

## Potency and vulnerability: Troubled 'selves' in the context of antiretroviral therapy

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## Potency and vulnerability: Troubled ‘selves’ in the context of antiretroviral therapy

The concepts of health and self have become intimately entangled in contemporary western society. Health is figured as a marker of identity, as a vehicle of self-production and self-actualisation, while the individual is also made increasingly responsible for his or her health. In this paper, we explore how “self” is constituted in discourses that shape the ways in which people understand and do health and medicine, particularly discourses of neoliberalism and of the immune system. Of interest here is how the productive and unpredictable intra-action of medicine and bodies may come to trouble these discursive selves. Drawing on qualitative interviews, we situate our discussion in the context of *efavirenz*, an antiretroviral drug prescribed and consumed for the treatment of HIV infection. This drug, commonly described as “potent”, can have a number of troubling effects on a person’s everyday sense of self, including insomnia, confusion, cognitive disorders, depression, depersonalisation, psychosis, and suicidal ideation. While efavirenz may be clinically effective in its capacity to suppress the virus, these effects are at odds with the implicit aim of HIV medicine to restore and secure the self by way of immunological integrity and strength. These effects also bring into focus the predicament of choice under the contemporary political conditions of neoliberalism with its emphasis on health as an enterprise of the autonomous, rational self. In exploring first person accounts of efavirenz, the paper unpacks a number of the binary concepts on which contemporary discourses of health and medicine rely, such as immunity and vulnerability, potency and fragility, rationality and madness, self and non-self, and asks whether the individual under neoliberalism is being asked the impossible.

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## Potency and vulnerability: Troubled 'selves' in the context of antiretroviral therapy

The concept of health is absolutely central to modern identity ... 'health' is employed as an implicit language of the self (Crawford 1994: 1348).

On May 21, 2004, the following question was posted on TheBody, a popular website for HIV information: "I heard that taking Sustiva turns you into a nutcase ... Do you have any personal experience that would cause you to avoid it?" Resident expert, Dr. Frascino from the AIDS Foundation good-humouredly responded that "nutcase" was probably too general a term considering that Bush, Cheney and Rumsfeld "are all nutcases, but I'm not aware any of them are taking Sustiva". He went on to say that his own personal experience of Sustiva, a brand name for the HIV drug *efavirenz*, did not include any of the known "neurological side effects" but that, yes, about 50 percent of people taking this drug do experience them. However, these effects, he explained, usually resolve after a few weeks, and therefore, "waiting them out" is advisable (Body Health Resources Corporation, 2004).

Besides relativising the notion of madness, this exchange raises a number of compelling questions around the relationship between medicine, health and subjectivity in contemporary western society. Presumably HIV-positive, the inquirer is seeking information about a particular antiretroviral drug to help him, as a "health consumer", make an informed decision about suitable treatment. His concern about the rumoured capacity of *efavirenz* to turn one into a "nutcase" implies a perceived threat to individual agency, to the integrity and soundness of the self. In the medical literature, this potential effect of *efavirenz* on the self is

described by a number of troubling symptoms, including nightmares, confusion, depression, psychosis, depersonalisation, and suicidal ideation. These symptoms, which are unique to efavirenz among the available antiretroviral drugs, would seem to, in turn, trouble both neoliberal philosophies of health as an enterprise of the self-regulating, self-actualising subject, and the paradigm of biomedicine itself; its mission to eliminate all that which threatens the self. Specifically, these symptoms are at odds with the implicit aim of antiretroviral therapy to restore and secure the self by way of immunological integrity and strength.

The effects associated with efavirenz present some very distinctive problems that provide a unique site for a conceptual exploration of the relationship between health and self. Our intention in this paper is to elaborate on Crawford's opening statement that "health" is an implicit language of the self in modern society (1994). In doing so, our discussion is based in an understanding of "self" as, firstly, a phenomenological, indeterminate, and enculturated *process of being* that emerges and shifts through embodied engagement with the world, a process that gives rise to a *sense* of self. Secondly, "self" is understood as a *concept* that is discursively constituted, and deeply enmeshed in contemporary political processes, power relations and moral values. While Crawford is primarily concerned with "health" as a social currency and signifier in constructions of identity vis-à-vis imagined "Others", we are more interested here in notions of the self at play in contemporary discourses and practices of health and medicine. Situating our discussion in the context of efavirenz, we ask: how is self constituted in discourses that shape the ways in which people understand and do health and medicine; in particular, the discourses of neoliberalism and of the immune system? How are conditions of *vulnerability* and *immunity* of this self defined, and what happens when consumption of medicines, prescribed to ensure the *potency* of this self, has the contrary

