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On the Margins of Pharmaceutical Citizenship: Not Taking HIV Medication in the “Treatment Revolution” Era

With the expanding pharmaceuticalization of public health, anthropologists have begun to examine how biomedicine’s promissory discourses of normalization and demarginalization give rise to new practices of and criteria for citizenship. Much of this work focuses on the biomedicine–citizenship nexus in less-developed, resource-poor contexts. But how do we understand this relationship in resource-rich settings where medicines are readily available, often affordable, and a highly commonplace response to illness? In particular, what does it mean to not use pharmaceuticals for a treatable infectious disease in this context? We are interested in these questions in relation to the recent push for early and universal treatment for HIV infection in Australia for the twin purposes of individual and community health. Drawing on Ecks’s concept of pharmaceutical citizenship, we examine the implications for citizenship among people with HIV who refuse or delay recommended medication. We find that moral and normative expectations emerging in the new HIV “treatment revolution” have the capacity to both demarginalize and marginalize people with HIV. [HIV treatment, pharmaceutical citizenship, demarginalization, normalization, Australia]

Introduction: The HIV “Treatment Revolution” and Pharmaceutical Citizenship

With the ascendancy of biomedicine and the increasing emphasis in global public health discourse on medication as a human right, anthropologists have turned their ethnographic gaze to questions of “citizenship” across a range of cultural settings (Biehl 2007a; Cataldo 2008; Chabrol 2014; Ecks 2005; Lock and Nguyen 2010; Nguyen 2005; Richey 2012; Sanabria 2010). Their inquiries locate citizenship in a broad sense, encompassing not only the legal status of a person in society, but also their social status, sense of belonging, and ability to exercise political and civil rights. What they seek to understand is how citizenship is enacted and redefined by what João Biehl (2007b) calls the “pharmaceuticalisation of public health”: the contemporary trend toward reliance on biomedical interventions to not only treat and prevent conditions, but also manage risks, “normalize” diseases, de-marginalize people, and regulate populations. It is this “promissory discourse” (Sunder Rajan 2006) that is seen to drive the “hype and hope” that surrounds biomedical technologies and their accelerating global distribution (Marsland and Prince 2012:455). To date, scholarly interest in citizenship has largely focused on pharmaceutically based public health programs in less-resourced countries, but the apparent ambition of biomedicine to go beyond merely treating conditions to empowering individuals and protecting populations also has relevance to high-resource settings.

HIV medicine provides a timely example to contemplate questions of citizenship, given the emergent global goal to create an AIDS-free generation and curb the epidemic through early and universal treatment of HIV infection (amfAR/AVAC 2012; PEPFAR 2012; UNAIDS 2011; UNICEF 2013). HIV is undoubtedly one of the most feared and demonized conditions in history. Better knowledge and education have been pivotal in gradually reducing the stigma attached to the virus and the marginalization of those affected. But equally pivotal has been the continued refinement and effectiveness of antiretroviral therapies over time, which has transformed both the reality and the perception of HIV from lethal disease to manageable chronic condition (WHO 2002), particularly in high-resource settings. In countries such as Australia, the setting for our research, the early mobilization of affected communities to campaign for access to HIV treatment and for social and legal rights was essential to these developments (Power 2011).

HIV treatment has now been imbued with a new sense of urgency. There are mounting indications that early treatment of HIV infection has long-term health benefits (Le et al. 2013). Treatment is increasingly also seen as playing a crucial role in HIV prevention by reducing the virus to undetectable levels in people’s blood and thereby their infectiousness (Lundgren and Wood 2013). This follows recent high-profile clinical trials that showed a dramatic reduction in sexual transmission of HIV with sustained and effective treatment (Cohen et al. 2011; Rodger et al. 2014). This reframing of HIV treatment as a global prevention strategy has been widely heralded as a “game-changer” (Sidibé 2011) and has been invested with great hopes of “turning the tide” and ultimately ending the pandemic (Havlir and Beyer 2012; 19th International AIDS Conference [<http://www.aids2012.org>]). The theme of the most recent International AIDS Conference, “stepping up the pace” (<http://www.aids2014.org>), urged the global community to do more to implement this new strategy.

