

Autonomous Health Movements: Criminalization, De-Medicalization, and Community-Based Direct Action

NAOMI BRAINE

Abstract

This paper proposes the concept of autonomous health movements, drawing on an analysis of harm reduction in the United States and self-managed abortion globally. Harm reduction and self-managed abortion appear in the professional literature largely as evidenced-based public health strategies, more than as social movements. However, each began at the margins of the law as a form of direct action developed by activists anchored in social justice movements and working in community contexts independent of both state and institutional control according to a human rights perspective of bodily integrity and autonomy. An analysis of the history and dynamics of harm reduction and self-managed abortion as social movements underlies the proposed framework of autonomous health movements, and additional potential examples of such movements are identified. The framework of autonomous health movements opens up new pathways for thinking about the development of autonomous, community-based health strategies under conditions of marginalization and criminalization.

NAOMI BRAINE, PhD, is a sociologist and Professor at Brooklyn College, City University of New York, USA.

Please address correspondence to the author. Email: nbraine@brooklyn.cuny.edu.

Competing interests: None declared.

Copyright © 2020 Braine. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

Health and health care have increasingly been a locus of social movement action in the late 20th and early 21st centuries, often mobilizing a language of human rights. The health social movements that have been most visible since the 1980s have organized around particular disease constituencies and access to care, and have forced significant changes in institutional practices.¹ However, during this same time period, activists working in domains not generally considered “health social movements” have engaged in direct action to create de-medicalized, community-based practices with sufficient reach and effectiveness to visibly affect health statistics and receive scientific validation.² This is particularly noteworthy since this work has been done in highly stigmatized, often criminalized, contexts—locations where autonomous movements, based outside political parties and other institutional systems, may be more comfortable than service providers.³ While these movements demand policy change, their core practices enable autonomy and self-determination for marginalized populations regardless of state or institutional action. These movements challenge us to recognize the role of social movements and direct action in the creation of autonomous community-based practices that have transformed health risks in highly marginalized contexts.

This paper will analyze harm reduction (HR) in the United States and self-managed medication abortion (SMA), primarily in Latin America, as forms of collective action that emerge from larger social justice movements to respond to particular health issues in marginalized, criminalized contexts. Organized action around SMA is clearly anchored within feminist movements, and there is a globally evolving set of shared practices to assist women with the use of medication for abortion in contexts of limited access.⁴ HR in the United States, specifically syringe exchange and overdose prevention, initially emerged from within social movements that were not primarily concerned with drug use, and went on to develop multiple practices anchored in drug user autonomy and critical analyses of medical institutions and criminalization.⁵ In both cases, activists developed practices that were

simultaneously radical and pragmatic to empower people to autonomously manage their health in contexts where the primary risks result from stigma and law. The work of these movements has entered the literature as evidence-based public health, often with little attention to the processes through which activists developed community-centered practices anchored in the right to bodily autonomy and self-determination. I will use the common elements of these two movements to propose the concept of autonomous health movements as a framework for thinking about certain forms of collective action at the intersection of criminalization, health, and human rights. I believe that this theoretical framework has the potential to shift our thinking about forms of direct action within social movements and the development of human rights-centered, evidenced-based public health in criminalized contexts.

It is important to note that the phrase “harm reduction” has been adapted and used across a range of locations, including by medical providers who support women with SMA under highly restrictive conditions.⁶ While this reflects the power of the ideas and practices of activists globally who coined the term to describe street-based work with illicit drug users—activists whose work is central to this paper—the use of the term within more institutional settings creates linguistic ambiguities. For the purposes of this paper, HR (capitalized) will be used to refer to the US movement that emerged in the late 1980s and early 1990s with regard to users of illicit drugs. In some countries, drug-related harm reduction was supported by the state as a public health measure, which would affect the dynamics discussed here. For that reason, the analysis in this paper will focus on HR in the United States.

Overview of the literature on HR and SMA

The majority of the research done with HR and SMA has focused on evaluating the effectiveness of the practices as health interventions, rather than on the social organization of the work. This research has been done largely by scientists allied with or actively involved in the movement who collaborate

with (other) activists to validate movement practices, understand the needs and experiences of people who access the practice, or otherwise answer questions of shared interest. The largely epidemiological focus of this work examines the experiences of people who engage with the practice, whether drug users at syringe exchanges or people who contact an abortion hotline, and leaves implicit how these practices were developed by activists under conditions that range from provisional legality to outright clandestinity.⁷ I have participated in this at times; a paper describing the drug user networks that distributed sterile needles from an underground syringe exchange addressed an issue of core interest to the collective running the exchange as well as to me as a sociologist funded by the National Institutes of Health, without substantive discussion of the exchange itself as a long-term activist collective engaged in clandestine action.⁸ The underlying disciplinary and methodological structures of research tend to direct attention to *either* the work of activists *or* the experience of persons who engage with the movement practice.⁹ The predominant focus on the latter creates valuable literatures that scientifically validate social movement-generated practices and enable both political and medical discourses about evidenced-based medicine, yet the work of creating and maintaining these practices remains understudied. While disciplinary and methodological explanations may seem limited, the public health literature recognizes the role of movement organizations, and activists make no efforts to hide their work. It is worth noting that the one report I am aware of that directly connects the experiences of both SMA activists and women seeking abortions was self-published by an activist collective (<https://womenhelp.org/en/page/1103/el-aborto-con-medicamentos-en-el-segundo-trimestre-de-embarazo>).

