

Body–drug assemblages: theorizing the experience of side effects in the context of HIV treatment

Marilou Gagnon* RN PhD and Dave Holmes† RN PhD

*Associate Professor, and †Full Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa, Ottawa, ON, Canada

Abstract

Each of the antiretroviral drugs that are currently used to stop the progression of HIV infection causes its own specific side effects. Despite the expansion, multiplication, and simplification of treatment options over the past decade, side effects continue to affect people living with HIV. Yet, we see a clear disconnect between the way side effects are normalized, routinized, and framed in clinical practice and the way they are experienced by people living with HIV. This paper builds on the premise that new approaches are needed to understand side effects in a manner that is more reflective of the subjective accounts of people living with HIV. Drawing on the work of Deleuze and Guattari, it offers an original application of the theory of ‘assemblage’. This theory offers a new way of theorizing side effects, and ultimately the relationship between the body and antiretroviral drugs (as technologies). Combining theory with examples derived from empirical data, we examine the multiple ways in which the body connects not only to the drugs but also to people, things, and systems. Our objective is to illustrate how this theory dares us to think differently about side effects and allows us to originally (re)think the experience of taking antiretroviral drugs.

Keywords: antiretroviral, ART, assemblage, Deleuze and Guattari, HIV/AIDS, side effects.

The day after I took the medication. Like, my body was like, ‘What is this?’ You know, it just told me like something’s different. And I noticed it, it just... like my ear would start to ring or I would see little spots or something,

but it wasn’t me, it was my body telling me, ‘This is something different and we have to deal with it somehow’, you know? It was weird and I didn’t like it.

Correspondence: Dr Marilou Gagnon, Associate Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa, 451 Smyth Road, Ottawa, ON K1H 8M5, Canada. Tel.: (613) 562 5800 ext. 8249; fax: (613) 562 5443; e-mail: marilou.gagnon@uottawa.ca

Introduction

Despite the availability of new (and supposedly less toxic) antiretroviral drugs in industrialized countries and the simplification of treatment options (i.e. all-in-one combination tablets such as Atripla®), side

effects continue to affect people living with HIV (PLWH) (Esté & Cihlar, 2010; Hawkins, 2010; Reust, 2011; Margolis *et al.*, 2014). Short-term and long-term side effects are well documented in PLWH, although at present, it remains difficult to determine exactly how many people experience side effects and what side effects are most commonly reported (Hawkins, 2010). Short-term side effects typically include gastrointestinal toxicities (e.g. diarrhoea, nausea, vomiting, and bloating), central nervous system toxicities (e.g. vivid dreams, off-balance or unsteady walking, light-headedness, drowsiness, feeling ‘hungover’, feeling like falling over, spinning or room spinning, and difficulty concentrating), fatigue, anaemia, hypersensitivity reactions, and drug-induced organ toxicities (Hawkins, 2010). Short-term side effects can dissipate on their own after weeks and months of treatment, but they can also persist over time and have long-lasting effects on PLWH. Long-term side effects include cardiovascular, hepatic, renal, metabolic, neurologic, and musculoskeletal events such as myocardial infarction, hepatotoxicity, renal dysfunction, dyslipidaemia, insulin resistance, diabetes, lipodystrophy, distal sensory peripheral neuropathy, cognitive deficits, and bone loss (Hawkins, 2010). In addition to the common side effects listed above, each antiretroviral drug currently available has a unique side effect profile and a comprehensive list of potential drug–drug interactions (Reust, 2011).

For PLWH, side effects are central to the experience of living with the treatment but rarely have they been studied alone (Persson, 2004, 2005; Gagnon & Holmes, 2011, 2012, 2016; Gagnon, 2012). Unlike other aspects of that experience, like quality of life (Wong & Ussher, 2008), treatment adherence (Mykhalovskiy *et al.*, 2004), health (Persson *et al.*, 2003), and the imperative of achieving ‘good results’ (Persson *et al.*, 2003; Rosengarten *et al.*, 2004; Wong & Ussher, 2008; Persson, 2013), side effects have not benefited from the same level of empirical and theoretical engagement from scholars. As such, we continue to see a clear disconnect between the biomedical view of side effects which dominates the field of HIV and the actual experience of PLWH who continue to struggle with side effects. In order

to better understand this experience in all of its complexity, we must turn to theories that allow us to do two things: first, we need to rethink the experience of side effects as a whole. Finding new ways of theorizing this experience is the only way we can challenge the status quo, which is clearly not working for healthcare providers and, most importantly, for PLWH. Healthcare providers lack the necessary understanding to properly assess, recognize, and manage the experience of side effect (Gagnon & Holmes, 2016). They also tend to minimize and simplify this experience (Gagnon & Holmes, 2016). In turn, this has a negative impact on PLWH. Key issues identified by PLWH include the lack of information and conversation about side effects, the ‘5-min’ consultation model which limits interactions with physicians, the overemphasis on laboratory results, the overreliance on medications to treat all problems, the ‘pathologization’ of normal reactions to side effects, the authoritarian and paternalistic attitudes of physicians, the tendency to minimize and even disregard the experience of side effects, and the lack of understanding of what that experience entails for PLWH (Gagnon & Holmes, 2016). Second, we need to critically examine how we conceptualize the relationship between the body and antiretroviral drugs (as *technologies*). This paper will seek to address both of these points by drawing on Deleuze and Guattari’s theory of assemblages and empirical findings on the experience of side effects (Gagnon & Holmes, 2016). We begin by situating the empirical work which will serve as the foundation for our theoretical analysis. We then provide a brief overview of Deleuze and Guattari’s theory of assemblages and apply this theory to the experience of side effects using three types of assemblages. We conclude this paper with a general discussion of the broader implications of using this theory in health sciences and its potential contribution to the development of a critical nursing scholarship on the relationship between the body and technology.

