The Right to Remedies: On Human Rights Critiques and Peoples' Recourses

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This post is part of a symposium on Amy Kapczynski's essay <u>"The Right to Medicines in an Age of</u> <u>Neoliberalism."</u> All contributions to the symposium can be found <u>here</u>.

Across the Americas, peoples (let's keep them multiple) live in exhausted worlds. Worlds on the edge of autocracy, of financial collapse, of infrastructural breakdown and environmental tipping points—mediated by extreme populism and state and corporate efforts to dismantle piecemeal, though meaningful, agendas of socioeconomic rights. Violence and deadly health disparities are persistent realities that, time and again, are couched by experts in a rhetoric of recovery even as conditions stagnate or worsen. Meanwhile, against the backdrop of alarming political shifts, scholars are wrestling with the fact that their critiques took democratic institutions and human rights advancements for granted. All kinds of shortsighted generalizations, wishful thinking, and selective political agendas have made social analysis ethnographically out of touch, if not irresponsibly immaterial.

Amy Kapczynski's thought-provoking essay "The Right to Medicines in an Age of Neoliberalism" speaks to her commitment to be critically relevant when conventional wisdoms are up for grabs and to help "build a human rights adequate to our times."[1] Kapczynski's essay comes amidst, and responds to, a wave of handwringing about the power of human rights' discourse and practice to advance a progressive politics and to support radical change. This anxiety over human rights' relevance and potency is to be expected in the face of mounting challenges and amidst the marginalization of human rights among even Western nations that once championed them. Kapczynski provides an innovative take on right-to-health litigation in South America as she seeks to explore if a more progressive human rights movement exists or could exist, one that confronts neoliberalism instead of sitting on the sidelines as a bystander. Focusing on the right to health and the issue of increasing cases of lawsuits seeking access to medicines (or "judicialization"), Kapczynski exhorts human rights advocates not to "merely mainstream or judicialize socioeconomic rights, but take on questions of political economy."[2]

In closely reading Kapczynski's provocative essay and in supporting her call for a "more ambitious vision of justice," three key points jump out for deeper elaboration:

- While Kapczynski provides a thorough summary of the literature around the "judicialization of medicines" in Brazil and Colombia, the essay barely addresses the specific "questions of political economy" she urges attention to and which underlie how the judicialization of health emerged in each.[3]
- After citing Philip Alston on the "polycentric nature of the human rights enterprise," Kapczynski presents a human rights movement that is oddly narrow, leaving out the perspective of many who are engaged in the effort to foster a "more fair and egalitarian order" or simply to realize their individual rights and demand accountable governments.[4]
- As Kapczynski takes to heart critiques of the human rights movement's limited horizons and imbrication in the "prevailing market order," she also seeks to harness glimmers of human rights' alternative "potential ... particularly at the periphery."[5] Yet, in this emerging mode of critique from "marginal places," the global scale of analysis remains dominant, glossing over localized, heterogeneous counterforces that create their own conditions of political futurity.[6]

After reviewing a series of studies about the judicialization of medicines, Kapczynski concludes that "at least in Latin America" the direct impact of health litigation "has been to accentuate rather than ameliorate health inequities."[7] We disagree. The limitations in available data, along with the heterogeneity of the phenomenon, make such a sweeping judgment suspect.[8] Importantly (and often left out from debates on judicialization), Kapczynski does note the evidence of judicialization's potential indirect effects, which include improved health care delivery, legal empowerment, and social mobilization. In the context of what has been at times a polarized and overly narrow debate, broadening the understanding of judicialization beyond cases, medicines, and cost is analytically helpful.[9]

This said, Kapczynski's larger concern in the essay is not trying to settle the score on the pros and cons of the judicialization of health, but rather to examine whether human rights scholars and advocates are being played for fools. That is, focusing on the rules of one game (equitable access to courts to get medicines) when more powerful players are changing the pharmaceutical playing field (rewriting intellectual property rights, for example). Worse, Kapczynski claims that "this right to medicines [pursued through judicialization], in short, reflects and even intensifies a neoliberal approach to medicines. It mandates discrete individual relief, but rarely sees, much less disrupts, the underlying logics and structures that help produce radical health inequities."[10]

But where is the question of political economy and who exactly is Kapczynski imagining is behind judicialization?

Places and peoples matter. In our research in southern Brazil, judicialization was driven by older, poor patients with chronic diseases.[11] Surely, this is not who Kapczynski claims is driving, intensifying even, a neoliberal approach to medicines. Patients sought legal counsel

mostly from public defenders who filed lawsuits for medicines claiming that the public health system that guaranteed these patient-citizens' right to health was not living up to its obligation. As one public defender from Porto Alegre put it, "When there are no defined public policies, or when they exist but are not executed, or when policies are not in touch with new maladies and medical advancements . . . what do we have? We have a diseased citizen. Her right to health has been profoundly injured by public power."[12] Overwhelmingly, progressive local judges agree and rule in favor of plaintiffs.