Changes in treatment guidelines in several resource-rich countries, including Australia, reflect this paradigm shift from using HIV drugs solely for the purpose of health to using them as a public health intervention (Wilson 2012). In effect, people with HIV are now encouraged to start treatment early, regardless of clinical markers, to not only protect their own health and that of their sexual partner, but also to protect the health of the population by “doing their bit” to help reduce the overall viral load in the community. In the Australian state of New South Wales, which has the largest population of people with HIV, the Health Ministry’s *HIV Strategy 2012–2015: A New Era* took on this paradigm with gusto by setting bold targets for testing, treatment uptake, and “the virtual elimination of HIV transmission” by 2020 (NSW Health 2012). This move was supported by key community and clinical HIV organizations (ACON 2013; ASHM 2013; NAPWHA 2014) and subsequently endorsed in the national HIV strategy (Commonwealth of Australia 2014).

Considerable energy has been invested in promoting this new paradigm, both to people with HIV and to HIV clinicians, through campaigns such as Ending HIV (endinghiv.org.au) and *Start the Conversation* (napwha.org.au/news-information/campaigns/start-conversation), as well as calls to action (www.melbournedeclaration.com) and numerous public forums. Of note, treatment coverage in Australia is already high by international standards, with up to 73% of people with diagnosed HIV reported to be using antiretroviral therapy at the end of 2014 (Kirby Institute 2015). Treatment for HIV is publicly subsidized and readily accessible from public and private clinics, but is not obligatory.

In this so-called HIV treatment revolution era, antiretroviral therapy has thus acquired the potential to accomplish more than its original purpose of improving individual health and survival (Mykhalovskiy 2010). With its added capacity to render people *non-infectious*, and so removing HIV’s most stigmatizing aspect, treatment has emerged as an agent for both community protection *and* normalization, promising to turn HIV into an ordinary chronic illness and people with HIV into safe and regular citizens, “just like anyone else” (Squire 2010:407). As with any social development, there is much benefit to be gained from this reinscription of HIV treatment, just as there are likely losses and unforeseen upshots, which intersect with discursive ideas around citizenship. There are various conceptualizations of “citizenship” in the context of biomedicine (e.g., Nguyen 2005; Rose and Novas 2004). In relation to our research, anthropologist Stefan Ecks’s (2005:241) work on *pharmaceutical citizenship*, which he defines as the “biomedical promise of demarginalization,” provides a particularly interesting and useful lens through which to consider empirical implications of the HIV treatment revolution.

Ecks’s (2005, 2013) ethnographic work focused on mental health and anti-depressants in India. He coined the term pharmaceutical citizenship to capture the way Indian pharmaceutical companies modeled their marketing strategies on Western examples, drawing in particular on the American ideal of happiness, but also the language of public health organizations and other global agencies that frame marginality as a form of social inequality that should be eliminated through fairer distribution of goods and services, including biomedical substances. In this framework, therefore, providing pharmaceuticals to those at the margins is defined as the best way to help them become full citizens. Ecks traces how out-of-sync this solution is with local understandings of depressive symptoms and remedial

practices. Here we want to mobilize his broader insight, that the biomedical promise of demarginalization defines global discussions of many diseases, such as malaria, tuberculosis and, indeed, HIV. As Ecks notes, not only is access to pharmacological treatment for these diseases framed as a human right, but also as having the power to restore citizenship by drawing disadvantaged or stigmatized people “back into society” (Ecks 2005:239–241; Ecks and Sax 2005).

Ecks’s work raises some vital questions that are also relevant to developments in resource-rich settings, including the Australian push for early and universal treatment in response to the global HIV treatment revolution. In this ambitious environment, what are the implications for citizenship and people’s sense of inclusion if they decide to *not* take HIV treatment? “What kind of *person* is required by biomedicine” in this context and what about those who do not fit the criteria (Marsland and Prince 2012:466)? As Davis and Squire (2010:306) note, the relationship between citizenship and biomedicine can be “a site for the exercise of disciplinary requirements on citizens.” Similar observations are made by others who argue that, on the flip-side of pharmaceutical citizenship is an “unwritten social contract”: an enjoinder to engage and comply with biomedical solutions on offer in order to fulfill one’s obligations as a citizen and become “acceptable to society” (Pound et al. 2005:146; Sanabria 2010). So, what does it mean, then, to *not* take therapeutic substances in view of this “contract”? What kind of subjects and citizenship take shape when people with treatable diseases such as HIV refuse, desist, or delay taking recommended medication?