effect and renders a person's sense of self more *fragile*? What are the consequences when medical prescription undermines the presumed capacity of this self to make rational choices for health and immunity? In short, how do particular effects of efavirenz bring about experiences and predicaments that come to trouble these discursive selves in significant ways?

In exploring these questions, we draw on accounts of consuming efavirenz from the *Side effects project*, a qualitative study conducted by the National Centre in HIV Social Research in Australia between 2002 and 2004. The aim of this study was to investigate how people experience and negotiate adverse effects from antiretroviral therapy, such as diarrhoea, nausea, fatigue, lipodystrophy, neuropathy, and “psychiatric” symptoms (Carr & Cooper, 2000; Machon & Batrouney, 1999). Semi-structured, in-depth interviews were conducted with 40 participants. While the study included women and heterosexual men, the majority of participants were Anglo-Australian middle-class gay men in their late 30s to mid-50s, reflecting the particular pattern of the HIV epidemic in Australia. Participants were recruited primarily through representative community organisations by means of mail-outs, newsletters, flyers, and snowballing. The basic criteria for inclusion in the study were HIV-positivity, past or present treatment with antiretroviral therapy, and past or present experience of adverse medical effects. Gender and sexuality were not specified. Participants were asked a range of open-ended questions about their medical history, their attitudes to HIV therapy, their interpretation of bodily symptoms, the impact of symptoms on everyday life and self, their understanding of “health”, and their daily health routines, including management of adverse medical effects. To enable geographical and cultural comparisons, the study included an urban arm (Sydney) and a regional arm (Northern Rivers, northern NSW). Thus the focus

and scope of the study were much broader than the issues considered here (see Persson, 2004; 2005; Persson, Fogarty, Rawstorne & Prestage, 2005).

While it is important to acknowledge that antiretroviral therapy has been of enormous benefit to many people with HIV/AIDS in parts of the world, it has also had many adverse, often unexpected consequences, with complex impact on experiences and subjectivities. For example, clinical constructions of HIV “health” through medical technologies may conflict with, but also mediate lived experience in complex ways (Persson, Race & Wakeford, 2003). Moreover, the *productive* capacity of medicine can bring about paradoxical and unpredictable effects that are contrary to its “restorative” objectives (Persson, 2004). Although many people have been shown to have serious reservations about taking medicines, there has been little debate in either the medical or the sociological literature about “the effects [medicines] have on peoples’ bodies and minds” (Pound, Britten, Morgan, Yardley, Pope, Daker-White, et al., 2005: 151). Having said that, in our discussion, we do not assume an implicit causal relation between medicine and bodies wherein drugs are seen as the agential force that impinges upon or determines passive bodies. This would require a belief in some pre-existing, pure body-self that is compromised or enhanced by pharmacological substances or by “medicalisation” (Berg & Akrich, 2004). Rather, we write from a position that does not privilege either bodies or medicine as given or *a priori*, but that sees any phenomenon (bodies, medicine, discourses, selves) as arising through “agential intra-action” (Barad, 2003).

Accordingly, we view the effects associated with efavirenz not as determinate, but as arising unpredictably in the encounter between bodies and medicine, a phenomenon clearly born out by the empirical material. Not all thirteen study participants who had consumed efavirenz experienced any symptoms. And of the eight participants who did, two described pleasurable

erotic dreams and a favourable increase in energy levels. Such pleasurable effects also point to the contingency of medicines by revealing how their consumption can enhance lived experience in unintended and unexpected ways. In this paper, however, we wish to explore the more problematic tensions between self and medicine that materialise when the self is vulnerabilised by prescribed drugs, an outcome that contradicts the restorative promise of biomedicine. We do so by focusing on the stories of Ethan and Thomas who experienced troubling effects on their everyday sense of self.