Situating the empirical work

In 2014, we interviewed 50 participants as part of a 2-year grounded theory study designed to (1) gain a

critical understanding of the experience of side effects; (2) explore an alternative approach that takes account of the multiple connections between the body and antiretroviral drugs; and (3) describe to what extent these connections constitute an important aspect of daily experiences and allow for more connections to be formed with people, things, and systems. This study was undertaken in Canada's capital region. This region includes the city of Ottawa (Ontario), the city of Gatineau (Quebec), and their surrounding urban and rural communities. Together, the province of Ontario and Quebec account for 65.9% of PLWH in Canada (Public Health Agency of Canada, 2010). After obtaining ethics approval from the Research Ethics Board at the University of Ottawa, we recruited and interviewed the participants. Each interview was audio-recorded using a digital voice recorder and transcribed. Data analysis followed the principles of constructivist grounded theory as defined by Charmaz (2006, 2014). During the analysis, three main categories were identified: (1) the side effects; (2) the experience; and (3) the connections. The first category focused on the context in which side effects are experienced, the different types of side effects that participants described, and the nature of the side effect experience. The second category described the experience of side effects through three interrelated processes: becoming with, living with, and dealing with. Finally, the third category revealed that new connections are formed with people, things, and systems in the presence of side effects. These categories are discussed more explicitly in a separate publication (Gagnon & Holmes, 2016). For the purpose of this paper, we will focus exclusively on the theoretical openings that were identified during the analysis and more specifically, during the development of the third category (the connections). These theoretical openings are particularly valuable and provide a useful starting point to rethink the experience side effects.

Rethinking side effects

Poststructuralism can be described as a philosophical tradition mainly developed by Continental philosophers in the 1960s and 1970s (Williams, 2005).

Philosophers such as Deleuze & Guattari, Derrida, Foucault, Lyotard, and Kristeva have been known to develop and nurture this philosophical tradition that focuses, amongst other things, on truth, discourses, knowledge, power, norms, structures, effects, and subjectivities (Williams, 2005). More specifically, according to Scott (2001) poststructuralism is an antifoundationalist approach that attends to language and meaning-making: 'a starting point for understanding how social relations are conceived, and therefore—because understanding how they are conceived means understanding how they work—how institutions are organized, how relations of production are experienced, and how collective identity is established' (p. 255). Through such a critique, we begin to understand that our social order is neither necessary, natural, nor 'true'; things might have been otherwise, which implies that we might intervene in that social order and open a world of possibilities for the future. In this, we might say that poststructuralism destroys the idea of foundations as far as truth, discourses, knowledge, and subjectivity are concerned.

Poststructuralism has had and continues to have a profound impact on various disciplines that make up the social sciences and humanities such as philosophy, history, sociology, and linguistics. More recently, it has gained considerable popularity in health sciences as more and more scholars in nursing, social work, physiotherapy, and human kinetics are trying to find alternative (and more critical) ways of studying health-related phenomena and new tools to produce knowledge outside the biomedical paradigm. In nursing, for example, we have seen an important increase in research and scholarly analyses that draw on poststructuralism over the past 20 years. This is largely due to the work of one poststructuralist thinker, Michel Foucault. His writings were highly influential in the development of a critical tradition in nursing scholarship (Gastaldo & Holmes, 1999; Peron *et al.*, 2005). Poststructuralism also gained in popularity in health sciences because more qualitative researchers started using discourse analysis and learned about the theoretical underpinnings of this research methodology. While some may argue that discourse analysis remains at the margins (Cheek,

2004), it has made a significant contribution to the development of critical research in health sciences (Crowe, 2005).

Poststructuralism poses a challenge because it is not one thing (Williams, 2005). It brings together a group of thinkers (some of them listed above) who share a common focus and purpose, but whose perspectives are quite different from one another (Williams, 2005). In this study, we draw on the writings of Deleuze & Guattari (1987) and more specifically on their theory of assemblages. Over the past few years, we have seen authors draw on the theory of assemblages to study phenomena such as mental health recovery, schizophrenia, drug use, harm reduction education, ill-health, disability, anonymous public sex, raving, erectile dysfunction, medical/health history, action research, feminist research, surveillance, and urban policies on homelessness (Jordan, 1995; Haggerty & Ericson, 2000; Malins, 2004a, 2004b; Potts, 2004; Holmes *et al.*, 2010; Fox, 2011; Duff, 2014; Farrugia, 2014; Fletcher, 2014; Foley, 2014; Gale, 2014; Lancione, 2014; Ringrose & Renold, 2014; Diedrich, 2015; Stephens *et al.*, 2015). This theory is particularly relevant to our work because it dares us to not only (re-)think how bodies and antiretroviral drugs come together, but also how side effects become actualized in a given assemblage of bodies, drugs, objects, people, relations, events, discourses, practices, and institutions. Furthermore, it offers new insights into the productive power of antiretroviral drugs and the active role they play in the lives of PLWH (Rosengarten, 2009; Bennett, 2010).

