

HEALTH AS A HUMAN RIGHT

Does human rights law work? This book engages in this heated debate through a detailed analysis of thirty years of the right to health – perhaps the most complex human right – in Brazil. Are Brazilians better off three decades after the enactment of the right to health in the 1988 Constitution? Has the flurry of litigation experienced in Brazil helped or harmed the majority of the population? This book offers an in-depth analysis of these complex and controversial questions grounded on a wealth of empirical data. The book covers the history of the recognition of health as a human right in the 1988 Constitution through the Sanitary Movement's campaign and the subsequent three decades of what Ferraz calls the politics and judicialisation of health. It challenges positions of both optimists and sceptics of human rights law and will be of interest to those looking for a more nuanced analysis.

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The Politics and Judicialisation of Health in Brazil

OCTÁVIO LUIZ MOTTA FERRAZ

King's College London



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to Franziska, Joe, Bia and Kefa

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PREFACE

The idea of a human right to health goes back at least to the constitution of the World Health Organization of 1946 and is now firmly established both in international and domestic laws. The International Covenant on Economic, Social and Cultural Rights, whose Article 12 recognises a ‘right of everyone to the enjoyment of the highest attainable standard of health’, has been ratified by 166 countries. An increasingly larger number of constitutions and other domestic laws also recognise the right to health in some form or another.¹ But does the right to health matter?

When we look at the reality of health conditions around the world, it remains appalling for a large proportion of individuals. According to the latest data from the yearly *World Health Statistics 2020*, 800 women still die every day of complications during pregnancy or childbirth, a rate of 211 per 100,000 live births, more than fifty times the rate in the most developed countries in the world. Approximately 144 million children under the age of five suffered from stunting in the world in 2019. Of the 38 million people living with HIV, 33 per cent (13 million) had no access to antiretroviral treatment (690,000 died in 2019 alone). Further, 400,000 people died of malaria, the vast majority of whom were children under the age of five, and 1.4 million people died of tuberculosis, a treatable and curable disease.²

Are we to conclude from this saddening state of affairs that the human right to health has been of little or no significance? Is the right to health

¹ G. Backman et al., ‘Health Systems and the Right to Health: An Assessment of 194 Countries’, (2008) 372 *Lancet*, 2047–2085; E. D. Kinney, B. A. Clark, ‘The Right to Health: Institutional Effects of Constitutional Provisions on Health Outcomes’, (2004) 37(2) *Cornell International Law Journal*, 285–355.

² For all data cited in this paragraph with the exception of data on HIV-AIDS, see World Health Organization, *World Health Statistics 2020*, available at <https://apps.who.int/iris/bitstream/handle/10665/332070/9789240005105-eng.pdf?ua=1>. For data on HIV-AIDS, see World Health Organization, ‘HIV/AIDS data and statistics’, available at www.who.int/hiv/data/en/. Both accessed 23 July 2020.

just another ‘phantom right’ that is ‘systematically marginalised’ alongside other social and economic rights?³

The effectiveness of human rights law, and law in general as a tool of progressive social change, has always been the subject of controversy. Highly visible and persistent gaps, such as the one just mentioned, between the ideal normative world of human rights law and the real world of human rights deficits has provided continuous fuel for this discussion. No one seems to seriously dispute the existence of such a discrepancy, but there is enormous variation of opinion in how it should be interpreted. Some see it as clear evidence of the failure of law, whereas others, pointing to empirical data showing actual decreases in that gap in some areas, view it in a more positive light, that is, as evidence that human rights law, despite limitations, actually works.