### **Efavirenz**

At present, there are several classes of antiretroviral drugs on the market, each designed to interfere in the viral replication process in different ways. Efavirenz, which belongs to the nonnucleoside reverse transcriptase inhibitor class, was originally developed by DuPont Pharmaceuticals and is today manufactured and marketed by Bristol Myers-Squibb in the United States and by Merck Sharp Dohme in Australia. The drug became available in Australia in 1998 through the Compassionate Access Scheme and was given general release in October 1999. Today, efavirenz is one of the most prescribed HIV drugs on the market. It is popular with both patients and health-care providers in America and Australia because its once-a-day dosing regimen and lack of food restrictions makes it easy to take, which is seen as favourable in terms of lifestyle and adherence. This drug is also popular because it is regarded as highly effective in terms of maximal viral suppression. Due to its renowned “potency”, efavirenz is considered a viable alternative to the protease inhibitor class of antiretroviral drugs, the so called “big guns” of HIV medicine, which are more demanding to take and are known for their adverse effects. However, while efavirenz is generally considered to be comparatively well-tolerated, it is not free from undesirable effects.

A number of potential effects are unique to efavirenz. Medical researchers refer to these as “neuropsychiatric adverse reactions”, “brain-related disorders”, or more commonly as “central nervous system effects”. The prevalence and severity of these effects vary widely in the medical research literature, with incidence rates ranging from 20 to 73 per cent among trial patients and with varying degrees of impact and persistence. In some studies, symptoms such as insomnia, dizziness, abnormal dreaming, anxiety, confusion, irritability and depression were described as “mild to moderate” with little impact on quality of life, and as “short-term” and primarily associated with the drug’s induction phase. Only in rare cases were symptoms considered as “severe” and as “long-term”. For that reason, central nervous system (CNS) effects were not construed in these studies as an obstacle to the therapeutic use of efavirenz or to patient adherence (see Molina, Ferchal, Rancinan, Raffi, Rozenbaum, Sereni, et al., 2000; Blanch, Martínez, Rousaud, Blanco, García-Viejo, Peri, et al., 2001; Fumaz, Tuldrà, Ferrer, Paredes, Bonjoch, Jou, et al., 2002; Fumaz, Muñoz-Moreno, Moltó, Negrodo, Ferrer, Sirera, et al., 2005). To minimise patient fear and severity of symptoms, thorough patient preparation and information is commonly recommended as a best practice strategy. In an article in the Australian community-based HIV media, US HIV clinician David Butcher argued that:

These side effects are very common, and very real, so you have to start off by understanding that pre-education is very important: they have to know exactly what to expect ... Half of the time, it’s fear of ‘What is going on with me?’ that makes the experience so intense they stop the drug. With all the trials worldwide, there have been thousands of people on efavirenz, and overall, the discontinuation due to CNS side effects has been very low – two to three per cent ... But you’ve got to go into it prepared. I ask everyone who starts to start taking it when they’re going to have a



weekend off, when they don't have to do anything intensive. I ask them not to drive. I ask them to have a support person around just in case ... There are anecdotal reports of depression and even psychosis, but those are incredibly rare worldwide (in Machon, 1999: 4).

Recent studies, however, have suggested that “moderate to severe” CNS effects, such as insomnia, abnormal dreams, anxiety, cognitive disorders, hallucination, depression and suicidal ideation, are much more common and long-lasting than previously reported (eg AIDS Alert, 2003; Lochet, Peyrière, Lotthé, Mauboussin, Delmas & Reynes, 2003). And other studies have shown that rates of discontinuation of efavirenz due to CNS effects are relatively high (eg Spire, Carrieri, Garzot, L’Henaff & Obadia, 2004). The aetiology of CNS effects is another issue of debate in medical science. Several studies individualise these effects, arguing that they are more common in patients with a history of mental illness and substance abuse, while other studies have shown no relation between such patient histories and CNS symptoms (eg Blanch, et al., 2001). Others have argued that HIV itself is associated with a number of “psychiatric manifestations” generally (see Foster, Olajide & Everall, 2003 for a review of the literature). More commonly, however, the drug is constituted as the active agent of side effects and efavirenz plasma levels as the exclusive predictor of some CNS symptoms (eg Núñez, deRequena, Gallego, Jiménez-Nácher, González-Lahoz & Soriano, 2001). Indeed, the pharmacokinetics of efavirenz are prioritised in that researchers argue that low plasma levels are associated with treatment failure and high plasma levels with CNS effects. However, it remains unclear what causes this pharmacokinetic variability, and therefore therapeutic drug monitoring and individual dose adjustment are now strongly recommended (Marzolini, Telenti, Decosterd, Greub, Biollaz & Buclin, 2001; Haas, Ribaudó, Kim, Tierney, Wilkinson, Gulick, et al., 2004).