The relative lack of research on HR and SMA as social movements is particularly noticeable given the identities and self-representations of activists and collectives themselves. Organizations providing education and assistance with SMA unambiguously represent themselves as feminist, including lesbian-feminist, on websites

(for example, <https://socorristasenred.org>) and in printed materials, and are referenced as such in the public health literature.¹⁰ In Latin America, SMA collectives integrate feminist political education within workshops and materials about the safe use of medication for abortion.¹¹ In the United States, syringe exchange emerged largely as an outgrowth of AIDS activist and anarchist formations, and a visible social movement identity continues today among some HR workers and organizations despite an overall shift to nongovernmental service organizations.¹² The US-based National Harm Reduction Coalition's description of the principles of harm reduction states, "Harm reduction is a set of practical strategies and ideas aimed at reducing negative consequences associated with drug use. Harm Reduction is also a movement for social justice built on a belief in, and respect for, the rights of people who use drugs."¹³ This statement brings together the dual nature of both HR and SMA as movements rooted in struggles for justice that develop pragmatic, autonomous practices that enhance self-determination and address stigmatized, often criminalized, health issues.

For this analysis, I will draw on the existing literature on HR and SMA, supplemented by my own observations and experiences from decades of both activism and research in street-based HR. The social movement literature on HR is even more limited than that on SMA, and my analysis is based in part on my own engagement with the movement. My involvement in HR ranges from membership in an unauthorized needle exchange collective to overseeing research funded by the National Institutes of Health, and includes attendance at the majority of US harm reduction conferences and syringe exchange conventions over the past 30 years. My activist and professional history does not constitute research data, but I draw on it to construct the analytical arguments made in this paper. The organizational structure of HR in the United States has largely evolved into a system of nongovernmental service organizations in ways that expand access but limit the potential for social movement-focused research.

This paper presents an analysis that emerges from thinking across movements; a detailed de-

scription of either HR or SMA is beyond the scope of this paper. However, I will provide a brief overview of each movement as a basis for an analysis of their commonalities and to develop the concept of autonomous health movements. In the final sections of the paper, I will briefly suggest some other examples of autonomous health movements as part of a discussion of the utility of the framework for thinking about social movements, public health, marginalization, and human rights.

Harm reduction

While HR is often understood in terms of particular forms of outreach to and services for people who use drugs, as a movement it is anchored in an analysis of the social and political marginalization of people who use drugs and their communities. HR emerged as a community-centered response to HIV among people who inject drugs, initially focused on providing sterile injection equipment as a way to prevent the spread of HIV. The first documented needle exchanges were created by the *junkiebonden*, or drug user unions, in the Netherlands in the early 1980s in response to hepatitis B, and the strategy spread globally in response to the AIDS epidemic.¹⁴ In the United States, needle exchanges were created largely by HIV/AIDS activists who had a wide range of personal drug use histories and practices but were not, for the most part, organizing around identities as people who use drugs.¹⁵ While explicit human rights language is rare among US activists, a commitment to self-determination was central to evolving HR practices, at times framed as “nothing about us without us” (a phrase shared with disability rights activists).

The second HR practice to emerge on a wide scale was overdose prevention, which began in the late 1990s and quickly became more broadly accepted in the United States than syringe exchange. Naloxone is a medication—long used by emergency medical services—that interrupts the action of opiate drugs and thereby reverses an overdose. Overdose prevention involves distributing naloxone to people who use drugs and community members, along with a brief training on how to

recognize an overdose and use the medication to interrupt it.¹⁶ The practice began when a Chicago syringe exchange program started to hand out naloxone to program participants and teach them how to use it; this practice then spread to other cities.¹⁷ Initially, providing naloxone in this manner was a violation of prescription laws, although this may not have been widely known outside core activist networks.

The emergence and spread of HIV coincided with the escalation of the United States’ War on Drugs, creating a context of extreme criminalization within which activists created the first syringe exchanges.¹⁸ It is important to note that the War on Drugs—and US drug policy overall—functions primarily as a policy tool for racialized criminalization, targeting African American and other racially marginalized communities more than drug users per se.¹⁹ This entrenched political context for drug law amplified the stigma of HIV/AIDS and the centrality of criminalization over public health, drawing on long-standing representations of drug users as dangerous residents of urban ghettos. In US cities, the presence of a syringe exchange in the 1990s was more strongly associated with AIDS activism and the prevalence of HIV in LGBT communities than with measures of drug use or HIV prevalence among people who inject drugs.²⁰ This highlights the role of larger movements in the genesis of syringe exchange and HR, as the severity of the local epidemic among people who use drugs does not appear to be the driving factor. It also draws attention to the invisibility of HR as a social movement, despite its connection to forms of HIV/AIDS activism that have been central to the study of health social movements.