Through the lens of biomedicine, the perceived “failure” to make use of available resources might be construed as people irrationally working “*against* therapy” (Meyers 2013:10) or shirking their obligations as citizens by *choosing* not to take care of themselves or do the right thing (Beckmann 2013; Marsland and Prince 2012). But as Pound and colleagues’ literature review reveals, there can be a range of competing rationalities or constraints at play in relation to medication use and, more often than not, people “have understandable and logical reasons for not taking their medicine” (Pound et al. 2005:151). Common reasons why people in resource-rich countries do not take HIV treatment include concerns about medication side effects, safety, and effectiveness, doubts about the need to commence treatment, and reluctance to commit to a daily regimen of pills (Alfonso et al. 2006; Fagan et al. 2010; Gwadz et al. 2014; Horne et al. 2007). The biomedical promise of demarginalization through pharmaceutical intervention seems particularly challenged by another often reported explanation: the desire to maintain a sense of normality and the feeling that daily medication is an unwelcome reminder of having HIV (Grierson et al. 2011; Mills et al. 2006).

To render such sentiments as simply misguided or irresponsible would be to set up a false dichotomy between people on treatment who get it and those who do not. As researchers have argued in response to the HIV treatment revolution, even when treatment is willingly taken and effective, discourses of HIV normalization are complicated by a number of social and historical factors that shape experiences of having HIV, stigma being a major one (Colvin 2011; Flowers and Davis 2013; Moyer and Hardon 2014; Persson 2013). Not taking treatment takes on an added complication in the current context, as people with HIV are now asked to commit

to life-long treatment not only for their own health, but as a moral obligation to protect the health of the community.

Here, we examine stories of not taking HIV treatment to see what they reveal about biomedicine's promissory discourse of demarginalization and citizenship. We are interested in how the pharmaceuticalization of health, so obviously effective in the treatment and prevention of HIV infection, nonetheless materializes new social relations, as Biehl (2008) argues. To paraphrase Marsland and Prince (2012:458), if the technologies and rationalities of biomedicine not only transform but also differentiate, then "what kind of life spills out" at the margins of the HIV treatment revolution?

Approach

Our interest in these questions stems from our many decades of combined experience in researching social issues around HIV. Over the years, our attention has continued to be captured by the shifting landscape of HIV medicine and its implications for people with HIV, HIV clinicians, and the community more broadly (e.g., Mao et al. 2013; Newman et al. 2006; Newman et al. 2013; Persson 2004, 2013; Persson et al. 2014). Our extensive work has given us a well-grounded ethnographic feel for the field, developed through doing many hundreds of qualitative interviews and through close and sustained engagement with affected communities through numerous collaborative projects, committees and working groups, friendships, and myriad conversations. In this article, we focus on in-depth interviews with people with HIV who were not taking antiretroviral therapy at the time of their interview. These interviews are drawn from the qualitative arm of a larger multi-method study, which was funded by a National Health and Medical Research Council grant to examine issues affecting the use and non-use of HIV treatment from the perspectives of both health care providers and people with HIV in Australia (Mao et al. 2013).

The interviews were conducted between 2012 and 2014, following ethics approval by the University of New South Wales Human Research Ethics Committee. Participants were recruited through the websites and print media of HIV community organizations and had to be 18 years or older, diagnosed with HIV, not taking treatment, and living in Australia. Potential participants were invited to contact the National Association of People with HIV Australia (NAPWHA), who explained the research aims: to understand the views and experiences of people who do not use treatment at a time when there is growing policy emphasis on treatment uptake.

Twenty-seven people took part in an interview, including 19 gay men, four heterosexual women, three heterosexual men, and one bisexual man, a sample that reflects the pattern of HIV infection in Australia, a low HIV prevalence country with a concentrated epidemic and an estimated 27,150 people with HIV (Kirby Institute 2015). There was considerable diversity among participants in terms of age, cultural background, education, length of time since diagnosis (ranging from 27 years to just a few months), and key clinical markers such as CD4-cell count and HIV viral load. A majority of participants were currently single, six had children, and two-thirds were employed.

Interviews were conducted face to face or by phone. Given the geographical dispersal of the population across such a vast continent, phone interviews are often

necessary for studies of national scope such as this one for logistical and budgetary reasons. Using a semi-structured guide, the interviews explored a range of issues related to HIV treatment, including clinical history, beliefs and information about treatment, discussions with health care providers regarding treatment decisions, use of complementary/alternative medicine, views on using treatment to prevent HIV transmission, and perceived benefits and drawbacks of starting HIV medication. Of particular relevance to our analysis here, interviews also explored perceived community attitudes toward treatment non-use, including those of family and friends, especially any HIV-positive friends. Interviews were digitally recorded, transcribed verbatim, and de-identified to protect participant confidentiality.