These diverse and contested assessments of CNS effects not only hint at the indeterminate intra-actions of medicine and bodies, but are a source of considerable debate among people with HIV, on HIV information websites, and in community-based HIV media both overseas and in Australia (eg Haire, 1998; Furner & Kelly, 2000; Machon, 2000b; Lederer, 2004; Hoyt, 2000; 2004). In magazine articles and in online HIV discussion forums, experiences are relayed, tips are provided on how best to manage symptoms, the options for changing drugs are debated, anger and fears are vented, and clinical trial results that suggest efavirenz is well-tolerated are frequently challenged, along with notions of what constitutes a “good” or “normal” patient. For example, in POZ, a magazine for positive people available online, Spencer Cox (2000) dryly remarks: “Oddly, it always seems that subjects in clinical trials withstand drugs better than real people like me and you”.

Amid these debates, one theme that has been persistent in the medical literature and in the Australian community-based HIV media is that of *potency*; the notion of efavirenz as a highly “potent” substance with many prospects for therapeutic success. In this discourse, potency is used as a synonym for therapeutic efficacy, in other words, the power of the drug to suppress the virus, another substance commonly conceived of as “potent” in popular and medical discourse (for a discussion of the significations of HIV, see Treichler, 1991; Rosello, 1998; Waldby, 1996; Sontag, 1990). However, in medical discourse, the potency of efavirenz is also paired with a more complex representation of the dynamics of medical treatments. For example, in *Positive Living*, an HIV clinician is quoted as saying: “‘It is clear that these are very potent agents but it is also clear that they are very fragile agents’ ... which means that high level resistance develops very quickly to this class of drug if there is any HIV replication taking place” (Haire & Batrouney, 1998: 10). This pairing of the binary concepts of potency

and fragility resonates with the experiences of taking efavirenz explored in this paper. While the medical implication of this language appears to be organised around the careful prescription of such “potent yet fragile agents”, it can also be seen as metaphorically linked to a notion of the self as both potent yet fragile in the context of the productive capacity of efavirenz. To explore this connection, we turn to a ‘troubling’ of selves, firstly in immune system discourse and, secondly, in relation to neoliberal expectations of autonomous, rational subjectivity.

### **Self and immunity**

In 1994, Emily Martin proposed that “the immune system has moved to the very centre of our culture’s conception of health” (186). This statement captures a moment in history when medical, scholarly and popular interest in the immune system peaked with the rise of the AIDS epidemic in western societies. Today, “fitness” may have become equally central in response to the current “obesity crisis” (Monaghan, 2005), but the immune system continues to be a significant part of understandings and practices of health generally, and is clearly central to conceptions of HIV health. A “historically-specific terrain”, as Donna Haraway describes it, the immune system, in western medical discourse and in popular imagination, is the means by which the boundaries of the self are maintained, a self that is seen as ontological, yet always vulnerable to disintegration and contamination. What is at stake is the capacity to distinguish self from non-self, normal from pathological, inside from outside, and to launch a defence reaction if boundaries are crossed and the integrity of the self is threatened (Haraway, 1989: 27, 30; see also Martin, 1992: 126). In this model, as Crawford suggests, “a compromised immunity is a compromised self”, a self “overrun by other” (1994: 1358). The fear of AIDS is partly a fear of this “spoiling” of identity, of the tenuous relations and meanings that make up the boundaries of the self. It is the capacity of HIV to undermine

defences and dissolve *immunity* that makes it particularly threatening: “The fantasy is one of ultimate loss of control and loss of self” (Crawford 1994: 1358).