In their theory of assemblages, Deleuze & Guattari (1987) challenge our very understanding of the body by doing two things. First, they insist that the body has no meaning in itself, it has no essence and cannot be defined as a single physical unit; it exists in the form of a political surface able to connect with other bodies and a myriad of heterogeneous elements (Duff, 2014). Second, they recognize that bodies are not just human bodies but also animal, chemical, social, virtual bodies (Duff, 2014). In order to work with a Deleuzian–Guattarian perspective, scholars have to challenge their understanding of the world and the structures that organize it (e.g. linguistic, discursive, symbolic,

semiotic). To achieve this, they must first abandon the differentiation of subjects and objects, humans and nonhumans, inside and outside, macro (molar) and micro (molecular) in favour of a new ontology capable of explaining how these entities come to being and *connect* together in various ways (Duff, 2014). In other words, they have to disrupt traditional boundaries to see the world differently – a world constantly in flux, composed through complex connections between heterogeneous elements that exist interdependently and non-hierarchically on a single plane (Farrugia, 2014). These connections contribute to what Deleuze & Guattari (1987) call assemblages. One immediate consequence of this new ontology is the need to study the formation and effects of such assemblages more closely and in various contexts.

The existing literature on the theory of assemblages suggests that human bodies form connections with others bodies, persons (e.g. friends, partners, researchers, healthcare providers), parts of persons (e.g. anus, lips, penis, vagina), or things (e.g. clothes, drugs, music, syringes, computers), in order to allow *intensities* to flow in different directions, producing new potential *becomings* and therefore new subjectivities. Assemblages take the form of multiple and creative connections that are forever in flux – and therefore, never completely stable nor fixed (Fox, 2011). According to Deleuze & Guattari (1987), human bodies tend to create their own configurations with a range of diverse animate and inanimate elements; they seek to form new and original assemblages that have the potential to transform them or to experience new modes of being. Therefore, assemblages have the capacity to *territorialize* by bringing together elements and create original connections, but also the capacity to *de-territorialize* itself by cutting connections with former elements and creating new ones with other elements. In short, some connections work towards the stability (*territorialization*) of the assemblage increasing its internal stability, while other connections are simply working to destabilize it (*de-territorialization*). The same assemblage can be made of components working to stabilize and destabilize it at the same time (DeLanda, 2013). This is why assemblages are so

complex – always open to becoming otherwise in shifting fields of connections (DeLanda, 2013).

In theory, assemblages differ from one person to another and are comprised of ephemeral connections and therefore forever in the process of *becoming* something else (Deleuze & Guattari, 1987). It is thus important to understand and acknowledge that this long-lasting state of *becoming* signifies not a transition from one point to another, but rather, a perpetual state of transition and never actually achieves a final form. An assemblage is perpetually transforming itself ‘into other assemblages, breaking apart and having its sub-assemblages growing into, joining, or producing, in their turn, other assemblages, and so on’ (Holmes *et al.*, 2010, p. 254). This ongoing re-organization of connections that shape assemblages occurs against multiple contextual inductions that force the person to behave in certain ways, attempting to impede the re/creation of oneself. The person runs the risk of being ordered and trapped through and within discourses (Malins, 2004a, 2004b) that tend to identify, classify, and hierarchize his or her behaviours (Holmes *et al.*, 2010). Thus, multiple and disparate forces attempt to block the creative process (*becoming*) of assemblages forcing them to comply to equally multiple and disparate grids threatening the person’s potential to ‘become-other’. In short, assemblages often work in opposition to rigid (social, medical, pharmaceutical, etc.) grids. They are, more often than not, caught between the fix and the flux, the stratified and the smooth, and the norm and the margin. When assemblages, either transiently or permanently, become stratified, assemblages become *machinic*.

The machine has neither identity nor objective: ‘it is defined by the specificities of its components’ (Nixon, 2012, p. 109). Within the machine, the fluid and flexible compositions of assemblages are replaced by static connections between elements that make up assemblages. The latter are then stratified to the point that creativity is shunned. It is not that *machinic* assemblages are negative in and of themselves, but they become fixed and unable to afford the same level of creativity (dependency to a specific treatment for instance for the human *machine* to survive). In fact, we can assert that assemblages become

machines when experimentation and flux are replaced by dependent connections and fixation. In their words, the ‘machine is like a set of cutting edges that insert themselves into the assemblage undergoing *detritorialization* [the act of ‘coming undone’], and draw variations and mutations of it’ (Deleuze & Guattari, 1987, p. 367; also see Deleuze & Guattari, 1983, p. 322). In other words, from the moment those connections become rigidly combined (i.e. antiretroviral drugs–body–virus) and (over) coded, these connections become part of a stratified assemblage: a machine. As Malins (2004a, 2004b) points out, bodies of knowledge that tend to classify and hierarchize (like medicine) have stratifying tendencies. As stated above, according to Deleuze & Guattari (1987), assemblages must avoid stratification and remain forever in flux or run the risk of transform themselves into an apparatus of capture.