The debate is not academic. Human rights law is one among other potential means of advancing the moral values of dignity, freedom and equality that underpin the *moral* idea of human rights. Knowing if and how human rights law is effective is therefore immensely important for one’s choice of strategies for advancing those values, especially as time and resources are not unlimited. As Kathryn Sikkink has aptly and concisely put it, ‘we need to determine what works and what doesn’t work’, in order to ‘stop doing what doesn’t work and do more of what does’.⁴

This book aims to contribute to this debate through a more detailed and focused analysis than is often seen in the literature. Although it may be possible to draw some interesting insights about the effectiveness of human rights law *in general*, these insights will be necessarily limited due to inevitable and crucial variations that *specific human rights* are likely to manifest in *local contexts*. Human rights law forbidding torture, for instance, will likely have different effects in Honduras and in the United Kingdom, or in the Philippines and in Canada. Peculiar characteristics not only of the legal systems in these countries, but also of how they interact with many other political, social, economic and cultural factors will most certainly lead to different outcomes. The same is true, I suggest, of any right in the human rights law system. Thus, although the recent interest in the effectiveness of human rights law in general is

³ P. Alston, ‘Phantom Rights: The Systemic Marginalization of Economic and Social Rights’, Open Global Rights, 6 August 2016.

⁴ K. Sikkink, *Evidence for Hope: Making Human Rights Work in the 21st Century* (Princeton: Princeton University Press, 2017), 227.

welcome, it is important to conduct more fine-grained analysis of specific rights in local contexts if we really want to reach more robust and useful conclusions.⁵

It is in that spirit that I have delved into what is perhaps one of the most complex rights of the human rights law system, the *right to health*, and in one of the countries that has embraced that right most avidly from an early stage, Brazil. As Brazil has now undergone three decades of experience of a constitutionally recognised right to health, reinforced by the ratification of several international law treaties that include that right, it provides us with a very good case study to probe its effectiveness. Are Brazilians better off in the actual enjoyment of their moral right to health three decades after its legal recognition in the Constitution of 1988? If so, can we attribute any role in such improvements to the legal recognition of health as a human right?

The Brazilian experience is particularly interesting and relevant for testing effectiveness as it is one of the first and few countries outside the developed world to have expressly committed, through constitutional and ordinary law, to provide the whole of its large population (currently 210 million people) with health-related actions and services funded by general taxation as a ‘right of everyone and a duty of the state’ (art. 196 of the 1988 Constitution). It is also one of the countries where litigation grounded on the right to health (the so-called judicialisation of health) seems to have occurred more intensely, with hundreds of thousands of lawsuits having reached the Brazilian courts since the mid-1990s.

The balance of these first three decades of legal recognition of health as a human right in Brazil has been so far mixed and complex, but overall positive, or so I argue in this book. International and domestic human rights law have certainly helped to improve the profile of health in society’s and government’s agenda of priorities and, as a consequence, the actual health conditions of the Brazilian population. But there is still a long way to go and no guarantee that the right to health can provide the required fuel for the long journey ahead or that it is sufficiently resilient to withstand the pushbacks that are always lurking around and have increased in recent years. As I also argue, the constitutionalisation of the right to health has produced negative unintended consequences that need to be urgently addressed, namely, the appearance and growth of a type of litigation that does not advance the right to health on any plausible

⁵ To cite Sikkink again: ‘We must look at human rights issue by issue since it is impossible to make accurate general statements about all human rights.’ Ibid., 51.

interpretation of that right, but rather distorts health policies and enhances health inequities.

The lessons that can be drawn from three decades of the right to health in Brazil are therefore neither entirely positive nor wholly negative, as many tend to claim in our age of heightened polarisation. My hope is that this book's detailed study and arguments may help to improve our understanding of the complex role of health as a human right, as well as human rights in general, in the advancement of people's well-being.