In contemporary health discourses that emphasise health as an enterprise of the self (eg Peterson & Lupton, 1996), the onus is on individuals to protect and bolster their immune system by minimising stress and engaging in responsible habits and healthy lifestyle choices. This notion that one can transform one’s immune system suggests a moralist discourse wherein a strong immune system becomes equated with superiority of self (Lupton, 1999: 50). These themes can be identified in contemporary advertising for antiretroviral drugs. While such advertising is not distributed directly to consumers in Australia, unlike in the United States, it is readily available to consumers on drug manufacturers’ websites and also appears on many HIV information websites that are accessed globally. In contrast to early media representations of HIV-positive people as isolated, bedridden patients ravaged by disease, the emphasis in contemporary advertising has shifted to HIV as a chronic, manageable illness and the HIV-positive person as an active, empowered and informed health consumer (Fuqua, 2002; Rosengarten, 2004). Frequently framed by vignettes of happy, robust people engaging in mountain climbing and other vigorous or adventurous activities, antiretroviral drugs are presented in these ads as not only enabling a return to bodily “normality” through their capacity to restore and strengthen the immune system, but also, by extension, as enabling individuality and potency of self. This discursive theme is similarly present in promotional material for efavirenz on the Bristol-Myers Squibb website, captured in cheery tag-lines, such as: “HIV medication with as many goals as you” and “Learn more about how you can focus on your goals with Sustiva” (Bristol-Myers Squibb Company, 2005).

These aspirational calls to self-production sit rather oddly beside the stories of those who experience the more common symptoms of efavirenz, such as confusion, speediness, or loss of concentration, and find themselves unable to focus on everyday tasks let alone their future goals. There is an even greater contrast with those who experience more severe symptoms, such as disengagement from reality, delusion, disorientation, psychosis, depersonalisation, or loss of identity. The story of Thomas provides an example of this. In his late thirties, Thomas was first prescribed efavirenz when a routine blood test indicated a deterioration of his CD4 count and an increase in viral load. He explained that he personally rationalised these clinical changes as a temporary effect related to a busy but stimulating working life at the time, and that overall he was feeling healthy and happy. However, his then consulting doctor was concerned that his existing HIV drug regime might be failing and suggested that efavirenz would be a good solution. He agreed to give it a try. One week into his new regime, Thomas began to experience severe sleep difficulties, fogginess, and “total confusion”, gradually making him feel like he was “going crazy” and losing his grip on reality. Over the following month, his mental state caused significant strain on his relationship and eventually led to him attempting to end his life:

It was very tumultuous. Oh, it was shocking. And basically, yeah, it culminated in me leaving my long-term partner with very much an attitude of – I was depressed that I was destroying her life by involving her with all this HIV stuff in the first place. My thinking had gone so fucking bizarre that I was making a decision for her that she didn't need me in her life. And that led to a nervous breakdown and me running a hose from the back of the car to try and kill myself ... I thought I was making her life better by destroying mine. And I have never felt like that in my entire life and can only associate it with the change in combination [therapy]. And it nearly killed me.

Thomas was found by a passer-by who dragged him out of his car. He subsequently sought professional help and was given information about efavirenz and the potential effects associated with it, which he felt were not properly explained to him at the commencement of the medication. This information, he said, “saved my life”, along with the medical advice that he should seriously consider stopping efavirenz, which he did. “Virtually after two weeks of not having it, I just knew a way forward ... what was totally confusing and abstract to me, was just clear as a bell”. With the support of a psychologist, Thomas began to rebuild his sense of self and pick up the pieces of his life and relationship.

Thomas’ story strains the imagined association between strength of immunity and potency of self. Although efavirenz had a positive clinical effect on his immune system, his sense of self became fragile and vulnerable to the point of depression and attempted suicide, exposing the untenability of the implicit assumption that a strengthening of immunity leads to, or is tantamount to, a strengthening of the self. What is intriguing and significant about efavirenz is its capacity to invert this assumption. For Thomas, it was not a compromised immune system that threatened to dissolve his self, but the very medication prescribed and consumed to ensure the self’s potency and integrity, a phenomenon that uncouples the moralistic discursive dyad of immunity and self. As we discuss below, what is also significant about the productive capacity of efavirenz is that this uncoupling of biological immunity and potency of the self brings into focus the predicament of *choice* under the contemporary political conditions of neoliberalism with its emphasis on health as an enterprise of the autonomous, rational self.