It is difficult to overstate the radical nature of HR in the United States in the late 1980s and the 1990s. A relatively objective measure of this can be seen in the extended restrictions on federal funding for syringe exchange programs despite a near endless succession of studies demonstrating their effectiveness as a public health strategy.²¹ The radical stance of HR as an emerging social movement was to develop a community practice centered on people who use drugs as active agents of public

health, independent of state control or institutional supervision. Syringe exchange positions injection drug users as people who can and will organize their use of (illicit) drugs in ways that effectively limit the spread of blood-borne disease. Overdose prevention again situates people who use drugs and members of their communities as valued actors who can recognize and effectively intervene in a health crisis through the autonomous use of a medication previously controlled by credentialed health professionals. This disrupted dominant cultural, medical, and political understandings of people who use illicit drugs as primarily criminal or, at best, severely dysfunctional. The creation of a set of community-based, autonomous practices that locate stigmatized persons as key actors in relation to their own health and self-determination is also central to the movement for self-managed abortion.

Self-managed abortion

While the contemporary movement for SMA emerged in the 21st century, abortion itself has long been an area of autonomous health action and self-determination among women. To choose some well-documented examples, the feminist health movement of the 1960s and 70s taught women how to perform “menstrual extraction” and other de-medicalized approaches to abortion in the first trimester, and the Jane Collective in Chicago may be the most direct predecessor to contemporary activism.²² As a movement, SMA combines online feminist telemedicine services and activist-driven community-based strategies to assist women with the use of widely available medication.

The standard medical abortion protocol uses two medications—mifepristone and misoprostol—but misoprostol alone is effective and more readily available.²³ Misoprostol is a medication for gastric ulcers that has obstetric uses, including abortion and treatment for postpartum hemorrhage; the label warns against use by pregnant women and lists miscarriage as a side effect.²⁴ Women in Brazil began to use misoprostol to induce abortion in meaningful numbers in the 1990s, leading to a measurable decrease in complications from unsafe

abortion.²⁵ The practice spread in contexts with limited legal access to abortion, despite difficulty in obtaining accurate instructions for use.²⁶ Starting in the 2000s, feminist websites, hotlines, and other education and support strategies began to provide women with accessible and trusted information on how to use the medication, which has increased women’s acceptance of SMA.²⁷ As with HR, the practices developed by SMA activists are used by women who may not themselves identify with the movement.

Feminist activism for SMA began at the margins of the medical system and has since developed fully de-medicalized practices that have spread globally. In 1999, Women on Waves began to offer abortions on board a ship that would anchor in international waters near countries with highly restrictive laws.²⁸ In the early 2000s, Women on Waves initiated a telemedicine service, Women on Web, that provides online consultations and sends medication by mail. Women on Waves and Women on Web were founded by a doctor and both operate technically within, although at the margins of, institutional systems of medical practice. Additional online telemedicine platforms have emerged since, all of which medically prescribe and then mail standard abortion medications.

Since then, a series of more autonomous initiatives developed outside institutional medical systems. In 2008, a collective in Ecuador launched the first autonomous safe abortion hotline, providing information on how to use medication for first-trimester abortions, and hotlines soon appeared in other Latin American countries.²⁹ Around the same time, a practice of *acompañamiento*, or accompanying women through the abortion process, developed in Mexico in both Guanajuato and Mexico City and subsequently spread in Latin America.³⁰ In some African contexts, community health workers teach the use of misoprostol for the management of both postpartum hemorrhage and first-trimester abortion, using the legitimacy of the former to obscure the centrality of the latter.³¹ Variations on the strategy of a hotline have been implemented globally, including in Indonesia, Poland, Thailand, and multiple sub-Saharan African

countries; by 2018, at least 20 community-based projects operated globally.³²

HR and SMA reflect different, though related, circumstances and dynamics of marginalization and collective action. Both movements advocate for systemic institutional change (for example, full access to abortion on demand and fundamental changes in drug policy) but the primary focus of their work is the development of autonomous health practices that enhance self-determination. In each case, activists faced a health crisis created by stigma and criminalization and responded with community-level direct action that brought professionally controlled knowledge and technology into lay use. Syringe exchange programs combine community education about disease transmission and injection hygiene with the distribution of a medical technology (syringes) that was already in use but difficult to access. Overdose prevention and SMA both have community education components that centrally involve the de-medicalization of pharmaceuticals as a technology for use by ordinary persons with no professional training. Both movements developed practices that enable people to engage in autonomous health action (for example, safe injection, overdose prevention, and SMA) without any requirement to identify with or join the movement itself, thus separating questions of access from those of identity or political commitment. Syringe exchange and overdose prevention have had widely varying levels of government involvement and legal status in different parts of the world, although in the United States they emerged from social movement networks working at the margins of the law. At this writing, abortion globally is almost universally regulated through criminal law, and SMA has not been legalized (or decriminalized); the organizations that provide education and support have clear roots in feminist organizing.³³

