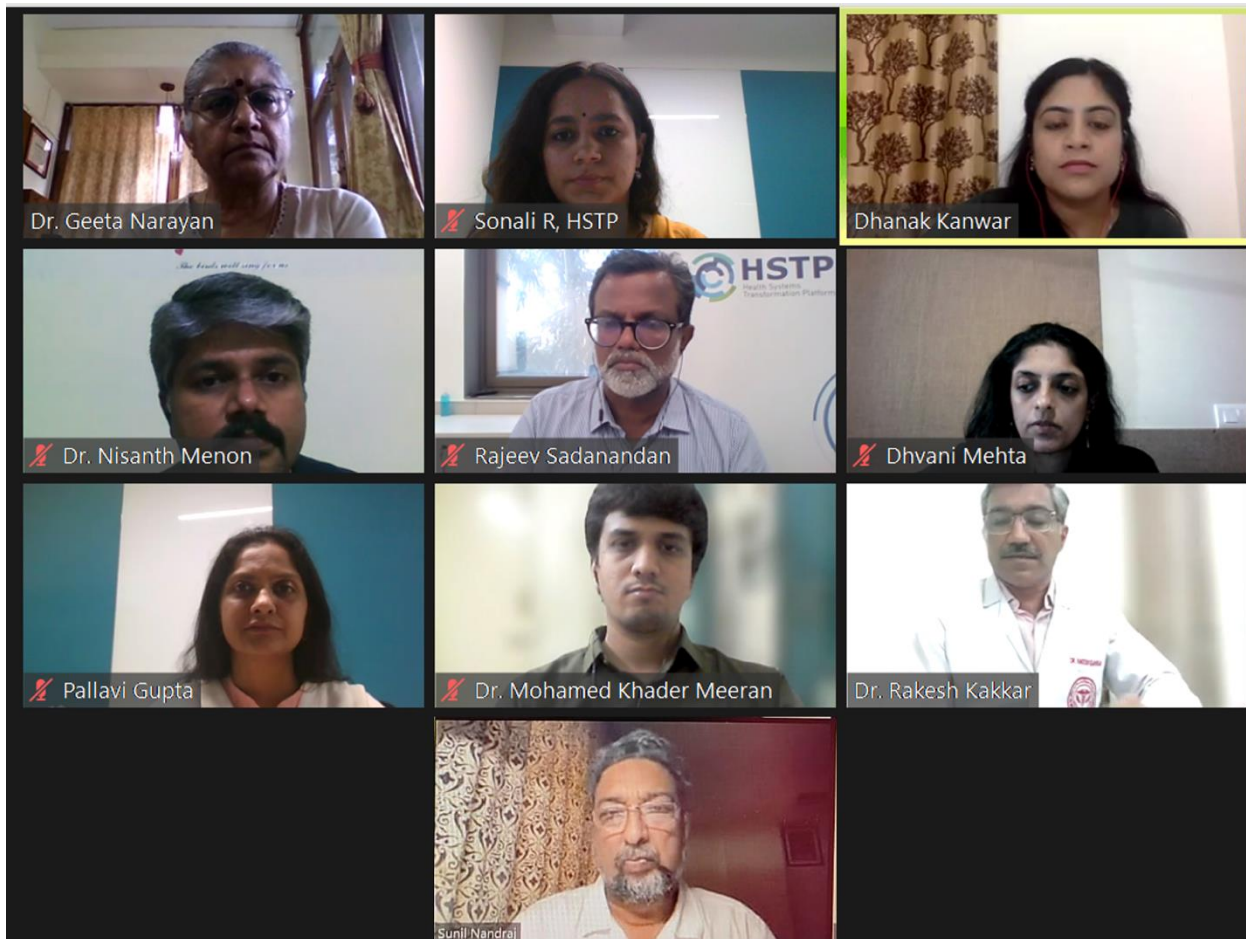


# Webinar Report

**Cries that have no tears - understanding elderly patients' rights in India**  
**29th September 2022**



## Introduction

According to a report by the Technical Group on Population Projections, by 2036, there will be 67 million men and 71 million women aged 65 years and above living in India. In many areas of healthcare system, ageing of the global population and prevalence of chronic diseases are having a significant impact. These are potential patients who will increasingly require appropriate care for their conditions.

We decided to discuss the different perspectives on Elderly Patients' Rights, their experiences, and challenges in accessing healthcare. There is a need to understand the challenges associated with the legislative provisions in India to ensure the rights of the elderly population and redressal system in case of violation of these rights.

We, invited Dr. Rakesh Kakkar (Professor and Head, Department of Community and Family Medicine, AIIMS Bathinda), Dr. Nisanth Menon (MD Emergency Medicine, M. Med Family Medicine, Amala Institute of Medical Sciences, Kerala), Dr. Dhvani Mehta (Lead-Health and Medical Law at Vidhi Centre for Legal Policy), Dr. Geeta Narayan (Retired, United Nations Population Fund) and Dr. Mohamed Khader Meeran (Physician, MGIM, Wardha) to share their thoughts and perspectives and a possible way forward on the current status related to patients' rights of the elderly in India.