### **Self and neoliberalism**

Although the study of “neo” or “advanced” liberalism has become increasingly broad in recent years, many of its key thinkers agree that the contemporary purchase of neoliberal discourse as both a political philosophy and economic mantra has had considerable effects on the relationship between health and subjectivity (see for example, Rose, 1993; Petersen, 1997; Rimke, 2000). One of the key indicators of this transformation is the increasing emphasis on the individual’s responsibility for health (Galvin, 2002). As governmentality theorists argue, the neoliberal values that infuse the “political mentalities of the modern West” emphasise the entrepreneurial, autonomous individual who possesses the capacity and rational agency to care for him or herself (Rose, 1992: 142). Examples of these processes of “responsibilisation” in the medical domain include the escalating “genetic responsibility” of those at risk of a genetic condition such as Huntington’s Disease (Novas & Rose, 2000), and the increasing obligation for populations as diverse as “heterosexual men”, “sex workers” and “illicit drug users” to consume and adopt complex media directives for healthy living (Newman, 2005a; 2005b).

In the story of Ethan, the problematic currencies of responsibility and choice under neoliberalism are brought to the fore. Ethan, a 40 year old man, was diagnosed in 1995 as a late presenter with HIV-related opportunistic infection. His treatment history was long and complex, involving several changes in antiretroviral medication due to viral resistance and various undesirable effects. He had been informed by his doctor that his HIV was particularly “virulent” and that he was likely to need ongoing treatment, a notion he seemed to accept and act in accordance with. In 2001, Ethan was prescribed efavirenz in the hope that the drug, because of its renowned potency, would be more successful in controlling the virus than other HIV drugs had been. Shortly after commencing the drug, Ethan began to experience severe

insomnia, confusion, uncontrollable anger, and what he described as a sense of madness:

This was like a twenty-four hour a day thing that you just couldn't escape from. Your head was just in a scramble ... It was like I had no balance in the centre of my head ... You couldn't centre anything. Nothing made sense. Just total confusion ... You wanted to think one way, but your mind was wanting to go another way. And, yeah, you were just being pulled in every direction ... It was like I had no control over what was coming through my head.

Unable to sleep or think clearly, and finding it increasingly difficult to interact with other people or perform everyday tasks, Ethan found the experience of consuming efavirenz profoundly altering. "I felt like I needed to go into a mental home at one stage", he recalls. "I thought, 'I'm losing the plot!'" Exhausted and frightened, he rang his doctor almost every day, asking "what's wrong with me?" His doctor urged him to persevere, assuring him that the effects would eventually settle down. After initially complying with his doctor's advice, Ethan decided three weeks into the treatment that he could no longer cope. "I could live with most things, but not that", he explained, referring to the period as one of the worst experiences of his life. "You had no control over your life ... no control over your mind". He told his doctor that his decision was non-negotiable and a few days after he ceased the medication, the side effects resolved. Ethan was subsequently put on a different combination of drugs and has since had to change drugs a number of times due to ongoing problems with viral resistance and other side effects.

Ethan's story is revealing of the difficulties and tensions of trying to negotiate the effects of efavirenz in the context of contemporary expectations of the neoliberal self. As an active,



rational subject, Ethan was obliged to make the right choice in line with relevant expert advice in the interest of his health, and to take responsibility for the outcome (eg Lupton, 1997). Yet, his capacity as a rational subject was severely undermined by the very clinical prescription he was meant to follow. In his pursuit of health, and thus responsible citizenship, the prescription and consumption of efavirenz became a dissonant site where neoliberal ideals of autonomous agency and self-production converged with the experience of loss of control and a vulnerable, fragile self. In one sense, Ethan's decision to act against medical advice can be read as closely aligned to the neoliberal model of individual responsibility and rational choice. The act of choosing has itself become a marker of neoliberal subjectivity, as Rimke argues: "Above all, we are told, individuals possess the ability to *choose* happiness over unhappiness, success over failure, and even health over illness" (2000: 73, italics in the original). Efavirenz posed a threat to Ethan's capacity to act as a self-regulating subject and his decision to stop taking the drug can be seen as a rational decision to salvage this capacity. Indeed, reflecting on his experience, Ethan was very clear that he would never take efavirenz again because of the obliterating effect on his sense of self:

If there was another drug with [that] side effect, I would never take it. Even from the point where it may or may not help. I just wouldn't go near it any more ... if I was like that twenty-four hours a day, constantly, indefinitely, I'd prefer life to end, rather than be that way. Even just looking at that compared to having the virus, [the virus] is nothing.