I started to think about the idea of health as a human right in the late 1980s due to a combination of biographical factors. During the day, I was pursuing a law degree at the University of São Paulo in the first cohort of students to study for the whole degree under the new Constitution of 1988, the 'Citizen Constitution', so nicknamed for its lavish chapter on human rights (or fundamental rights as they are called in the Constitution). Among these rights, there was of course the right to health, recognised in Articles 6 and 196 of the text. In the evening, back at my family home, my father Fernando would often complain about the significant lack of resources under which he had to carry out his work in the public hospital of the Federal University of São Paulo. As a neurosurgeon working under the newly created National Health System (SUS), he would often tell us about operations cancelled at the last minute, with the patient already in the operation theatre, for lack of some essential surgical material, medication or equipment abundantly available in the private system. He would also complain about materials of inferior quality breaking in the middle of operations, making his work much harder and putting the lives of his patients at risk. Employees of our middle-class residential block (cleaners, porters) and soon of the whole neighbourhood would often knock on our door to see if my father could help them or some relative to be admitted to his overly subscribed public hospital. Surely, I thought then, the law, that is, the new Constitution, can be used by lawyers to do something about all these cases! But I don't recall my father ever mentioning a single case of litigation in those five early years of the Constitution when I was still doing my law degree.

Things have obviously changed dramatically since then. The public health system, though still underfunded and inefficient, has improved significantly. Litigation grounded on the right to health has become a common practice. According to the latest numbers that I present and

discuss in this book, more than 100,000 cases are now reaching the courts every year to claim that right. Whether and how these two relate to each other is a matter of fierce controversy that I discuss at length in this book. I regret that my father is not around any longer to witness and contribute to (as I am sure he would) my effort to shed light on this complex and controversial issue. But I feel lucky to have had him as a close interlocutor in those important formative initial years of my thinking about health as a human right.

I was also lucky enough to have encountered, often serendipitously, a large number of knowledgeable and generous people during my decade-long studies that culminated with this book. My early collaboration with pharmacologist and health economist Fabiola Sulpino Vieira, which resulted in our joint article ‘The Right to Health, Scarce Resources, and Equity: Inherent Risks in the Predominant Legal Interpretation’ (2009) – my very first on the topic – provided me with a solid foundation on which I built all my later work. I am grateful to Fabiola for initiating me in the complexities of public health systems and saving me from the arrogant mistakes I was bound to make had I remained isolated in the ivory tower of the legal world. I am also grateful to her for providing always timely and insightful advice on literature and data during the writing of this book.

Alicia Yamin, after reading my piece with Fabiola, gave me the first opportunity to develop my initial research further and make my findings available to a broad international audience. Her invitation, together with Siri Gloppen, for me to become a part of what I call in this book the Harvard–Bergen project – culminating with the book *Litigating Health Rights: Can Courts Bring More Justice to Health?* (2011), in which I author the Brazil chapter – was a crucial step on the path towards this book. The discussions we had during that project in Buenos Aires, Cambridge (MA) and Bergen were the ideal environment for me to test and develop my ideas. I am deeply grateful to Siri and Alicia for that opportunity, as it was during that project that I met some of the people who would become important interlocutors and collaborators and whose influence can be easily identified in the pages of this book. It was then that I met Roberto Gargarella, Varun Gauri, Dan Brinks, Bruce Wilson, Paola Bergallo, Oscar Parra-Vera, Camila Gianella, Ottar Møestad, Lise Rakner, Ole Frithjof Norheim, Cesar Rodríguez-Garavito and Malcom Langford, all of whom, during the last decade, have proven invaluable interlocutors (and often critics), without whom my ideas would not have received the probing criticism that is so vital in any academic endeavour.

Another international network from which I benefited immensely in the development of my views was the International Social and Economic Rights Project (iSERP), led by Lucy Williams and Karl Klare from Northeastern University. I am grateful to them and all the participants for invaluable discussions in workshops in Italy and India.