Body–drug assemblages

In order to rethink side effects through the work of Deleuze & Guattari (1987), we need to start with the most basic assemblage: *antiretroviral drugs–body*. This particular assemblage requires us to challenge the traditional divide between the material (antiretroviral drugs) and the living (body). From this perspective, antiretroviral drugs and bodies are no longer seen as separate entities with a clear and logical path of action – with bodies functioning as determinants and drugs as ‘things’ that are passively absorbed, distributed, metabolized, and excreted. Instead, both bodies and antiretroviral drugs are understood through the connections they form and what they actively produce as a result of these connections – including side effects. Such connections are neither fixed nor predictable. They are in constant flux – in constant transition and movement. They also vary from one person to another, meaning that every person who takes antiretroviral drugs experiences these connections differently. As such, each assemblage is unique even when it is stripped to its most basic elements: antiretroviral drugs and bodies. This further intensifies as additional connections are formed with other bodies, drugs, objects, people, relations, events, discourses, practices, and

institutions. It also becomes increasingly complicated by the fact that antiretroviral drugs have a ‘life of their own’ (Bennett, 2010). Their efficacy and agency depend on the nature of these connections, which are highly variable from one person to another.

It is impossible to conceptualize the body–drug assemblage as consisting only of bodies and antiretroviral drugs. Starting at the time of treatment initiation, it quickly evolves to include connections with laboratory tests (i.e. genotype, phenotype, viral load, and CD4 count), healthcare providers (i.e. physician, nurse, pharmacist, social workers, and so forth), service providers (i.e. community-based workers and peer navigators), and a range of interventions (i.e. monitoring, support, education, counselling, and so on). Over the course of treatment, it is further elaborated into a broader network of connections with other PLWH (including special interest groups), organizations, providers, programmes, companies, laboratory tests, objects, forms, other drugs, just to name a few. Again, it is important to highlight that the body–drug assemblage is never fixed but rather, that it remains in a constant *state of becoming*. This is where side effects come in. Side effects result from the constant flux and reorganization of the connections mentioned above. As such, they can arise at any point in time over the course of the treatment. Side effects have the potential to produce new modes of being for PLWH. They also have the potential to transform the body–drug assemblage into a stratified/machinic assemblage. Both of these can be assumed to take place simultaneously as people come to experience side effects.

People who take antiretroviral drugs share a common desire to be healthy, stay alive, and live well. The desires to achieve an undetectable viral load and reduce the risk of HIV transmission are also very prominent at the moment because the preventative benefits of antiretroviral treatment (known as treatment as prevention) are increasingly being praised and used to inform how we provide HIV care. The body–drug assemblage allows these desires to materialize by suppressing the virus and restoring immune function. When this is the case, the body–drug assemblage is seen as a ‘life-enhancing assemblage’ – one that increases the potential

to form creative and productive relations that contribute to ‘desirable’ modes of being (Malins, 2004a, 2004b). In the context of HIV treatment, these include being healthy, undetectable, non-infectious, safe, adherent, responsible, proactive, successful, and so forth. At the same time, this assemblage is capable of producing new, sometimes unpredictable and conflicting modes of being. For example, it can contribute to PLWH becoming sick or disabled due to multisystem side effects that accumulate and persist over time. Here, it is important to recognize that these modes of being are not physical in essence. Rather, they are produced in a given assemblage of bodies, objects, people, relations, events, discourses, and institutions. As such, they are as physical as they are social, cultural, psychological, relational, institutional, and political.

We have already established that an assemblage is perpetually transforming itself. Side effects contribute to that transformation by producing new connections with people, tests, drugs, and objects. For the participants we interviewed, their experience of side effects was formed through an assemblage comprised of *antiretroviral drugs, body, virus, physician, medical specialists, physiotherapist, occupational therapist, pharmacist, nurse, peers, tests, assistive devices, monitoring devices, programmes, additional drugs, supplements, food, peers, and so forth*. Considering that PLWH experience multiple side effects, it is safe to presume that the complexity and multiplicity of connections within any given assemblage is endless. What is important here is not that all connections are mapped. It is the fact that this approach offers another way of thinking about the experience of ‘becoming-with’ (Farrugia, 2014) side effects and works in opposition to rigid grids that are typically used to define what this experience entails. When these grids are applied in such a way that the experience of side effects is the same for everyone, the assemblage becomes stratified/machinic. The most appropriate example to illustrate this phenomenon is the application of pharmaceutical grids to determine which drugs cause which side effects.