Kapczynski seems to take access to medicines cases as an impediment to courts acting to "actively encourage or even require states to intervene to promote a more just political economy."[13] Yet, in Brazil and elsewhere courts have considered such steps and chosen not to act.[14] The reasons for this non-action are varied and it would be a stretch to suggest that this is because individual cases impeded such an intervention. Alternatively, Kapczynski suggests that legislatures can "work around courts to create foundations for more equitable health systems."[15] The implication is that human rights activists should focus more on court cases that seek structural changes to the political economy of medicines or on lobbying legislative bodies to take such steps as reforming patent laws and imposing regulations on price. So, what is the rationale underpinning this either/or approach? The volume of court cases is itself pressure on both the judiciary and the legislature to adopt structural reforms. As yet, that pressure has been insufficient to match the power of lobbyists and special interests who oppose such reforms, but it may not always be so. While it may be more strategic in the long-term to fight for patent law reforms and hope for timely and effective implementation, those putting forward individual cases seeking medicines actually embody structural vulnerabilities and speak to the urgent need of remedying health systems. The immediate need for human rights advocacy for multitudes of individual patients is clear.

A right to health that transcends medicines and individual demands and that takes on the political economy of pharmaceuticals is undeniably important. Yet, in her critique Kapczynski does not actually use her case studies in the global south to search for deeper specificity about neoliberal workings and democratization processes, the privatization of health care, and the impact of present-day capitalism on social life. In the two case studies of right to medicines litigation presented (Brazil and Colombia), she too easily assumes political equivalences despite significant differences. Further, Kapcynski does not question her own theorizing of the all-encompassing and homogenizing force of neoliberalism.

In Brazil, judicialization emerged in the mid-1990s, at the time of the country's successful universalization of access to treatment for HIV and AIDS and against the backdrop of an increasingly "activist state" and an ailing constitutionally mandated universal health care system.[16] From this localized perspective, judicialization is a dynamic and critical dimension of democratic life, and responsive to the structure of differing responsibilities for medicines at the municipal, state, and federal levels.[17] In neighboring Colombia, where

the government in the early 1990s established individual private health insurance systems under the guidance of international financial institutions, such as the World Bank and International Monetary Fund, the courts soon became "an essential 'escape valve' in a health system that was incapable of regulating itself."[18] There, judicialization speaks to a progressive judiciary's efforts to counter, within limits, the realpolitik of privatization.[19] Kapczynski's analysis overlooks, in both instances, the patients and families who act in often desperate attempts to access lifesaving medicines and care—that is, to demand that their right to health, life, and dignity is realized. A similar case can be made for the importance of understanding the particularities of political economy—not as an advocacy strategy but as a critical analytical perspective—when examining the differences between Brazil and South Africa in the context of implementing a right to food while pursuing free market economic policies.[20]

Like Kapczynski, we are academics who care deeply about human rights, and we share Kapczynski's frustration with thousands and thousands of lawsuits seeking access to medicines, granted by courts (often under specific recognition of the right to health) and with little change to the underlying political economy. But we also worry about critiques that too easily de-dialectize peoples, caricaturizing them as merely self-interested homo economicus producing false social knowledge. We are in favor of public health systems that engage local populations and can be held accountable to them, and that are transparent, deliver on right to health obligations, seek appropriate reforms to patent laws and invest in innovative approaches to R&D costs and pricing. The reality of judicialization we chronicled in southern Brazil is not one other countries should seek to emulate: often medicines granted by courts were never fulfilled by the government, leaving patients with a legal victory, but no medicines. Or courts were slow to act, while patients suffered waiting for a resolution. We did document some responsiveness by the government to litigation though, with some of the most sought after medicines not on drug formularies later officially included—theoretically increasing the likelihood of availability.[21] Within Brazil, the sentiment that there "must be a better way" is common, but the answer (by some parts of the government and some scholars) has often been that the better way is to eliminate access to justice and hope that pharmaceutical delivery systems improve with "expert" advisory panels or simply on their own.[22] That view seems naïve, if not dangerous. Local accountability may not be efficient but it is a critical part of a broader progressive rights campaign. There is value in answering claims of an "end of human rights" with a cry of "we're not dead yet."[23]