52 researchers, students, academicians, and practitioners attended the webinar.

## Summary & Key Takeaways

Dr. Sonali Randhawa (Research Associate, Health Systems Governance, HSTP) opened the webinar and invited Mr. Rajeev Sadanandan (CEO, HSTP) to present his opening remarks. Mr. Sadanandan welcomed all the panellists and talked about the policy and health systems background related to elderly patients' rights in India. He spoke about the demographic shift in India and the capacities of the states to work on the same, the feminisation of ageing, the lack of competence in geriatric healthcare and the scanty policies, programmes and provisions tending to the needs of the elderly in India.

Mr. Sunil Nandraj (Advisor, Health Systems Governance, HSTP) addressed the audience to underline the importance of patients' rights and the challenges faced by people in exercising them. He emphasised the issue of power relations in medicine and how there is a power struggle between the healthcare provider and the patients (specifically the elderly). He emphasised that healthcare in India is not patient-centric because the value of life in India is insignificant and highlighted that very little work has been done to address the larger issues around healthcare regulation. Commercialisation of medicine and supplier-induced demand were factors responsible for the status of patient rights in India. Lastly, he posed questions regarding the grievance redressal mechanism in India for patients or lack thereof.

Ms. Pallavi Gupta (Specialist - Health Systems Governance, HSTP) shared the work of the Health Systems Governance (HSG) team, repository of healthcare legislations, policy documents, gazette notifications, government-issued circulars, court judgements, and evaluation reports (<https://www.hstp.org.in/health-systems-governance/>). Ms. Gupta invited the attendees to collaborate with HSTP to build the repository further.

Dr. Dhanak Kanwar (MPH student at AIIMS Rishikesh and Intern at HSTP) invited the panellists to share their experiences and views.

Dr. Rakesh Kakkar highlighted the demographic shift in India wherein every 4<sup>th</sup> person will be 50 plus in the next 15 years in India. He talked about the need for changes in the policies as greater resources would be required to render services and care to the elderly. He spoke about the health care insurance being provided to the elderly currently being meagre. Dr. Kakkar cast light on the Charter of Patients' Rights in India and the need to create awareness about these rights among the people. He also talked about the most vulnerable section of the elderly in terms of neglect and abuse being found in the urban areas. He highlighted the issue of ageism in healthcare, where the elderly is often ignored as they are thought to be just old, not sick. Physicians often dismiss a treatable pathology as a feature of old age. He was of the opinion that ageing not only increases the burden of diseases but also changes the nature of demands on the healthcare systems. He emphasised the need for intersectoral coordination to tackle the issues related to accessing health care services by the elderly.

Dr. Nisanth Menon shared his personal experiences on the lack of enough avenues for doctors to pursue geriatric medicine as a specialisation in India. He specified that out of 650 medical colleges in India only 16 offer seats in MD Geriatric Medicine. He shared about the National Programme for the Healthcare of Elderly under which there is a provision for the establishment of 'geriatric clinics' at subcentres, primary health centre and community health centre levels and 'regional geriatric care centre' at the tertiary level, and proceeded to discuss the factors differentiating elderly patient healthcare from the others, which include lack of decision making for oneself and dependency on children or caretaker/relatives or home-nurses for care and accessing the basic health services.

Dr. Geeta Narayan shared her experience as a caregiver to an elderly person and her perspective on the issue as a representative of patients and their family members. She spoke about her challenges and experiences as the primary caregiver of her late mother. She mentioned the process became even more taxing as it took place during COVID-19 as her mother was not vaccinated. She highlighted that COVID-19 was the time when it was necessary to prioritise the elderly, but sadly provisions such as at-home vaccinations for the elderly, among others, were unavailable. She mentioned about the lack of attention to basic requirements of elderly patients in hospitals which directly impacts their right to dignity. She mentioned that it is of utmost importance that we make efforts to include training of the medical as well as paramedical staff as part of their curriculum to treat elderly patients with dignity and respect. She also emphasised the importance of paying attention to the needs

and apprehensions of the caregiver. In her closing statement, she spoke about the need to involve diverse sectors and in providing care to the elderly such as the Ministry of Housing and Urban Affairs, as it plays a crucial role in providing convenient access to services for the elderly.

Dr. Dhvani Mehta provided a legal perspective on the issue of loss of decision-making capacity in elderly patients and also on the legal framework around end-of-life care in India. She explained the provision of advance medical directives, providing the chance to execute living wills by health-proxies, who take end-of-life decisions on their behalf, in case there is a loss in the decision-making capacity of the elderly. She was of the opinion that in hindsight, although this is a progressive step, it is cumbersome to execute these documents. She highlighted that to execute, the wills must be signed by a Judicial Magistrate in the presence of two eyewitnesses. She discussed the issues related to the misuse of these powers by acquisitive relatives of dependent elderly patients. She mentioned that the freedom to take end-of-life decisions for oneself is the extension of the Right to Autonomy, Right to Privacy and Right to Dignity promised under Article 21 of the Indian constitution. She concluded her session by highlighting the lack of a legal framework for people with impaired decision-making (elderly, persons with disability etc.) and how India is still in the grey area when it comes to the implementation and execution of the same.