Body–drug assemblage can become machinic when connections are rigidly combined in a ‘one size fits all’ fashion. This is often the case with side effects

and their clinical management. It can also become machinic when fixed categories and hierarchies are used instead of allowing creativity to flow. This typically happens when both PLWH and healthcare providers are positioned in fixed roles (i.e. patients and experts) or when providers are seen as the only credible source of knowledge on side effects. In this particular case, allowing for creativity to flow would mean acknowledging that people who take antiretroviral drugs possess an expertise on side effects and creating a space for people-to-people connections to take place outside the clinical setting. The body–drug assemblage can also become machinic if we categorize its effects as either good *or* bad. Its effects cannot be categorized in such a way as to reinforce a fixed system of binaries as the assemblage itself is always in a state of becoming – becoming bad or good, or both at the same time (Malins, 2004a, 2004b). Rhizomatic thought provides an interesting standpoint for understanding this process because it acknowledges that multiple relations are formed simultaneously at any point in time and acknowledges that any given assemblage has multiple potentials – some ‘good’, some ‘bad’ (Malins, 2004a, 2004b).

To further illustrate the complexity of the body–drug assemblage, we will draw on the data collected for our study. More specifically, we will focus on three key interviews which were conducted with male participants, aged between 50 and 60 years of age. All three participants had been living with HIV for more than 10 years at the time of the interview and had been on multiple drug regimens. Specific excerpts from interviews will not be used. Instead, we will use the complete interviews as reference points to provide three different examples of body–drug assemblages. As previously argued, it is impossible to map all of the connections contained in a given assemblage. As such, our intention here is not to capture all of these connections, but rather to expose the ones that were most significant to participants and highly influential in shaping their experience of side effects. Three specific examples of assemblages are used to expose the numerous interfaces PLWH connect with in terms of people, things, and systems.

Assemblage #1

When we interviewed informant 9, his current drug regimen had been unchanged for many years. His experience with prior drug regimens had been difficult one; he experienced severe drug toxicities including hepatotoxicity resulting in a serious health scare and a long hospitalization. At the time of the interview, he lived with chronic diarrhoea, cramping, nausea, headaches, extreme fatigue, and cognitive impairments. These side effects forced him to create new connections with medical specialists and medical tests including tests to determine the origin of his cognitive impairments. His gastrointestinal side effects changed the way he related to familiar objects in his environment. For example, his whole life was organized around his ability to access a toilet. This not only restricted his movements, travels, and activities, but it also made him isolated and withdrawn from all spheres of social life. Leaving the house meant that he had to know where the toilets were at all times. This information determined his itinerary, how far he could go, where he could, and who he could go with. Maintaining a constant connection to a toilet became a priority for him – something he needed to plan for and always think about. Gastrointestinal side effects also changed his relationship to food: what he ate, how much he ate, and when he ate. Food became yet another thing to be managed. Because of the episodic and unpredictable nature of his side effects, he was forced to leave his employment and remain on a disability state programme for financial assistance (and coverage of antiretroviral drugs) until the age of retirement. His connections with state programmes, including the disability state programme and the pension state programme, made him feel extremely stressed and vulnerable. These connections provided some support, but they also put him in a precarious situation. He was worried about financial security, housing, access to and quality of drug coverage, and so forth. In his own words, side effects create ‘a chain of connections’: because of the side effects of the drugs, you cannot have a job; because you cannot have a job, you do not have a pension; because you do not have a pension, you worry about financial security; and so on. To add

further complexity, his connections with the health-care system care made it nearly impossible for him to move to a more affordable city with more accessible housing. Overall, the experience described by informant 9 clearly shows how body–drug assemblage expands well beyond the physical and the chemical. In the context of side effects, connections multiply and act in a various ways to shape the lives of PLWH. This is clearly illustrated here and in the next sections.

Assemblage #2

Informant 34 also tried various drug regimens over the years. However, unlike informant 9, he had stopped numerous times because of unpleasant and disruptive side effects. At the time of the interview, he had been on the same drug regimen for 9 years. He was experiencing side effects from that regimen (e.g. dyslipidaemia and nausea). In addition, he was still experiencing the long-term effects of past side effects including body shape changes (known as lipodystrophy) and peripheral neuropathy. The lipodystrophy changed his physical appearance permanently. However, his experience with peripheral neuropathy stood out during the interview because it clearly illustrated the power of connections formed in the body–drug assemblage. He had developed peripheral neuropathy at a time where antiretroviral drugs known as nucleoside reverse transcriptase inhibitors (or NRTIs) were widely used. As a result, he experienced severe pain in his feet which made it difficult for him to walk. He was prescribed Percocet (acetaminophen and oxycodone) to alleviate that pain. Gradually, he became addicted to opiates and was forced to seek methadone substitution therapy. At the time of the interview, he was still taking methadone and was actively followed by an addiction and mental health specialists. He explained that side effects made him ‘do more drugs’ and drink more. It multiplied and intensified the connections with substances that could help him cope with the difficulties he faced – including the difficulties in living with side effects. Starting with his first drug regimen, these connections evolved quickly to a point where a new problem (i.e. drug addiction) was created. He explained that side effects not only

increased the presence of substances in his life, but also increased the presence of prescription of drugs more generally. In other words, side effects created a vicious cycle in which medications are used to manage a problem caused by medications in the first place. He described how new medications were added one by one to deal with each side effect individually to the point that he had to take 10 more pills a day. Like informant 9, he relied on a disability state programme for financial assistance and coverage because he could no longer work – primarily because of the peripheral neuropathy. Because of his financial situation and recovering addictions, he was in a transitional housing facility. Overall, his experience supports the idea that antiretroviral drugs exercise their own power and agency. In the context of side effects, this can lead to connections that are neither fixed nor predictable as conveyed above.