This is a significant claim, since there are indeed limited treatment combinations available, and Ethan had already been exposed to many of them. In making this decision, Ethan seems to privilege the invulnerability of his rational self over immunological invulnerability, by

arguing that he would be prepared to compromise his immunity in order to *not* compromise his sense of self. If the price of immunological potency is a fragile self, or indeed madness, he is prepared to live with vulnerable immunity to protect the potency of his self. Yet, in another sense, it can be argued that what is at stake here is not only what *kind* of invulnerability is being sought, but what kind of *vulnerability* Ethan must *choose*. The productive capacity of efavirenz has forced Ethan into a making an invidious decision for which he must bear responsibility. He is obliged to choose between two undesirable alternatives: between a vulnerable self and vulnerable health, between madness and jeopardising the containment of his HIV.

### **Sleep, medicine, and bodies: The scrambling of phenomena**

Underlying this discussion is the caveat that we do not presume an implicit causal relation between medicine and bodies, wherein drugs are seen to act upon or determine a passive body. Rather than privileging either bodies or medicine as determinate, we view the experiences associated with efavirenz as arising through their unpredictable encounter. This is particularly brought to the fore in accounts of sleep, where sleep becomes a site of dissonance between neoliberal expectations of the self-regulating subject and lived experiences of consuming efavirenz. Stories of efavirenz explored in this study provide evocative examples of profoundly disturbed sleep and dreams, and are often concerned with how efavirenz denies access to what Meadows has described as “normative sleep embodiment”, that is, what medical and popular discourse of healthy living evaluate as “the appropriate, healthy amount of sleep” (2005: 246). Sleep has become a topic of increasing concern in the sociology of health and illness in the last few years. Researchers observe a “medicalisation” and “healthicisation” of sleep, as lack of sleep becomes framed as a risk factor in the onset of illness, and getting enough sleep of the right kind becomes central to the

quest for health (eg Williams, 2002, Meadows, 2005, Hislop & Arber, 2003). This trend includes the classification of new medical conditions such as “daytime sleepiness”, which is represented as a “risky somatic state and a problem of self-government” (Kroll-Smith & Gunter, 2005: 347).

As sleep is reconfigured in this way, the enactment of the healthy neoliberal self becomes at least partly characterised by the amount and quality of sleep achieved each night. Sleep becomes “an event we continually prepare for and rehearse, schedule and organize, as part and parcel of our normal everyday (waking) lives” (Williams, 2002: 174). And when sleep is compromised, whether through insomnia, restlessness or waves of intense dreaming, not only are the experiential dimensions of waking life transformed, so is the possibility of fulfilling the requirements of the waking, rational, self-regulating subject. This is evident in Ethan’s experience of efavirenz. His description collapses the categories of waking and sleeping, rationality and madness:

All I remember is either not being able to sleep, total insomnia, and when I could go to sleep it was for – as soon as I got into a deep sleep, I’d just have these really nightmarish type dreams. Like you were actually, it was actually happening and you were in them, but you weren’t? If that makes any sense ... If you were awake it was constantly – your head was just in a scramble. If you were asleep, you were still in a scramble, the dreams. So it was like just twenty four hours a day. And I’d just come out of it so exhausted.

For Ethan, the capacity to enact the rational self was destabilised as he moved through indeterminate phenomenal states: insomnia, nightmarish dreams, confusion, exhaustion. His

sense of self was “scrambled” by feeling as though he was never quite awake, never quite asleep; by a lack of distinction between alert consciousness and dream states. Not only does this “scrambling” make it difficult to privilege the rational waking self; it also pulls apart the fiction of fixed causal relations between sleep, medicine and subjectivity. It becomes difficult to make sense of what is causing what, as sleeplessness, nightmares, madness, and medical side effects blur and mesh. That is, the causality of disturbance is scrambled, hinting at the non-rational intra-action of the various phenomena involved. In Ethan’s case, this scrambling was compounded by a semiotic confusion between feeling like and unlike himself, as he was confronted with an uncharacteristic propensity for anger and violence:

I just felt like I wanted to rip someone’s head off ... I wanted to throw plates around the house, which was not like me ... I don’t have a violent streak in me. And yet all I wanted to do was destroy something.