Closer to home (both of them), I am indebted to several people who have contributed in different ways to the final product the readers now have in their hands. In Brazil, I have had the privilege of presenting and discussing many of the ideas, arguments and data of this book on several formal and informal occasions, with Conrado Hubner Mendes, Diogo Rosenthal Coutinho, Virgílio Afonso da Silva, Jean Paul Veiga da Rocha, Marcos Paulo Veríssimo, Oscar Vilhena Vieira, Ronaldo Porto Macedo, Diego Werneck Arguelles, Natália Pires, Fernanda Terrazas, Caio Mario Pereira Neto, Marta Arretche, Marcelo Medeiros, Teori Zavascki, Mario Schapiro, Marta Machado, Ana Luiza Chieffi, Ana Paula de Barcellos and Luciana Gross Cunha. I am particularly grateful to Marta Arretche and Marcos Paulo de Lucca Silveira for helping me organise the workshop ‘Thirty Years of the Right to Health in Brazil’ at the University of São Paulo in September 2018, where I learned a lot from all the participants: Lígia Bahia, Mário César Scheffer, Luis Eugenio Portela Fernandes de Souza, Carlos Octavio Ocké-Reis, Vera Lúcia Edais Pepe, Ana Luiza Chieffi, Fabiola Sulpino Vieira, Daniel Wang, Eduardo Levcovitz, Celia Maria de Almeida and Lenir Santos. For generous help with data and conversations with those who work on the front line of the Brazilian health and judicial systems, I am grateful to Alethele de Oliveira Santos, Paula Sue Facundo de Siqueira, Alberto Beltrame, Reynaldo Mapelli Jr, Luiz Duarte de Oliveira, João Pedro Gebran Neto, Gabriela Moreira de Azevedo Soares, Erik Jennings Simões and Maria Célia Delduque. For first-hand accounts by claimants who found themselves litigating the right to health on behalf of their children in rather challenging situations, I thank Lindamar Lima and Luiz Eduardo Serafim. For an invaluable opportunity to spend one week in the Secretariat of Health of the State of Bahia with access to data and staff dealing with litigation in 2015, I am grateful to Magnus Lindelow and David Oliveira de Souza from the World Bank, as well as Zaida de Melo from the Secretariat.

In the United Kingdom, I have had the incredible luck to live and work very near two leading academics on the topic of my book. I am grateful to Jeff King for several years of continuous conversations on the topic and, in particular, for his careful reading of and insightful comments on an earlier draft of what became Chapter 9 of the book. His early support of

my, then, less widespread and less well-received critical view of judicialisation was an important source of encouragement. To Daniel Wang, once my research assistant and now a rising star in the field, I also owe years of conversations and comments on Chapters 5 and 9 of the book. Before moving to King's College, at Warwick University, I benefited immensely from discussions and comments from Victor Tadros, James Harrison, Matthew Clayton, Andrew Williams (the philosopher), Andrew Williams (the lawyer), Ed Page, George Meszaros, William O'Brian, Sharifah Sekalala and Abby Kendrick. For incisive comments on some of the arguments of the book presented in the London Bioethics Colloquium in 2018, I am grateful to Jonathan Montgomery, Annette Rid, John Tasioulas, James Wilson, Benedict Rumboldt and Sridhar Venkatapuram. For help with references I am grateful to Felipe Tirado. At Cambridge University Press, I thank Tom Randall, Gemma Smith and Jane Bowbrick for steering the editorial process so smoothly and Trent Hancock for superb copyediting.

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Note on the cover image: Choosing the cover image of my book was not an easy task. Long searches during the writing were fruitless until I came across the magnificent book *Mais Médicos*, by the accomplished Brazilian photographer Araquém Alcântara. Araquém travelled across Brazil to

photograph the now extinct federal government programme Mais Médicos (More Doctors), which took primary care to the farthest and poorest corners of Brazil, often for the first time in history. The picture on the cover shows Cuban doctor Abel del Toro Pereza caring for a girl's broken arm inside the clinic-boat, which used to visit her village, Novo Airão, at the heart of the Amazon, once every three months. I am deeply honoured by Araquém's enthusiastic acceptance to associate his dazing picture with my work. It depicts perfectly, in my view, the ambivalence evoked by health as a human right that I describe in this book.