Assemblage #3

Much like the majority of PLWH who were diagnosed in the early days of the HIV epidemic, informant 32 had tried every available antiretroviral drug on the market since being diagnosed. At the time of the interview, he was taking insulin and 55 pills a day, of which 10 were for HIV only. He was a living proof that side effects multiply connections with prescribed and over-the-counter medications which, in turn, create additional side effects and responsibilities. Over the years, he had experienced every possible side effect on the list we provided at the beginning of the interview – including drug-induced diabetes, hypertension, myocardial infarctions, hypercholesterolaemia, peripheral neuropathy, and lipodystrophy, just to name a few. As a result, he was strongly connected with a range of medical specialists (e.g. endocrinologist, cardiologist, nephrologist, ophthalmologist, and neurologist) in addition to his HIV specialist and primary care provider. He was actually working with an entire team of cardiac rehabilitation specialists to change his diet, exercise more frequently, control his blood pressure and glucose level, and reduce his health risks. As a result of his side effects, he had to establish permanent and everlasting connections with ‘things’ such as glucometers, blood pressure monitors, syringes, and so on; in his

own words, a packsack full of things he has to carry around at all times. In turn, these devices were connected to his prescription drugs, insulin, food, and fluid intake. Side effects changed his relationship to food and fluids. Food had to be planned, timed, measured, controlled, replaced, and sometimes forced into the body to prevent hypoglycaemia. Similarly, fluid intake had to be reduced to manage his hypertension. All and all, side effects completely transformed the way he connected with food and fluid which now served as side effects management 'tools'. Unlike the other informants, he was also strongly connected with community-based organizations and peers. In fact, forming connections outside the healthcare system was central to his experience with side effects. Over the years, he had developed a strong network of peers with who could provide information and advice based on their first-hand experience of side effects. This was particularly interesting because it shows the creative potential of connections that can be formed with people in the context of side effects.

Final remarks

In the light of the recent efforts and developments to increase coverage and use of antiretroviral drugs in Canada as well as internationally, we strongly believe that a renewed commitment to side effects is necessary to better understand the experience of people who take these drugs and address their needs – which remain largely unmet despite all of the scientific and medical advancements in HIV care. Exploring new ways of thinking about side effects both theoretically and empirically should be part of this renewed commitment. Our position resonates with the view of Rosengarten (2009) who has written extensively on the need to challenge our current understanding of the relationships between 'the living' (i.e. the human body and the person) and 'the material' (i.e. the antiretroviral drugs, the virus, the tests, the information). In her book entitled 'HIV Interventions: Biomedicine and the Traffic of between Information and Flesh', she draws on the poststructuralist theory of performativity and actor-network theory to challenge the conventional nature

of these relationships. Rosengarten (2009) wants us to consider antiretroviral drugs as active agents with a life (and agency) of their own instead of passive 'things'. She also wants us to consider how information circulates through the textual (discursive), the material, the living, and the social to shape how HIV is understood and embodied. Evidently, these ideas align perfectly well with the work of Deleuze and Guattari.

Drawing on the work of poststructuralist thinkers such as Deleuze and Guattari has challenges. Not only are they difficult to understand because they have their own unique (hermetic) language and concepts, but they also require a complete transformation of the way we see and think about the world. And because poststructuralism is a radical departure from the existing structures (e.g. linguistic, discursive, symbolic, semiotic), it involves taking positions that can be seen challenging at times. For example, it is challenging to disrupt binary thinking because it is deeply rooted in our understanding of the world and it is seen as a universal, natural, and logical framework to organize our thoughts. Taking a position that calls into question and transforms this mode of thinking is daring, and to some extent, risky. Yet, it is increasingly being called for by scholars like Bennett (2010), Duff (2014), and Rosengarten (2009) who think the time has come to break down the binaries human/non-human, living/material, and person/thing, and pave the way for new ways of thinking about materiality in general. However, as pointed out by Bennett (2010), 'it is easy to acknowledge that humans are composed of various material parts (the *minerality* of our bones, or the metal in our blood, or the electricity in our neurons). But it is more challenging to conceive of these materials as lively and self-organizing rather than passive or mechanical means under the direction of something nonmaterial, that is, an active soul and mind' (p.10). The same goes for antiretroviral drugs. It is easy to see these drugs as passive chemicals (magic bullets) that operate in mechanical ways under the direction of the physician and the person taking these drugs. However, it is more challenging to recognize that antiretroviral drugs are active agents with their own vitality, energy, and agency. These drugs are capable

of collaborating by creating the desired connections with the virus (i.e. viral suppression). But they are also capable of creating their own connections with cells (i.e. mitochondrial toxicity, hypersensitivity reactions, inflammation), organs (i.e. neurotoxicity, hepatotoxicity, gastrointestinal toxicities, and so on), and other drugs. Recognizing antiretroviral drugs as ‘living chemicals’ is a difficult position to take and to maintain for the following reasons: it disrupt the way we generally think about antiretroviral drugs and how they work, it takes away some of our own power and control over these drugs, it creates uncertainties that are hard to explain and manage, and it raises questions about our own existence.