Interview transcripts were coded independently by the first three authors for the purpose of separate publications addressing different questions of interest to the study (e.g., Newman et al. 2015). For this article, the first author coded the transcripts by hand, generating “open” codes to organize the material into thematic categories based on key issues covered in the interviews that had explicit or contextual relevance to the concept of pharmaceutical citizenship. Drawing on thematic analysis, the foundational and most common method for qualitative analysis (Braun and Clarke 2006; Guest 2012), these broad categories were organized into sub-categories, focusing on inductive identification of recurrent and divergent themes. The resulting thematic codes were checked by the other authors for comprehensiveness and analytical possibilities, utilizing their familiarity with the material through their parallel coding. These codes were then analyzed in detail to build a contextualized understanding of the issues at stake. We now turn to examine narratives of HIV treatment non-use, before moving on to consider their significance in relation to pharmaceutical citizenship.

Normality and Normalization

Ten participants had no history of HIV treatment at the time of interview, including one man who had been HIV-positive for 18 years and was what is typically referred to as a “long-term non-progressor.” The remaining participants had used antiretroviral therapy in the past for a limited period or for a specific purpose, such as during pregnancy. With regard to treatment in the future, four distinctive positions emerged: those who were comfortable with the thought of starting treatment as soon as it was clinically indicated or recommended; those who were managing other priorities at the time of interview, such as employment stress, parental responsibilities, or mental health issues, which precluded treatment uptake; those who accepted that treatment would be inevitable at some point, yet were determined to avoid it as long as possible; and a small minority who were adamant that they would never take treatment no matter what.

Regardless of these different positions, and in contrast to the emphasis on patient failures and deficits in some of the treatment non-adherence literature, participants were generally well informed about treatment and nearly all were highly engaged with medical care, including regular monitoring of HIV-related clinical markers. Most employed standard strategies for keeping healthy, focused on nutrition, exercise, sleep, and moderate alcohol use, with only four participants using alternative therapies to manage HIV. Importantly, these participants could by no

means be generalized as anti-medicine or acting against clinical recommendations. In fact, many were following their doctor's advice to wait with treatment, or else felt supported in their decision to not currently take treatment, with only four participants reporting major conflict with their doctor. Moreover, the vast majority strongly believed that HIV medication is effective in controlling the virus, as typified in this quote by Dominic, a recently diagnosed 31-year-old gay man:

Absolutely. I've read nothing or heard anything to contradict that at all. So I couldn't contest that. I think they are effective. There's been so much positive research on that issue that I guess I really can't contradict that . . . so, yeah I would see it as definitely something positive.

Many spoke of HIV treatments as "life-savers" and expressed a sense of gratitude that they lived in Australia, where treatment is readily available. As 51-year-old Abby, who had only briefly taken treatment since her diagnosis in 1986, said: "I appreciate all that stuff. And I get angry sometimes when people knock things or, you know, take things for granted." Sam, a 55-year-old man with minimal treatment since his diagnosis in 2000, was similarly critical of what he described as "that small group of people who say you shouldn't take treatments because they're this kind of toxic thing for your body, and those medical conspiracy theories. . . . I completely reject that attitude." A few participants also voiced sentiments that conjured the biomedical promise of restoration and normality. This is how 34-year-old Camilla, who was diagnosed in 2005 and had only used treatment during pregnancy, described what treatment meant to her: "Oh, to live a normal, normal, healthy life. That's what it basically means to me . . . thank goodness we've got these medications around. So I mean I don't know how much longer it will extend our life expectancy, but I do know that it will definitely help."

But participants also gave a number of reasons for why they were not using treatment, many of which were decidedly at odds with the ethos of pharmaceutical citizenship. Consistent with the literature, concerns about immediate side effects and long-term harm were commonly raised, as was a reluctance to commit to the demands of life-long treatment, particularly the need for scrupulous adherence to prevent drug-resistant viral mutations and the perceived disruption this would cause to their work, family, and social lives. A few, deeply convinced participants invoked narratives emblematic of the early epidemic, expressing serious misgivings about HIV medical science and pharmaceutical companies and insisting that HIV drugs are toxic or ineffective substances. "These are tablets that were banned, not fit for human or animals, and yet they expect us to take it for HIV?" said 46-year-old Rachel who was diagnosed two years before her interview. "It doesn't matter how many ways they wash it, wrap it and colour it, it's still the same tablet."