Kapczynski is right that organizations such as Human Rights Watch (for which Amon worked for a decade) have spent little time working on disrupting the neoliberal order and challenging intellectual property regimes.[24] However, this is in part the nature of the "polycentric nature of the human rights enterprise," and missing from Kapczynski's analysis is an area where human rights activists and organizations like Human Rights Watch have put in a lot of effort: addressing access to medicines for populations systematically

discriminated against, such as migrants, prisoners, persons who use drugs, and others. Another area of focus is the availability of evidence-based medicines for substance abuse treatment and palliative care—unavailable or poorly available in many countries.[25] This work may not represent a blow to the neoliberal political order but it helps to strengthen the right to health and human rights more broadly. This work is not, in our view, merely "nipping at the heels of the neoliberal giant," but recognizing the fundamental importance of the state and its right to health obligations. Without establishing these obligations and institutionally sustaining advancements (albeit limited) in socioeconomic rights, pressing for states to recognize their duty to challenge medicine patents and negotiate pricing seems fanciful at best.

Philip Alston reminds us that "we should be very wary of any single account that purports to have found the answer to the puzzle and to have invalidated alternative interpretations. The human rights enterprise is intrinsically complex and multifaceted. Its origins are to be found in different and multiple sites, and they cannot usefully be traced back to any single source or through examining the evolution of a single theme, process, or institution."[26] Thus, as critics spar about the failure of human rights advocates to effectively counter neoliberalism, on the ground people in Brazil and in other democracies (many now witnessing a fast dismantling of liberal institutions) continue to find some power in claiming their rights, in seeking redress in the courts and demanding that the constitutional guarantee of a right to health is actualized in pharmacies and hospitals.[27] The polycentric nature of human rights movements requires more complex theorizing about its failures and acknowledgement of diverse strategies to achieve a common goal, not to mention a people-centered critical perspective. One could thus ask: What kinds of counterideologies and counterconducts that do not rest on an imaginary of human rights outside of capitalism might be at work? How can we make sense of the ways people are mobilizing in the present, making demands in the courts and on the streets or online for equality, protection, and workable infrastructures, while forging tenuous and often subversive links between themselves, the state, and the therapeutic marketplace?

Kapczynski ends her essay stating that "a revised human rights...must...be attentive to the need to build a broader politics, and structures of political accountability that are needed to achieve a more ambitious vision of justice at a global scale."[28] We agree. But human rights must also be attentive to an ambitious vision of justice at a local scale, and that may mean a focus on accountability within existing political and economic systems and sustaining hard-fought basic rights. Both are urgently necessary.

NOTES

[1] Amy Kapczynski, "The Right to Medicines in an Age of Neoliberalism," *Humanity* 10, no. 1 (Spring 2019): 95.

[2] Ibid., 95.

[<u>3]</u> Ibid., 95.

[<u>4]</u> lbid., 83 and 80.

[<u>5]</u> Ibid, 79.

[<u>6]</u> Ibid, 95.

[<u>7]</u> Ibid, 80.

[8] See João Biehl et al., "Between the Court and the Clinic: Lawsuits for Medicines and the Right to Health in Brazil," *Health & Human Rights* 14, no. 1 (June 2012): 36–52; João Biehl, Mariana P. Socal, and Joseph J. Amon, "The Judicialization of Health and the Quest for State Accountability: Evidence from 1,262 Lawsuits for Access to Medicines in Southern Brazil," *Health & Human Rights* 18, no. 1 (June 2016): 209–20; João Biehl et al., "The Challenging Nature of Gathering Evidence and Analyzing the Judicialization of Health in Brazil," *Cadernos de Saúde Pública*, 32, no. 6 (June 2016): e00086315.

[9] João Biehl et al., "Judicialization 2.0: Understanding Right-to-health Litigation in Real Time," *Global Public Health* 14, no. 2 (February 2019): 190–9.

[10] Kapczynski, "The Right to Medicines in an Age of Neoliberalism," 81.

[11] João Biehl, "The Judicialization of Biopolitics: Claiming the Right to Pharmaceuticals in Brazilian Courts," *American Ethnologist* 40, no. 3 (August 2013): 419–36; João Biehl, "The Postneoliberal Fabulation of Power: On Statecraft, Precarious Infrastructures, and Public Mobilization in Brazil," *American Ethnologist* 43, no. 3 (August 2016): 437–50; João Biehl, "Patient-Citizen-Consumers: The Judicialization of Health and the Metamorphosis of Biopolitics," *Revista Lua Nova* 98 (May/August 2016): 77–105; João Biehl et al., "Between the Court and the Clinic," 36–52; João Biehl, Mariana P. Socal, Joseph J. Amon, "The Judicialization of Health and the Quest for State Accountability: Evidence from 1,262 lawsuits for Access to Medicines in Southern Brazil," 209–20.

[12] Biehl, "The Judicialization of Biopolitics," 423.

[13] Kapczynski, "The Right to Medicines in an Age of Neoliberalism," 81.