The writings of Deleuze and Guattari do not provide answers nor does it produce absolute truths. Instead, they raise more questions and offer new insights. They provide tools for analysis and new ways of doing political action. At times, this can be frustrating for people who are looking for a ‘quick fix’ or practical solutions. Through our experience, we have come to appreciate the fact that questions must be asked if we ought to change how we understand side effects. There is no point in thinking about solutions if the existing structures are not problematized first. For more than 20 years now, these structures have maintained the status quo on side effects. It is through those very structures that side effects have been increasingly silenced, pushed aside, and virtually erased in recent years. Within these structures, there is very little space for critique. Antiretroviral drugs are either ‘good’ or ‘bad’. Talking about the ‘bad’ goes against the ‘good’. As such, we must refrain from talking about the ‘bad’ because simply put, who wants to take drugs that are ‘bad’ for them? This binary opposition could not be further from the lived experience of PLWH. People who live with side effects know that their drugs are ‘good’ and ‘bad’ for them at the same time (Persson, 2004; Gagnon & Holmes, 2011, 2012; Gagnon, 2012). However, as long as side effects are positioned in opposition to the ‘good’ of antiretroviral drugs, change will be impossible. It is our hope that this paper will encourage further discussions on this particular issue and offer an alternative logic that can guide both research and scholarly work on side effects in a

context where bold claims are increasingly being made about HIV treatment and its outcomes (Nguyen *et al.*, 2011).

Acknowledgements

This work was supported by an Operating Grant from the Canadian Institutes of Health Research [HHP - 131554].

Conflict of interest

The authors declare that there is no conflict of interest.

Ethics approval

This study was approved by the Research Ethics Board at the University of Ottawa [H09-13-14B].

References

- Bennett J. (2010) *Vibrant Matter: A Political Ecology of Things*. Duke University Press, Durham.
- Charmaz K. (2006) *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. Sage, London.
- Charmaz K. (2014) *Constructing Grounded Theory*, 2nd edn. Sage, London.
- Cheek J. (2004) At the Margins? Discourse analysis and qualitative research. *Qualitative Health Research*, **14**(8), 1140–1150.
- Crowe M. (2005) Discourse analysis: towards an understanding of its place in nursing. *Journal of Advanced Nursing*, **51**(1), 55–63.
- DeLanda M. (2013) *A New Philosophy of Society*. Bloomsbury, New York.
- Deleuze G. & Guattari F. (1983) *Anti-Oedipus: Capitalism and Schizophrenia*. University of Minnesota Press, Minneapolis.
- Deleuze G. & Guattari F. (1987) *A Thousand Plateaus: Capitalism and Schizophrenia*. University of Minnesota Press, Minneapolis.
- Diedrich L. (2015) Illness as assemblage: the case of hystero-epilepsy. *Body & Society*, **21**(3), 66–90.
- Duff C. (2014) *Assemblage of Health: Deleuze Empiricism and the Ethology of Life*. Springer, London.
- Esté J.A. & Cihlar T. (2010) Current status and challenges of antiretroviral research and therapy. *Antiviral Research*, **85**(1), 25–33.