What connects these different reasons for not taking treatment is a perception of HIV drugs as a potential *threat* to health and everyday life. Felix, a 51-year-old gay man with some treatment experience since his diagnosis six years earlier, recognized that this perception was counter to commonly held beliefs: "Well [treatments] mean sickness and fatigue and not living a life. Not *having* a life. It's contradictory, you know, contrary to what most people would say." This was the position taken by three of the participants who insisted they could not foresee a compelling enough

reason to ever start treatment. Many others, however, were quite prepared to reframe HIV drugs as a beneficial agent in the future if their circumstances changed. But at the moment, few were convinced of the need to start, primarily because they felt healthy and normal and wanted to protect that state of being, or because their doctor advised them to hold off until their clinical markers showed unambiguous signs of moving in the wrong direction. In the words of 46-year-old Sarah, who was diagnosed in 1998:

If my results are trending down, I'm going to have to take meds and I will take the meds and I'll be a hundred percent compliant. I know that they're there to save our lives and they'll prolong our lives. I'm just keeping that up my sleeve. I don't think I need to be on them. . . . I want to do everything I possibly can to delay that for as long as possible.

What also emerged in the interviews was the symbolic significance of starting treatment. It was described by several participants as crossing a crucial line, a milestone that would spell the end of normality rather than instate it. For recently diagnosed 52-year-old Gerard, this step would "mark a different phase of my life living with HIV . . . the reality of HIV kicking in." This sense of HIV being thematized by treatment was true also for 31-year-old Eddy, another newly diagnosed gay man, who explained that, "it's like the fear of knowing that you've actually got to take them, yeah, [HIV] hits home a bit more . . . because right now, like yeah, I'm just fine, I feel normal." As 34-year-old Camilla observed, along with others, one psychological benefit of not being on treatment was the ability to disengage from HIV:

Because I'm not on medications, I kind of forget I've got it. . . . Look, admittedly, it probably will be something that reminds me daily of what I've got. So, at the moment, I can sort of sail along life quite easily and not sort of think about those sorts of things because I'm not on medications.

Having to cross that line from no treatment to treatment was described by some as a loss of independence and freedom, or as the final thrashing in a series of losses already caused by HIV. For 34-year-old Alex, HIV-positive since 1999, starting treatment signified a "loss of control" over his condition and also his life, because he would have to "hand over everything . . . to a bunch of medical professionals [I] don't really know." This tension between self-sufficiency and treatment was voiced also by 38-year-old Caleb, who was diagnosed five years earlier: "Not taking treatment . . . every year that's passing by, I guess, it's another year of keeping my head above water. . . . I still have my natural immune system fighting and surviving, and that's what is important for me." Along similar lines, Simon, a 42-year-old gay man, explained that after 18 years without treatment, starting would feel like "giving in" to the virus:

Medically I don't give it a lot of thought, but emotionally I give it a tremendous amount of thought, and I think that what HIV medication means to me is final acceptance of my illness. . . . I'm quite defiant against the virus. I don't, emotionally, I don't want it to win and I know it sounds really simplistic, but

I find that by taking my first mouthful of medication, to me that's, it's huge, it's massive, it's something that I really don't want to do. . . . I've been living with [HIV] for 18 years, so I do accept it, but I find that by taking these medications, [the virus is] now dictating to me, not the other way around.

This symbolic dimension of treatment calls to mind van der Geest and Whyte's observation that, as "facilitators" of meaning, therapeutic substances invite "a concretization of ill-being" (1989:356). This ability of treatment to make HIV "real," or undo people's sense of well-being, strains the biomedical ambition to normalize life by transforming medical conditions; in the case of HIV, by making it inert and imperceptible at the molecular level, as if vanished from both blood and existence (Persson 2004). There are echoes of this theme in the broader literature on medication non-adherence: Taking prescribed treatment can be associated with illness rather than health, with loss of control and autonomy rather than empowerment, and with shame and difference, not normalization (Pound et al. 2005; Shoemaker and de Oliveira 2008). Clearly, many meanings that emerged in our study were at odds with the new agenda to encourage early treatment for personal health benefits. This agenda also urges people to start treatment to protect others and end the epidemic. This, as we discuss next, has some critical implications in relation to pharmaceutical citizenship.

Questioning Demarginalization

Nearly all participants were aware of the new agenda to maximize treatment-uptake to reduce HIV transmissions. Few disputed the scientific validity of HIV treatment-as-prevention, but their stories also revealed a sense of pressure to "do the right thing" for the sake of the wider community, regardless of sexual activities or health status, a call that brought about ambivalence and resentment among participants. Upending the demarginalization ethos of pharmaceutical citizenship, several participants raised concerns that this new treatment imperative could stigmatize people with HIV even further by framing them as a "threat to public health" in need of pharmaceutical control, as 62-year-old Robert put it. Or as 40-year-old Matt said: "I think within that message is an implied message, from my perspective as someone who is [HIV] positive, that I'm potentially irresponsible." Others, including 51-year-old Felix, were wary of the new treatment strategy's wholesale approach: "I'm uncomfortable with such a heavy push toward the medication . . . especially when you're giving medications to people that don't really need it, 'just in case.'"