This unpredictable intra-action between medicine and bodies is further evidenced by some of the other interview narratives of efavirenz that are beyond the scope of this paper, including stories about unexpected pleasures taken in highly erotic dreams, and bursts of energy channelled into the completion of tedious domestic chores. Indeed, pleasure is another important dimension of the drug-body-self nexus, signalling different *kinds* of unpredictable encounters between bodies and medicine that could be usefully explored in future research to further interrogate deterministic representations of medicine. In the stories presented here, efavirenz troubles the assumption in both immune system discourse and neoliberal discourse that it is possible to make rational choices between various determinate states of being. The logic of choice requires clear, binary distinctions between well-defined categories: health and illness, immunity and vulnerability, sleep and exhaustion, self and non-self. Yet these stories

suggest that experiences and practices of medicine and “health” may be far more ambiguous and “messy” than this model allows.

### **Troubled selves**

The introduction of new treatments and combination therapies in the mid 1990s has vastly improved the lives of many people with HIV in Australia and other parts of the world. Our intention in this paper has not been to argue to the contrary, or to make a case against “bad medicine”. Rather, it has been to explore how experiences associated with one particular antiretroviral drug challenge notions of the self that are at play in discourses and practices of health and medicine. As Robert Crawford was quoted at the start, increasingly, “health is employed as an implicit language of the self” (1994: 1348). The capacity of efavirenz to render vulnerable and fragile the very self that it is prescribed and consumed to secure has the concomitant effect of troubling the contemporary logic of health and medicine as practices of self-production and self-regulation, and the idea of an ontological self that is restorable or enhanced by way of immunological integrity and strength.

Firstly, the stories presented here invite us to question whether the self under neoliberalism is asked the impossible: to make rational choices about things that aren’t necessarily rational; to exercise choice and self-mastery where there is little choice and where the capacity for autonomy is limited; and to bear responsibility for outcomes that are in many ways beyond individual control. These stories clearly challenge the presumption that it is uncomplicated or always possible to choose health over illness, immunity over vulnerability, rationality over madness, sleep over exhaustion, self over non-self, or potency over fragility. These questions are particularly significant in relation to HIV medicine, a domain defined by indeterminacy

and change, a domain wherein discourses on treatment and best practice are diverse and often conflicting (Newman, Persson & Ellard, in press). On the other hand, it is perhaps precisely because of this indeterminacy that HIV medicine has given rise to not only an unparalleled consumer activist movement, but to an abundance of social research that has explored and unpacked concepts such as health, illness, compliance, and the patient.

Secondly, the stories presented here also invite reflections on the notion of the self implicit in medicine. Throughout its history, the vision and objective of western medical science have been to control and ultimately eliminate the conditions of vulnerability, delineating, in the process, the parameters of normative being (Shildrick, 2001: 155-156). The pledge of medicine is the restoration of an ontological self through the expulsion of that which is predicated as non-self, a paradigm that is articulated and affected in HIV medicine by a widespread emphasis on maximal viral suppression. In this discourse, as Haraway observes, “immunity and invulnerability are intersecting concepts” (1989: 30). Stories of efavirenz interrupt this conflation of self, immunity and invulnerability, not by denying the efficacy and merit of this drug, which are as real as its limitations, but by suggesting that, despite the medical effort to attain immunity, invulnerability of the self does not necessarily follow. This suggestion may be of little direct relevance or consequence in the lives of those adversely affected by efavirenz. However, the imperative of an undetectable viral load as an ideal and normative outcome in HIV medicine is increasingly being questioned by both clinicians and patients in terms of its potential costs to individual lives, health and well-being. In this respect, a move towards troubling the discursive and causal linkage of potencies – medicine, immunity, self – is significant indeed.

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