- Farrugia A. (2014) Assembling the dominant accounts of youth drug use in Australian harm reduction drug education. *International Journal of Drug Policy*, **25**(4), 663–672.
- Fletcher E.H. (2014) Dis/Assembling schizophrenia on youtube: theorizing an analog body in a virtual sphere. *Journal of Medical Humanities*, 1–18 doi:10.1007/s10912-014-9286-4 [Epub ahead of print].
- Foley R. (2014) The Roman-Irish batch: medical/health history as therapeutic assemblage. *Social Science & Medicine*, **106**, 10–19.
- Fox N.J. (2011) The ill-health assemblage: beyond the body-with-organs. *Health Sociology Review*, **20**(4), 359–371.
- Gagnon M. (2012) Understanding the experience of reconstructive treatments from the perspectives of people who suffer from facial lipoatrophy: a qualitative study. *International Journal of Nursing Studies*, **49**(5), 539–548.
- Gagnon M. & Holmes D. (2011) Bodies in mutation: understanding lipodystrophy among women living with HIV/AIDS. *Research and Theory for Nursing Practice*, **25**(1), 23–38.
- Gagnon M. & Holmes D. (2012) Women living with HIV/AIDS and the bodily transformation process known as lipodystrophy: a grounded theory study. *Journal of Research in Nursing*, **17**(3), 215–228.
- Gagnon M. & Holmes D. (2016) “So far it’s been choosing which side effects I want or I can deal with”: a grounded theory of the HIV treatment side effects among people living with HIV. *Aporia: The Nursing Journal*, **8**(1), 19–40.
- Gale K. (2014) Action research and assemblage: engaging Deleuzian pedagogy and inquiry beyond the constraints of the individual and the group in education settings. *International Journal of Qualitative Studies in Education*, **27**(5), 667–681.
- Gastaldo D. & Holmes D. (1999) Nursing and foucault: a history of the present. *Nursing Inquiry*, **6**(1), 17–25.
- Haggerty K.D. & Ericson R.V. (2000) The surveillance assemblage. *British Journal of Sociology*, **51**(4), 605–622.
- Hawkins T. (2010) Understanding and managing the adverse effects of antiretroviral therapy. *Antiviral Research*, **85**(1), 201–209.
- Holmes D., O’Byrne P. & Murray S.J. (2010) Faceless sex: glory holes and sexual assemblages. *Nursing Philosophy*, **11**, 250–259.
- Jordan T. (1995) Collective bodies: raving and the politics of Gilles Deleuze and Felix Guattari. *Body & Society*, **1**(1), 124–144.
- Lancione M. (2014) Assemblages of care and the analysis of public policies on homelessness in Turin, Italy. *City*, **18**(1), 25–40.
- Malins P. (2004a) Machinic assemblages: Deleuze, Guattari and an ethico-aesthetics of drug use. *Janus Head*, **7**(1), 84–104.
- Malins P. (2004b) Body-space assemblages and folds: theorizing the relationship between injecting drug user bodies and urban space. *Continuum: Journal of Media & Cultural Studies*, **18**(4), 483–495.
- Margolis A.M., Heverling H., Pham P.A. & Stolbach A. (2014) A review of the toxicity of HIV medications. *Journal of Medical Toxicology*, **10**, 26–39.
- Mykhalovskiy E., McCoy L. & Bresalier M. (2004) Compliance/Adherence, HIV/AIDS and the critique of medical power. *Social Theory & Health*, **2**(4), 315–340.
- Nguyen V.K., Bajos N., Dubois-Arber F., O’Malley J. & Pirkle C.M. (2011) Remedicalizing an epidemic: from HIV treatment as prevention to HIV treatment is prevention. *AIDS*, **25**, 291–293.
- Nixon R. (2012) Machinic assemblages. In: *Demystifying Deleuze* (eds R. Shields & M. Vallee), pp. 107–110. Red Quill Books, Ottawa.
- Perron A., Fluet C. & Holmes D. (2005) Agents of care and agents of the state: bio-power and nursing practice. *Journal of Advanced Nursing*, **50**(5), 536–544.
- Persson A. (2004) Incorporating pharmakon: HIV, medicine, and body shape change. *Body & Society*, **10**(4), 45–67.
- Persson A. (2005) Facing HIV: body shape change and the (in)visibility of illness. *Medical Anthropology*, **24**, 237–264.
- Persson A. (2013) Non-infectious corporealities: tensions in the biomedical era of ‘HIV normalisation’. *Sociology of Health & Illness*, **35**(7), 1065–1079.
- Persson A., Race K. & Wakeford E. (2003) HIV health in context: negotiating medical technology and lived experience. *Health*, **7**(4), 397–415.
- Potts A. (2004) Deleuze on viagra (or, what can a ‘viagra-body’ do?). *Body & Society*, **10**(1), 17–36.
- Public Health Agency of Canada (2010). HIV/AIDS Epi Updates. Retrieved from: http://www.phac-aspc.gc.ca/aids-sida/publication/epi/2010/pdf/EN_Intro_Web.pdf.
- Reust C.E. (2011) Common adverse effects of antiretroviral therapy for HIV disease. *American Family Physician*, **83**(1), 1443–1451.
- Ringrose J. & Renold E. (2014) “F**k Rape!”: exploring affective intensities in a feminist research assemblage. *Qualitative Inquiry*, **20**(6), 772–780.
- Rosengarten M. (2009) *HIV Interventions: Biomedicine and the Traffic between Information and Flesh*. University of Washington Press, Seattle.
- Rosengarten M., Imrie J., Flowers P., Davis M.D. & Hart G.J. (2004) After the euphoria: HIV medical technologies from the perspective of their prescribers. *Sociology of Health & Illness*, **26**(5), 575–596.
- Scott J.W. (2001) Deconstructing equality-versus-difference or, the uses of poststructuralist theory for feminism. In: *Theorizing Feminism: Parallel Trends in the Humanities and Social Sciences* (eds A.C. Herrmann &

- A.J. Stewart), 2nd edn, pp. 254–270. Westview, Boulder, CO.
- Stephens L., Ruddick S. & McKeever P. (2015) Disability and Deleuze: an exploration of becoming and embodiment in children's everyday environments. *Body & Society*, **21**(2), 194–220.
- Williams J. (2005) *Understanding Poststructuralism*. Acumen Publishing Limited, Chesman.
- Wong W.K.T. & Ussher J.M. (2008) Life with HIV and AIDS in the era of effective treatments: 'it's not just about living longer!'. *Social Theory & Health*, **6**, 117–131.