This perception of an increasingly pro-treatment atmosphere in relation to HIV in Australia was a recurrent theme. "Everybody encourages it," said 31-year-old Dominic, who was recently diagnosed. "Everybody has done nothing but try to encourage getting on treatment sooner." Contrary to what might be assumed, HIV doctors were not always seen as the only or even primary source of this pressure. In fact, many felt assured that their personal health, rather than HIV prevention imperatives, was the main priority for their doctor when advising about treatment, a perception supported by HIV doctors (Mao et al. 2013; Persson 2014). As mentioned, stories of intense conflict over treatment were not absent from the interviews, but most felt their decision to not take treatment was respected, even if their doctor did not

always agree, and almost half stated that it was their doctor who recommended delaying treatment. This was a source of bemusement for some, given the general push for early and universal treatment. Gerard, 52 years old and recently diagnosed, said:

[My doctor]'s advising me not to go on treatments yet. So there's a bit of, a sort of discord between the public health campaigns and what I'm hearing from my doctor. So that's kind of a bit confusing to me. . . . [But] his focus seems to be on long-term outcomes.

As these quotes suggest, the pressure to take up treatment exceeded the clinic. It arose from a sense that HIV treatment had gained a normative status in the community. Time and again, participants mentioned that they did not know anyone else with HIV not taking treatment. "All the people I know in Sydney who are HIV are on treatment," said 53-year-old Bill, a gay man who had been HIV-positive for 17 years. "I am the only one I know of who is not." A few also mentioned the considerable currency that a medically suppressed viral load had acquired in gay sexual cultures, as 36-year-old Zach explained:

I think there is a general perception out there among gay men that somebody that's treated is less infectious than someone that's not treated or doesn't actually know [their status] . . . that someone that's positive and treated is actually a lot safer to be with.

Stories of being questioned or even reproached by friends, and in some cases family members, for not taking treatment were not uncommon. Neil was a 60-year-old heterosexual man who after nearly 20 years without treatment had recently tried it for a year but eventually decided it was not good for his health: "I've had plenty of people, arguments about my attitude to [treatment] . . . people who've said, 'You should be on it.'" Forty-three-year-old Ethan, diagnosed in 2002, spoke of similar experiences: "I know a lot of people on [treatment]. . . . They think I'm stupid! And I think they're stupid. We usually agree to disagree." These kinds of encounters made some feel delegitimized as people with HIV, as Simon explained, a 42-year-old gay man who had never taken any treatment since his diagnosis 18 years ago:

I found that I come up against a little bit of resistance and hostility when I'm talking to people, when people discover that I'm not on medication and I haven't been for a very long period of time. Other people, you get a real variation of reactions, and I've had people tell me that, "You have no idea. You don't know anything about this virus because you haven't experienced it. You haven't been what we've been through. You don't know what you're talking about." . . . It's a little bit unsettling because nobody deserves anything like that, but also people shouldn't be made to feel guilty because they're well.

Simon's quote speaks to a shared sense of being on the outside in a community where HIV treatment had lost its early activist beginnings as a right and instead had become repositioned as *de rigueur*. In this pro-treatment environment, participants

felt that not using treatment clearly rankled some, and that service relationships and situations could suddenly change and become alienating experiences once they disclosed their non-use of treatment. Alex, 34 years old and HIV-positive for 13 years, described how he had sought advice from an HIV service organization about helpful strategies to stay off treatment:

The response that I got back was, “Oh you’re just being stupid.” It was completely unsympathetic because, for some strange reason, the entire community, especially in Sydney, is pushing everybody onto medications. Like I was told, “You should do it because,” you know, “you shouldn’t have a problem. You should tell yourself that; I’m doing this so that other people don’t catch HIV from me.”

Such exchanges had a silencing effect, prompting many participants to keep quiet about their non-medication use. As 62-year-old Robert said: “I don’t openly tell anybody else that I don’t take the medication.” After 10 years of living with HIV and being active in the HIV sector, Robert explained that he had become more careful about disclosing this information after his relationship with an HIV service organization had “changed dramatically” when he informed them that he was not taking treatment. Not unlike the way an HIV-positive diagnosis can push people to the margins of society, Robert felt that his status and rights as a person with HIV were “branded” invalid by his own community:

I was feeling like a marginalised person within a marginalised group. . . . I thought, “Okay, this could be a new lot of branding.” . . . Within the [HIV] sector, whilst the HIV originally would have made [people with HIV] eligible, non-compliance with the medication and doing something alternative is enough to make them ineligible.