Autonomous health movements

Contexts for emergence

Based on these two examples, I argue that autonomous health movements may emerge within societal contexts that share four important charac-

teristics. First, there is a highly stigmatized health issue or population. HIV/AIDS in the United States demonstrates this clearly in the emergence of a new, initially fatal, disease that spread in stigmatized ways and largely among marginalized, often criminalized, populations. In contrast, abortion is a common and longstanding practice that has been criminalized in many countries, thereby creating socially marginalized contexts that carry stigma even for women of otherwise dominant status. Second, the government responds to the situation with criminalization and marginalization rather than health care. In the United States, HIV among people who use drugs was met with escalating criminalization through the War on Drugs, in the context of medical and social services systems that largely required abstinence as a precondition to care. Abortion continues to be restricted and criminalized in much of the world, and it is only under these conditions that hotlines and other SMA practices have emerged. The United States under the Trump administration offers a dynamic example of this, as interest in SMA has spread among feminist activists as the probable demise of *Roe v. Wade* becomes more proximate. Third, the criminalization primarily affects marginalized populations, as those with resources can often access privatized solutions. This has long been true for abortion, as women with resources obtain assistance from private providers or travel to locations where abortion has been broadly legalized. Similarly, drug users with socioeconomic resources are often able to obtain sterile syringes or to access various forms of care without first becoming abstinent, despite the overall criminalization of drug use and users.

Fourth, the health issue is of concern to an existing social movement, which then provides the context within which activists develop a de-medicalized, community-based response anchored in the principles of bodily autonomy and self-determination. This last element appears to be crucial, as a variety of health issues meet the first three criteria but autonomous health movements do not appear to develop unless a larger social movement provides the initial context and resources for the emergent autonomous health movement. The first

HR programs in the United States were created within the context of a militant response to the AIDS epidemic, although both criminalization and drug-related health issues were common and longstanding among drug users. As noted previously, syringe exchange programs initially had a stronger statistical association with the level of HIV among gay men, and associated AIDS activism, than with the level of HIV among drug users, highlighting the importance of the context and resources provided by a larger social movement. Abortion outside the medical system is hardly a new phenomenon, but the reemergence of feminist movements enabled a shift toward organized, publicly accessible, movement-based assistance (for example, 1970s feminist self-help, the Jane Collective, and, more recently, SMA). In each of these cases, activists working within a larger movement began to develop direct action practices to address a criminalized health issue, leading to the formation of independent organizations and movements. Attention to the centrality of the role of a larger social movement in the emergence of autonomous health movements leads to consideration of autonomous health movements themselves as both practices and movements.

Characteristics of autonomous health movements

Autonomous health movements share certain characteristics that are connected to, but somewhat independent of, their conditions of emergence. Three characteristics appear to be conceptually central, particularly in relation to the “autonomous” element of autonomous health movements; I will first list these characteristics and then develop them in subsequent paragraphs. One, the health practice involves de-medicalization through community use and control of medical knowledge and technology. Two, this process of de-medicalization results in significant shifts in power relationships between marginalized, often criminalized, contexts and populations and mainstream medical institutions in ways that enhance the autonomy and self-determination of the marginalized. And three, activists within autonomous health movements demonstrate a willingness to work at the edges of

or outside the law when necessary.

The de-medicalization of medications, technologies, and knowledge sits at the heart of autonomous health movements, enabling their autonomy from medical systems and development of effective community-based practices. The clearest illustration of this may be various forms of autonomous abortion, whether contemporary use of medication or earlier community-based feminist practices. Safe abortion outside the medical system brings together the different elements of de-medicalization in a straightforward way; women take control of knowledge and technologies that enable safe abortions, which directly empowers them in relation to medical institutions and enhances their autonomy and self-determination. Perhaps less obviously, HR de-medicalizes important technologies (such as sterile syringes and naloxone) that people who inject drugs need to autonomously manage their own health and bodily self-determination while using drugs, reducing their vulnerability to medical (and other) institutions that typically stigmatize and marginalize users of illicit drugs. More radically, HR positions active users of illicit drugs as valued members of their communities, fully capable of health-sustaining action on their own and another’s behalf. Similarly, SMA positions women as persons with the knowledge and authority to make decisions about their own bodies, sexuality, and reproduction, which continues to be a contested claim even in contexts where abortion is legal.

The combination of criminalization and stigma, on the one hand, with strategies of de-medicalization, on the other, can locate the work of autonomous health movements at the borders of the law. Again, abortion outside the medical system provides clear examples of this in the work of earlier feminists and in contemporary SMA, which has been criminalized in much of the world. In the early days of syringe exchange in the United States, many programs were of, at best, ambiguous legal status, and many were outright illegal, sometimes for years. New Jersey did not legalize syringe exchange programs until 2007, despite relatively high rates of injection-related HIV. Syringe exchange programs in New York State were “legalized” in

1992 when the state health commissioner declared a state of emergency; the declaration had to be reissued annually until the early 2000s, when the state legislature legalized possession of up to 10 syringes for personal use. Similarly, naloxone distribution for overdose prevention began in at least technical violation of prescription laws.

Through their willingness to work at the edges of the law, autonomous health movements challenge mainstream cultural and public health assumptions that medical safety lies within institutional systems. These movements take medications and other technologies out of institutional settings and train ordinary people to safely use them in ways that had previously been exclusively the purview of professionals. SMA and overdose prevention are obvious examples of this, but the idea that people who inject drugs could consistently inject safely—reducing bacterial infection and viral transmission—was largely unimaginable to medical and public health officials prior to the work of syringe exchanges. The collaborative work between autonomous health movements and affiliated or allied scientists to prove the efficacy of their community-based practices provides traditional scientific evidence that medical safety can exist within de-medicalized, community-controlled practices and contexts. This scientific validation of social movement practices then enables a discourse of evidence-based medicine and public health. However, it must be emphasized that these practices are developed and sustained as autonomous community action, not as “second best” or provisional pending integration into institutional systems.