Dr. Mohamed Khader Meeran highlighted the challenges in the existing grievance redressal process and what may be the obstacles to patients' rights. He briefly explained the 17 rights in the Charter of patients' rights and proceeded to explain the grievance redressal mechanism. He mentioned about the standards of care as the essential key to upholding the rights of an individual patient. He concluded by explaining how patient education is the key to patient awareness concerning their rights and transparency of documents and how it will lead to enhanced awareness levels among the public.

The presentations by the panellists were followed by a question & answer session moderated by Mr. Sadanandan. In response to a question from the audience whether our health system is in line with the rights of older persons, Dr. Kakkar responded that the health system is in its initial phases of preparation. He emphasised the requirement for human resource training subjective to geriatric care. There is a need to reorient the attitudes of all health care providers towards not only the elderly but all patients who seek care, in general, and to treat them with dignity. The next remark was made by Mr. Sadanandan about the onerous process of executing the advance medical directives and whether there is any scope for further facilitating the same. Dr. Dhvani responded by sharing her experience of being at the Supreme Court, for a hearing on the modification of a judgement filed by the Indian Society of Critical Care Medicine and mentioned that the present directives are impractical especially for the elderly. She also mentioned that the Vidhi Legal Policy team has framed a model 'End of life care' draft bill, available on their website, which ensures certain safeguards and tries to make the existing ones less onerous.

Furthermore, Ms. Pallavi asked about facilitating care for the elderly at home, to which Mr. Sadanandan responded by highlighting the community-based palliative movement in which people are volunteering to be trained as outreach workers, backed by the health workers providing elderly care. In response to a question raised by an audience member, Mr. Sunil Nandraj pointed out, how can we use technology (apps, social media) to promote and provide information regarding elderly patients' rights and emphasised the importance of activism to push forth for one's rights as a patient seeking quality health care services.

Mr. Sadanandan concluded the event with an extremely compelling point that with the demographic shift, majority of the voters will become a part of the 60-plus population, and the issues related to ageing are going to get salient over time.

To conclude the webinar, Dr. Sonali Randhawa expressed heartfelt gratitude to the participants and the audience with a special thanks to Dr. Geeta Narayan for sharing her personal experience as a caregiver.

### **The Way Forward**

The webinar highlighted diverse issues that challenge exercising patients' rights in the elderly population. Mentioned below are some of the measures suggested during the webinar as a way forward for further action:

- Making policy changes to incorporate resources for training healthcare providers in geriatric care, increasing post-graduate seats for the specialisation, and changing the training curriculum was suggested to call forth an attitudinal change in the healthcare providers for the elderly.
- Creating awareness among people on the available legislative provisions which may ensure the elderly their rights, such as the Maintenance and Welfare of Parents and Senior Citizen Act, 2007, National Policy on the Healthcare of Elderly, Hindu Adoption and Maintenance Act, 1956, Section 125 of Code of Criminal Procedure etc.
- Harboring the digital sphere such as social media or specialised applications as grievance redressal platforms, and to promote and provide information regarding elderly patients' rights.
- Adopting an inter-sectoral approach while addressing the issue of patients' rights in the elderly like the inclusion of various fields such as medical, legal, urban planning and development to come forth with ideas and solutions for the betterment of the older population.
- Lastly, along with ensuring patients' rights such as autonomy, privacy and consent of the elderly in medical care institutions, attention needs to be paid to the aspect of home healthcare for the elderly.

### **The Panel**

1. Prof. (Dr.) Rakesh Kakkar (MBBS, MD)

Dr. Rakesh Kakkar is presently the Professor and Head of the Department (Community and Family Medicine) at AIIMS Bathinda. His key areas of interest are Geriatrics, Health Systems Research, Tuberculosis, and Non-communicable diseases.

2. Dr. Nisanth Menon (MBBS, MD)

Dr. Menon is presently appointed as a Consultant for Emergency Medicine, Amala Institute of Medical Sciences, Thrissur, Kerala. As a clinician involved in Geriatric care, and Trauma/Critical care, he is interested in collaborative research in the fields of Geriatrics, Family Medicine, Primary care, critical illness and Emergency Medicine.

3. Dr. Geeta Narayan

Doctorate in International Relations from the Jawaharlal Nehru University, Dr Geeta retired as a programme officer with the United Nations Population Fund, 3 years ago. She has more than 25 years of experience in the development sector.

4. Dr. Dhvani Mehta

Dr Dhvani has pursued her Bachelor of Legal Science & Bachelor of Legislative Law from the University of Mumbai and Bachelor of Civil Law, from the University of Oxford. She is a co-founder at Vidhi, Centre for Legal Policy.

5. Dr. Mohamed Khader Meeran

Dr. Meeran completed his M.B.B.S at Mahatma Gandhi Institute of Medical Sciences, Wardha. He is an independent researcher and avid activist for patients' rights. He has also authored a book titled '*Patient's Rights in India*'.

## Contact

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The webinar report 'Cries that have no tears-Understanding patients' rights in India' is developed by Health Systems Transformation Platform (HSTP) to share the record of proceedings.

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