The impression that acceptance and inclusion now hinged on taking treatment was reinforced by a perceived lack of support in the HIV sector for those who choose to do otherwise. A feeling of being rendered invisible, even disqualified, was especially pronounced among those who did not subscribe to the HIV treatment revolution agenda or who were determined to avoid treatment for as long as possible, such as recently diagnosed 46-year-old Rachel: “It’s really weird. . . . We’ve got this disease and they hide us in that little corner and hope we all go away, you know? That’s what it feels like. There’s just nothing for people like us.” Alex elaborated along similar lines:

There doesn’t seem to be any real sort of support for people who don’t take medication because when you mention it to people . . . they’re incredibly pro-medication and they’ll put you down. . . . Why is there no group for us to meet and discuss . . . a place where we can meet that is safe, that embraces us rather than judges us?

These experiences sometimes coalesced into a profound sense of being on their own, of not seeing their experience mirrored or affirmed anywhere. To quote Alex

again: “I don’t have any friends who are positive but not on treatment. I wouldn’t know where to find them, mainly probably because they do isolate just like me.” Felix also mentioned feeling “very alone and isolated.” This 51-year-old gay man was utterly convinced that HIV drugs are ineffectual and potentially detrimental to health. His friends, HIV care providers, and even his naturopath had all strongly advised him to start treatment. He felt particularly pressured by his friends who were “really, really worried for me” and chastised him for jeopardizing his health after they had looked after him when he was very unwell when first diagnosed six years ago. “We can’t go and do that again, if you get sick again,” they told him. “And so I virtually have nobody . . . so, you know, it’s almost like you’re standing up by yourself against the whole world.”

In the previous section, we noted that one of the reasons for not taking treatment was its perceived capacity to undo normality and, thus, to marginalize. As we have shown in this section, by seeking to avoid being marginalized from everyday life by treatment, participants found themselves marginalized in a different way, by increasingly normative expectations and “responsibilities” around HIV treatment. Revealed, then, in these stories is some of the life that Marsland and Prince (2012:458) inquired about, the life that “spills out” at the margins of biomedicine’s promise of demarginalization. This lends weight to the converse side of Ecks’s theory: Pharmaceutical citizenship does not simply pull people from the edges, it also pushes them there (Ecks and Sax 2005).

New Margins: Concluding Reflections

In Australia, early treatment for the twin purposes of promoting personal health and population prevention has become a central component of the domestic HIV strategy, echoing and marshalling the global trend toward universal treatment of HIV infection. We noted that this trend follows growing evidence of the health benefits of early treatment and, above all, the remarkable trial results supporting HIV treatment-as-prevention. However, no matter how effective, drugs take on different tenors and trajectories as they relocate from the logics of the clinical space to the “complex calculus” of everyday lives, what Meyers 2013 refers to as the *afterlife* of therapies. There, treatment becomes a register for various human expressions and social positions that “can give value *to* and deprive value *from* emergent therapies” (Meyers 2013:20). One effect of this “afterlife” is the enduring issue of treatment non-adherence, which has become a major concern for global health agencies that see it as a costly threat to the management of chronic diseases worldwide (e.g., WHO 2003). With the burgeoning pharmaceuticalization of public health, this concern is likely to only deepen and put increasing pressure on people to comply with recommended treatment. The widespread hostility toward parents who refuse to immunize their children is one complex example of this.

As we have shown, there are multiple reasons why some people with HIV do not take treatment, ranging from acting on clinical advice, having concerns about potential side effects and not wanting to commit to life-long treatment sooner than might be necessary, to being unconvinced that HIV drugs will bring about (rather than undermine) the very premise of pharmaceutical citizenship: normality. Pound and colleagues (2005) claim that there is a tendency in some of the non-adherence

literature to focus on patient attributes and failings, or else on the meanings people give to pills. This, they argue, “makes the person, rather than the medicine, the focus of attention” (Pound et al. 2005:151). While we agree that a shift away from individuals is productive, our purpose in this article has not been to critique medicines per se, nor has it been to question the merits of early treatment or the potential for HIV medication to support people’s well-being and sexual and reproductive lives. Rather, we have taken inspiration from more recent theorizing of pharmaceuticalization and its relationship to contemporary citizenship to explore the implications of not taking treatment in the HIV treatment revolution era.