The legal risks taken by activists in autonomous health movements elicit obvious questions about the social and political commitments underlying the willingness to engage in what, in certain locations, could be considered routinized, ongoing civil disobedience. It is not possible to understand the risks taken by SMA or early HR activists without attention to the larger social movements that provided the contexts within which these autonomous health movements emerged. The Ecuadorian activists who created the first abortion hotline were committed feminists and members of a youth-run

nongovernmental organization focused on issues of gender and sexuality.³⁴ The safe abortion hotlines and *acompañamiento* collectives that subsequently formed in other Latin American countries also emerged from networks of feminist, often lesbian, activists.³⁵ Early syringe exchange programs in the United States were often linked with AIDS activist organizations or anarchist networks, and the HR movement that emerged through the 1990s has been consistently driven by a strong social justice analysis that provides the framework within which risks are assessed and taken.³⁶ Based on these examples, I argue—or at least hypothesize—that autonomous health movements emerge from within larger social movements that provide the initial analytical frameworks for the development of autonomous practices (for example, hotlines and street-corner syringe exchange), as well as the motivation to accept legal risk.

Autonomous health movements and human rights

The practices of these movements lie within a human rights framework of bodily autonomy and self-determination, although, to paraphrase Alicia Yamin, they may use civil disobedience as a strategy for the epistemic disobedience necessary to address health problems created by law and policy.³⁷ Autonomous health movements refuse to remain within a state- or institution-focused paradigm, using de-medicalization and direct action to create effective health practices outside of institutional control. HR and SMA offer immediate strategies for action without waiting for state policies to change, challenging marginalization and isolation as well as criminalization, and recognizing that bodily autonomy and self-determination for marginalized communities require engagement and resources. SMA activists do more than hand out pills and instructions; they create pathways for communication and support around the management of unwanted pregnancy as a moment within the lives and communities of pregnant persons. Similarly, HR activists do more than hand out syringes and naloxone, instead creating spaces within which socially stigmatized drug users are

valued community members and health educators. These movements prioritize autonomous forms of direct action rather than battles over state policy and obligation, which may render them less visible as movements engaged in a struggle for human rights. In practice, autonomous health movements step outside state- and institution-centered debates around policy change, political pragmatism, and technocratic development goals.³⁸

High-profile confrontation is often key to the visibility of a social movement, and I believe that part of why autonomous health movements have been largely overlooked as movements comes from the dynamics of low-profile direct action rather than visible challenge. In some US cities, the activists who *intentionally* provoked an arrest for handing out syringes, in order to argue in court that their actions were “necessary to preserve life,” were AIDS activists who supported HR but were not engaged in ongoing outreach, and those arrests did not occur at syringe exchange sites. Arguably, they were part of the larger movement that “birthed” the autonomous health movement but not part of the autonomous health movement itself, as they were not involved in ongoing HR work. Within SMA, an abortion hotline is unlikely to formally lead a campaign to change the legal status of abortion, but hotline activists may well be involved through other feminist organizations. The dynamics of deliberate, visible confrontation are, in reality, not conducive to developing trust and accessibility among marginalized people in a criminalized context in which encounters with authority are to be avoided as much as possible. The collective action frameworks and community-oriented strategies central to the work of both SMA and HR go beyond questions of state repression or obligation and embrace an understanding of autonomy anchored in shared connection and support.

Autonomous health movements in a broader perspective

While I have developed the concept of autonomous health movements around the examples of HR and SMA, these are clearly not the only potential cases. The practice of safer sex among gay men and

MSM was created and initially circulated by gay male activists as an act of liberation and communal self-determination at a time when sodomy was still criminalized in parts of the United States and when there were credible fears about the escalating marginalization of populations identified with AIDS.³⁹ While the condom is not a medical technology, there is a profound de-medicalization in the direct action of creating practices to control the spread of a new, terrifying disease. Much of the health organizing done by sex worker activists, including but not limited to HIV, falls within the general frameworks described here and is anchored in decriminalization, bodily autonomy, and self-determination within the framework of collective action. Moving beyond HIV, the work of *No Más Muertes* (No More Deaths) in the US-Mexico border region emerged as a response to the public health crisis created by the escalating criminalization of migration, which forced migrants into the most dangerous deserts of Arizona. Activism surrounding transgender identity and bodily autonomy may well function as an autonomous health movement in contexts where trans identities and access to medical care are restricted or criminalized.