[14] See Tiago de Lima Marinho. "Direito à saúde e o Supremo Tribunal Federal: mudanças de posicionamento quanto ao fornecimento de medicamentos." Âmbito Jurídico, Rio Grande, XVI 118 (2013), <u>http://ambito-juridico.com.br/site/?</u>

n_link=revista_artigos_leitura&artigo_id=13813&revista_caderno=9 (accessed September 25, 2019)

[15] Kapczynski, "The Right to Medicines in an Age of Neoliberalism," 82.

[16] João Biehl, "The Activist State: Global Pharmaceuticals, AIDS, and Citizenship in Brazil," *Social Text* 22, no. 3 (Fall 2004): 105–32; João Biehl, *Will to Live: AIDS Therapies and the Politics of Survival* (Princeton: Princeton University Press, 2007); João Biehl, "Pharmaceuticalization: AIDS Treatment and Global Health Politics," *Anthropological Quarterly* 80, no. 4 (Fall 2007): 1083–126.

[<u>17</u>] João Biehl, Mariana P. Socal, Joseph J. Amon, "On the Heterogeneity and Politics of the Judicialization of Health in Brazil," *Health and Human Rights* 18, no. 2 (December 2016): 269.

[18] Luz Stella Alvarez, J. Warren Salmon, and Dan Swartzman, "The Colombian Health Insurance System and its Effect on Access to Health Care," *International Journal of Health Services* 41, no. 2 (2011): 355–70; Alicia Ely Yamin and Oscar Parra-Vera, "Judicial Protection of the Right to Health in Colombia: From Social Demands to Individual Claims to Public Debates," *Hastings International and Comparative Law Review* 33 (2010): 431.

[19] César Ernesto Abadía Barrero, "Neoliberal Justice and the Transformation of the Moral: The Privatization of the Right to Health Care in Colombia," *Medical Anthropology Quarterly* 30, no. 1 (March 2016): 62–79.

[20] Sakiko Fukuda-Parr, "Developmental States, Neoliberalism, and the Right to Food: Brazil and South Africa," in *Economic and Social Rights in a Neoliberal World*, ed. Gillian MacNaughton and Diane F. Frey (Cambridge: Cambridge University Press, 2018), 217.

[21] João Biehl, Mariana P. Socal, Joseph J. Amon, "On the Heterogeneity and Politics of the Judicialization of Health in Brazil," 269.

[22] Ibid.

[23] See David Rieff, "The End of Human Rights? Learning from the Failure of the Responsibility to Protect and the International Criminal Court," *Foreign Policy* (April 2018); See also Graham Chapman et al, "*Monty Python and the Holy Grail*" (movie). Clip available at: <u>https://www.youtube.com/watch?v=Jdf5EXo6I68</u> (accessed September 25, 2019).

[24] The few exceptions include: Human Rights Watch "*The FTAA, Access to HIV/AIDS Treatment, and Human Rights: A Human Rights Watch Briefing Paper*" (New York: Human Rights Watch, October 28, 2002),<u>https://www.hrw.org/legacy/press/2002/10/ftaa1029-bck.htm</u> (accessed September 25, 2019); Human Rights Watch, "*Q&A: The Trans-Pacific Partnership*" (New York: Human Rights Watch, January 12,

2016),<u>https://www.hrw.org/news/2016/01/12/qa-trans-pacific-partnership</u> (accessed September 25, 2019).

[25] Human Rights Watch, *"Rehabilitation Required: Russia's Human Rights Obligation to Provide Evidence-based Drug Dependence Treatment"* (New York: Human Rights Watch, November 2007); Human Rights Watch, *"Barred From Treatment: Punishment of Drug Dependent Prisoners in New York State"* (New York: Human Rights Watch, March 2009); Joseph J. Amon et al. "Compulsory Drug Detention Centers in China, Cambodia, Vietnam and Lao PDR: Health and Human Rights Abuses," *Health and Human Rights Journal* 15, no. 2 (December 2013): 124–37; Diederik Lohman, Rebecca Schleifer, Joseph J. Amon, "Access to Pain Treatment as a Human Right," *BMC Medicine* 8, no. 1 (January 2010): 8.

[26] Philip Alston, "Does the Past Matter? On the Origins of Human Rights," *Harvard Law Review* 126, no. 7 (May 2013): 2078.

[27] Naomi Klein, *The Shock Doctrine: The Rise of Disaster Capitalism* (New York: Picador, 2007); Susan Marks, "Human Rights and Root Causes," *Modern Law Review* 74, no. 1 (January 2011); Samuel Moyn, *Not Enough: Human Rights in an Unequal World* (Cambridge, Mass.: Harvard University Press, 2018).

[28] Kapczynski, "The Right to Medicines in an Age of Neoliberalism," 95.