Anthropologist Vinh-Kim Nguyen argues that citizenship in the context of HIV treatment constitutes “a parallel and derivative citizenship” (2010:112) based on a “system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies” (2005:126). Nguyen focuses on how people with HIV in resource-poor countries have forged new biosocial identities based on biological status to leverage the state for therapeutic resources and rights. There are similarities here with the way affected communities in Australia and elsewhere used illness claims to rally for political recognition and access to treatment in the early HIV epidemic (Edwards 1997; Patton 2011; Power 2011). Today, in much of the developed world, citizenship in the legal sense automatically gives access to HIV treatment due to national health policies. Even so, with the expansion of the “globalized therapeutic economy,” Nguyen envisages that “the biopolitical production of subjects becomes ever more intimately tied to the biomedical” (2005:132). In this economy, where global health problems increasingly rely on “one size fits all” global solutions (Helman 2006:4), derivative configurations of citizenship emerge in relation to the various forms of engagement that people take up in relation to pharmacotherapeutic interventions, whether those engagements are enacted as advocacy, resistance, use, or non-use.

Ecks describes the biomedical promise of demarginalization as a contemporary citizenship project with the capacity to “redefine belonging, exclusion, duties and rights” (2005:241; see also Biehl 2007a). There is little dispute that biomedical technologies can reinstate citizenship to individuals and communities that have been excluded by virtue of their biological or social condition. However, it is worth pondering the other side of the equation and ask, as Ecks (2005:241) has done, “whether patients can only regain full citizenship rights if they undergo pharmacological treatment. In the era of global pharmaceuticalization, it is essential that this question extends beyond the scope of less-developed countries. As Cameron and Goodwin query in specific reference to the new HIV treatment agenda in Australia: “What will be the experience of those who do not toe the line and who, for whatever reason, do not go on treatment or test early? Should their right to manage their own health be applauded, supported, criticized or condemned?” (2014:204). Our findings provide a partial but significant rejoinder to these questions, tracing a sense of overt or subtle pressure to comply with this new agenda and, among some, disquieting feelings of exclusion and silencing, or a sense of no longer being seen as eligible in the HIV community because of their decision to delay or refuse treatment.

In global health discourses, access to treatment for people with HIV is now firmly established as a human right. There are, however, growing concerns among some activists and researchers that the rush to end the epidemic will override the

hard-won human rights and justice-based response to HIV championed by affected communities in Australia and elsewhere by putting increasing moral pressure on people to do their duty and act responsibly for the greater good, thereby undermining their right to autonomy, dignity, and freedom from discrimination (Barr et al. 2011; Cameron and Godwin 2014; Clayton et al. 2012).

Cindy Patton (2011) argues that the HIV treatment revolution also brings with it a troubling ontological shift in the way people with HIV are represented. Her genealogy of HIV rights argues that the new treatment paradigm, “superficially cloaked in rights-resonant language,” turns embodied *human beings* and their situated illness experiences into homogenized epidemiological *populations* whose aggregate viral load is to be reduced (2011:262). In this paradigm, treatment is promoted as the primary mechanism for HIV normalization by rendering void the stigma of infectiousness, but also as “the right thing to do.” As our findings suggest, the use of HIV treatment is itself being normalized, giving rise to a new criterion for citizenship among people with HIV.

The underbelly of these homogenizing tendencies is the power of pharmaceutical citizenship to become divisive by working to define *new margins* of inclusion and exclusion in relation to HIV: Who is “in” and who is not, who is acting wisely and responsibly or not, and who is deemed a proper HIV citizen and who is consigned to the “difficult” fringe. An intimation of this can be seen in the Australian Ending HIV campaign, which encourages members of affected communities to make a pledge—“I’m in”—to show their commitment to the new treatment agenda (<http://www.youtube.com/watch?v=ZwJWggUaht4> and <http://endinghiv.org.au/>). Through these kinds of practices, pharmaceutical citizenship becomes a process and a performance of “pharmaceutical subjectification” (Biehl 2007b:1114), which has the capacity to both demarginalize *and* marginalize (Ecks and Sax 2005:203).

As Ecks and Sax (2005:208) observe, and as our analysis bears out, “marginality is not an attribute or an essence, but rather a social practice: something that people do to each other.” Not paying heed to this relational aspect of marginality means that some people with HIV will “remain unheard despite all they have to say” (Biehl 2007b:1120). By giving voice to life on the new margins of the HIV treatment revolution, as we aspired to do in this article, anthropology has a vital role to play, along with other social sciences, in contributing to policy and practice by acting as a conduit between affected communities, local policymakers, and global health bureaucracies.

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