I am reluctant to set hard boundaries around autonomous health movements at this stage of conceptual development, but the characteristics outlined previously set some criteria for what does and does not lie within the framework. Health social movements organized around illness identities that demand inclusion and change in institutional systems are not autonomous health movements. Some potential ambiguities arise in relation to self-help and consumer movements, and here a return to the defining characteristics and the earlier discussions of HR and SMA offer some guidance. Autonomous health movements develop a practice that addresses a health issue, and they make the practice accessible to others without any requirement to identify as part of the movement. For example, feminist self-help groups of the 1970s may have assisted one another with menstrual extractions in the first trimester of pregnancy, but the requirement to be an ongoing group member creates an internal practice, which is very different than the explicitly open

work of the Jane Collective during the same time period. Many contemporary consumer movements would not fit well within the autonomous health movement framework, as they focus primarily or exclusively on institutional change rather than on autonomous practices and do not operate in a criminalized context. Marijuana buyers' clubs, however, are much closer to autonomous health movements, since they provide access to an often criminalized substance on the basis of a medicinal use and may have wide peripheries of "membership."⁴⁰ Autonomous health movements as conceptualized in this paper occupy a particular location within the larger domain of health and social justice movements, one characterized by autonomous health work as a form of direct action.

Locating certain practices as autonomous health movements expands and reorients our understanding of work that has largely been positioned as innovative and controversial public health measures, not as direct action by social movements. This is particularly true for HR but also to some extent for SMA, both of which appear in a public health literature that at least partially decontextualizes the experiences and processes being studied. In both cases, the effectiveness of a practice cannot accurately be understood independent of the work of the activists and movements that create contexts through which individuals realize the practices studied and validated by epidemiologists. The role of activists is visible within much of the epidemiological data, although primarily as sources of information (for women, drug users, and principal investigators) or locations for data collection, but this does not in itself enable an understanding of how these projects and practices were developed and how they are sustained. These absences are particularly notable given the self-representation of the organizations and the multiple, movement-connected social locations of many of the scientists and contributors to the published literature. However, from the perspective of activists, collaboration with epidemiologists directly advances the work of the movement, while research on social movements may be less obviously beneficial.

The conceptual framework of autonomous health movements has the potential to elicit new questions and directions for research in health, human rights, and social movements, particularly in relation to innovation and strategies to move beyond existing models.⁴¹ It challenges us to look for ways that social movements can sidestep the state or large institutions and how work may be divided within a field of related activity, with some elements specializing in policy while others engage with low-profile direct action. An understanding of direct action as a potential health strategy opens up questions about the contexts and processes that lead to significant innovations at the intersections of human rights, health, and criminalization. The role of larger movements in fostering the emergence of autonomous health movements directs attention to how social movements can initiate, or incubate, health practices that break with previous assumptions and move beyond established models for human rights-based approaches to health. In addition, the collaboration among activists and scientists that leads to scientific validation of direct action practices may encourage new ways of thinking about relationships between marginal communities and public health (or human rights) professionals.

Conclusion

As I finish this paper, in New York City in June 2020, the United States is immersed in simultaneous insurrection and pandemic, as protests against racist police systems erupt in cities still under quarantine from COVID-19. In this moment, activists are intrinsically working at the intersections of public health and collective action, adapting health guidelines to the ever-emergent processes of street protest. Some practices reflect creative innovation, such as the use of rhythmic clapping in place of chanting to allow collective expression without the widespread expulsion of potentially virus-laden droplets from hundreds or thousands of people chanting. Marches with evolving routes reduce the health risks of both COVID-19 and

encounters with the police, as highly mobile and low-density protests wind through the streets in unpredictable patterns. It is a powerful reminder that social movements not infrequently work in contexts where health risks must be managed as an intrinsic contextual element of organizing and action, troubling the theoretical boundaries around “health movements” and the relationship between health and human rights.

The coming decades are likely to bring sociopolitical turbulence and emergent health risks as climate patterns shift, populations of humans and other life forms migrate, and social systems scramble to respond in ways that range from authoritarian to liberatory. Environmental changes and associated migrations alone have the potential to create multiple, shifting contexts in which criminalization, health, medical technologies, and social movements interact. It is unsurprising that the examples of autonomous health movements in this paper involve intersections among gender, sexuality, and drug use, as these have long been domains where repression and social control use the language of health. Looking ahead, the anti-immigrant rhetoric that has gained power throughout Euro-American societies in the 21st century situates migrants as a threat to societal health broadly speaking and could easily be mobilized in more targeted ways, as signaled by the rise in anti-Asian prejudice with COVID-19. The criminalization of marginal contexts and populations has been a central tool of neoliberalism under centrist and right-wing governments alike and can lead to health crises under a range of circumstances and configurations.

The conceptual framework of autonomous health movements expands our thinking and the direction of our attention in relation to contexts where stigma and criminalization create or significantly amplify health risks and the role of social movements in forging new pathways in health and human rights. While policy change and destigmatization are vital, they are generally long term projects that do not immediately reduce health risks or enhance autonomy. The movements analyzed in this paper demand that we recognize and work

to understand the role of social movement-driven direct action in transforming health practices in contexts of extreme marginalization.

References

1. P. Brown and S. Zavestoski, “Social movements in health: An introduction,” *Sociology of Health and Illness* 26/6 (2004), pp. 679–694; P. Brown, R. Morello-Frosch, S. Zavestoski, et al., “Embodied health movements,” in P. Brown (ed) *Contested illnesses: Citizens, science and health social movements* (Berkeley: University of California Press, 2011); S. Epstein, “The politics of health mobilization in the United States: The promise and pitfalls of ‘disease constituencies,’” *Social Science and Medicine* 165 (2016), pp. 246–254.
2. J. Escoffier, “The invention of safer sex: Vernacular knowledge, gay politics, and HIV prevention,” *Berkeley Journal of Sociology* 43 (1998), pp. 1–30; D. C. Des Jarlais, M. Marmor, P. Friedman, et al., “HIV incidence among injecting drug users in New York City, 1992–1997: Evidence for a declining epidemic,” *American Journal of Public Health* 90/3 (2003), pp. 352–359; B. Winikoff and W. Sheldon, “Use of medicines changing the face of abortion,” *International Perspectives on Sexual and Reproductive Health* 38/3 (2012).
3. H. Pruijt and C. Roggeband, “Autonomous and/or institutionalized social movements? Conceptual clarification and illustrative cases,” *International Journal of Comparative Sociology* 55/2 (2014), pp. 144–165.
4. R. I. Drovetta, “Safe abortion information hotlines: An effective strategy for increasing women’s access to safe abortions in Latin America,” *Reproductive Health Matters* 18/36 (2015); J. N. Erdman, K. Jelinska, and S. Yanow, “Understandings of self-managed abortion as health inequity, harm reduction and social change,” *Reproductive Health Matters* 26/54 (2018); K. Jelinska and S. Yanow, “Putting abortion pills into women’s hands: Realizing the full potential of medical abortion” *Contraception* 97/2 (2018), pp. 86–88.
5. B. Tempalski, P. L. Flom, S. R. Friedman, et al., “Social and political factors predicting the presence of syringe exchange programs in 96 US metropolitan areas,” *American Journal of Public Health* 97/3 (2007); C. B. R. Smith, “Harm reduction as anarchist practice: A user’s guide to capitalism and addiction in North America,” *Critical Public Health* 22/2 (2012), pp. 209–221; N. E. Stoller, *Lessons from the damned: Queers, whores, and junkies respond to AIDS* (New York: Routledge, 1998); A. Henman, D. Paone, D. C. Des Jarlais, et al., “From ideology to logistics: The organizational aspects of syringe exchange in a period of institutional consolidation,” *Substance Use and Misuse* 33/5 (1998), pp. 1213–1230.
6. J. N. Erdman, “Harm reduction, human rights, and access to information on safer abortion,” *International Journal of Gynecology and Obstetrics* 118 (2012), pp. 83–86.
7. T. M. Piper, S. Rudenstine, S. Stancliff, et al., “Over-

- dose prevention for injection drug users: Lessons learned from naloxone training and distribution programs in New York City,” *Harm Reduction Journal* 4/3 (2007); P. Lurie and A. L. E. Reingold, *The public health impact of needle-exchange programs in the United States and abroad: Summary, conclusions, and recommendations* (San Francisco: Institute for Health Policy Studies, University of California, 1993); C. Gerdtts and I. Hudaya, “Quality of care in a safe abortion hotline in Indonesia: Beyond harm reduction,” *American Journal of Public Health* 106/11 (2016); S. Larrea, L. Palencia, and G. Perez, “Aborto farmacologico dispensado a traves de un servicio de telemedicina a mujeres de America Latina: Complicaciones y su tratamiento,” *Gaceta Sanitaria* 29/3 (2015).
8. N. Braine, C. Acker, C. Goldblatt, et al., “Neighborhood history as a factor shaping syringe distribution networks among drug users at a U.S. syringe exchange,” *Social Networks* 30 (2008), pp. 235–246.
 9. R. Zurbriggen, B. Keefe-Oates, and C. Gerdtts, “Accompaniment of second-trimester abortions: The model of the feminist Socorrista network of Argentina,” *Contraception* 97/2 (2018), pp. 108–115; J. MacReynolds-Perez, “No doctors required: Lay activist expertise and pharmaceutical abortion in Argentina,” *Signs: Journal of Women in Culture and Society* 42/2 (2017); Henman et al. (see note 5); Piper et al. (see note 7); Gerdtts and Hudaya (see note 7).
 10. Drovetta (see note 4); Gerdtts and Hudaya (see note 7); Larrea et al. (see note 7); Zurbriggen et al. (see note 9); S. Ramos, M. Romero, and L. Aizenberg, “Women’s experiences with the use of medical abortion in a legally restricted context: The case of Argentina,” *Reproductive Health Matters* Suppl 44 (2015), pp. 4-15; C. Gerdtts, R. T. Jayaweera, S. E. Baum, and I. Hudaya “Second-trimester medication abortion outside the clinic setting: An analysis of electronic client records from a safe abortion hotline in Indonesia,” *BMJ Sexual and Reproductive Health* 44 (2018), pp. 286–291.
 11. Drovetta (see note 4); MacReynolds-Perez (see note 9); C. Loaiza Cardenas, *Estrategias de amor e informacion entre mujeres: La Linea Aborto Libre* (dissertation, Universidad de Chile, 2016).
 12. Tempalski et al. (see note 5); Henman et al. (see note 5); A. Grieg and S. Kershner, “Harm reduction in the USA: A movement toward social justice,” in B. Shepard and R. Hayduk (eds) *From ACTUP to the WTO: Urban protest and community building in the era of globalization* (Brooklyn: Verso Press, 2002); Smith (see note 5); Stoller (see note 5).
 13. National Harm Reduction Coalition, *Principles of harm reduction*. Available at <https://harmreduction.org/about-us/principles-of-harm-reduction>.
 14. S. R. Friedman, W. de Jong, D. Rossi, et al., “Harm reduction theory: Users culture, micro-social indigenous harm reduction, and the self-organization and outside-organizing of users groups,” *International Journal of Drug Policy* 18/2 (2007).
 15. Henman et al. (see note 5); Grieg and Kershner (see note 12).
 16. Piper et al. (see note 7).
 17. National Harm Reduction Coalition, *CRA case study*. Available at <https://harmreduction.org/issues/overdose-prevention/tools-best-practices/naloxone-program-case-studies/chicago-recovery-alliance>.
 18. Stoller (see note 5); Henman et al. (see note 5).
 19. M. Alexander, *The new Jim Crow: Mass incarceration in the age of colorblindness* (New York: New Press, 2012); C. Acker, *Creating the American junkie: Addiction research in the classic era of narcotics control* (Baltimore: Johns Hopkins University Press, 2006); N. Campbell, *Using women: Gender, drug policy, and social justice* (New York: Routledge, 2000).
 20. Tempalski et al. (see note 5).
 21. Des Jarlais et al. (see note 2); Lurie and Reingold (see note 7).
 22. Boston Women’s Health Collective, *Our bodies, ourselves* (New York: Touchstone Press, 1976); M. Murphy, *Seizing the means of reproduction: Entanglements of feminism, health, and technoscience* (Durham: Duke University Press, 2012); L. Kaplan, *The story of Jane: The legendary underground feminist abortion service* (Chicago: University of Chicago Press, 1995).
 23. Winikoff and Sheldon (see note 2); A. R. A. Aiken, I. Digol, J. Trussell, and R. Gomperts, “Self-reported outcomes and adverse events after medical abortion through online telemedicine: Population based study in the Republic of Ireland and Northern Ireland,” *BMJ* 357 (2017), pp. 357–364.
 24. R. Allen and B. M. O’Brien, “Uses of misoprostol in obstetrics and gynecology,” *Reviews in Obstetrics and Gynecology* 2/3 (2009).
 25. R. Gomperts, K. van der Vleuten, K. Jelinska, et al., “Provision of abortion using telemedicine in Brazil,” *Contraception* 89 (2014), pp. 129–133.
 26. M. Wainright, C. J. Colvin, A. Swartz, and N. Leon, “Self-management of medical abortion: A qualitative evidence synthesis,” *Reproductive Health Matters* 24 (2016), pp. 155–167; N. Zamberlin, M. Romero, and S. Ramos, “Latin American women’s experiences with medical abortion in settings where abortion is legally restricted,” *Reproductive Health* 9/34 (2012); J. Sherris, A. Bingham, M. A. Burns, et al., “Misoprostol use in developing countries: Results from a multicountry study,” *International Journal of Gynecology and Obstetrics* 88 (2005), pp. 76–81.
 27. Wainright et al. (see note 26).
 28. R. Gomperts, “Women on Waves: Where next for the abortion boat?,” *Reproductive Health Matters* 10/19 (2002), pp. 180–183.
 29. Drovetta (see note 4).
 30. E. O. Singer, “Realizing abortion rights at the margins of legality in Mexico,” *Medical Anthropology* 38/2 (2018); A. Krauss, “The ephemeral politics of feminist accompaniment networks in Mexico City,” *Feminist Theory* 20/1 (2019); Zur-

briggen et al. (see note 9).

31. F. Coeytaux, L. Hessini, N. Ejano, et al., "Facilitating women's access to misoprostol through community-based advocacy in Kenya and Tanzania," *International Journal of Gynecology and Obstetrics* 125/1 (2014).

32. Jelinska and Yanow (see note 4).

33. M. Berer and L. Hoggart, "Progress toward decriminalization of abortion and universal access to safe abortions: National trends and strategies," *Health and Human Rights Journal* 21/2 (2019), pp. 79–83.

34. Drovetta (see note 4).

35. Drovetta (see note 4); MacReynolds-Perez (see note 9); Loaiza Cardenas (see note 11); Singer (see note 30).

36. Tempalski et al. (see note 5); Stoller (see note 5); Grieg and Kershner (see note 12).

37. A. E. Yamin, "Struggles for human rights in health in an age of neoliberalism: From civil disobedience to epistemic disobedience," *Journal of Human Rights Practice* 11 (2019), pp. 357–372.

38. A. E. Yamin and R. Cantor, "Between insurrectional discourse and operational guidance: Challenges and dilemmas in implementing human rights-based approaches to health," *Journal of Human Rights Practice* 6/3 (2014), pp. 451–485.

39. Escoffier (see note 2); D. Altman, *AIDS in the mind of America* (New York: Anchor Press/Doubleday, 1986).

40. R. A. Penn, "Establishing expertise: Canadian community-based medical cannabis dispensaries as embodied health movement organizations," *International Journal of Drug Policy* 25/3 (2014).

41. Yamin and Cantor (see note 38); Yamin (see note 37).

