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Éditorial/Editorial

Since the advent of highly active antiretroviral therapy (HAART) in the 1990s, people with HIV have begun living longer, healthier lives. This has accordingly afforded many of these men and women the opportunity to fulfil aspects of their lives that they previously could not have. From an HIV prevention perspective, though, these changes create new challenges: population-specific and population-sensitive initiatives are now needed to help HIV-positive people adopt, lead, and maintain healthy sex lives. Indeed, sexual expression is a vital aspect of human existence, regardless of one's HIV status, and thus constitutes an important topic for public health workers and researchers alike.

One strategy by which public health workers have attempted to assist HIV-positive people with the task of maintaining a healthy sex lifestyle has been by encouraging these men and women to disclose their HIV status to potential sexual and injection drug using partners. Recently, however, such disclosure has begun to be more frequently enforced via criminal law, even in cases where scientific evidence indicates that HIV transmission would not occur. For example, criminal convictions were levelled against an HIV-positive person who spit at another person. The court in this case ruled that the saliva of this HIV-positive constituted a deadly weapon. In other cases, HIV-positive people have been convicted for having performed oral sex without previously disclosing their HIV status. In these cases, the likelihood of HIV transmission is so low that scientific evidence refuted the criminal process; nevertheless, HIV-positive men and women have been convicted in these situations.

While such criminal prosecution might appear to be a sound approach for preventing HIV transmission, it has many problems. The most notable shortcoming is that these laws do not target the correct group. Research from the national public health agencies in Canada, the United Kingdom, the United States, and Australia (to name a few) indicates that people who are unaware that they are HIV-positive cause the majority of HIV transmission. Indeed, it is estimated that people who are unaware of their HIV-positive status (who only account for 25-30% of the foregoing country's national HIV prevalence) are responsible for upwards of 75% of the annual HIV incidence. Stated numerically, this means that, in Canada, 15,800 (i.e., the 26% who are unaware that they are HIV-positive) of all HIV-positive people (n=65,000) cause 1,750 (i.e., 75%) of the 2,500 annual cases of HIV. The remaining 49,200 people who are HIV-positive and aware of being are thus only responsible for 750 incident cases of HIV each year in Canada. Quite evidently, criminal laws which mandate HIV disclosure could only induce a minimal reduction in HIV transmission because they have no effect on people who are HIV-positive, yet unaware of being so. In fact, ignorance of one's HIV status is immunity to these laws.

Of even greater concern, though, is that these laws seem to oppose other HIV prevention initiatives. On one hand, public health workers encourage HIV testing because awareness of one's HIV status correlates with decreased HIV transmission; people often forego practices that can easily transmit HIV once they become aware that they are HIV-positive. On the other hand, however, criminal laws might discourage testing. If one can be criminally charged even when one's practices cannot transmit HIV (such as in the case of spitting), why would an individual want to know his/her HIV status? Because the benefits of early treatment are highly contestable, and the legal repercussions of non-disclosure are not, the foregoing question is both valid and pressing. Public health professionals and researchers must begin to tackle this problem, particularly because the rates of prosecution for HIV non-disclosure are accelerating worldwide.

The implications of this criminalization trend are widespread. As it stands, the police in many countries can both obtain supposedly confidential documents and can use these documents as evidence against HIV-positive people. Health care professionals must therefore be aware of the HIV criminal laws in their respective jurisdictions. This is imperative; inaccurate assurances about confidentiality could be given to HIV-positive patients if clinicians do not know the state of their local HIV disclosure laws. Problematically, false guarantees of confidentiality could diminish the reputation and usability of HIV prevention services. As public perceptions about confidentiality strongly predict the usage of sexual health and HIV testing/treatment services, anything which undermines the privacy of these services is likely to deter people from using them. Likewise, researchers who gather data from HIV-positive people should also proceed with caution. Locked filing cabinets, ethics approval, and promises of confidentiality are not sufficient to prevent police interference.

The foregoing thus necessitates action. Health care professionals and researchers must determine if and how their work could compromise the wellbeing and the safety of patients/participants. This would include, at a minimum, a review of documentation techniques and an examination of the methods by which informed consent is obtained. The significance of the current situation is pressing, particularly when one considers that awareness about being HIV-positive often corresponds with decreased HIV transmission, and that the prosecution of

HIV-positive people may deter testing. The immediate moment (i.e., now) is thus an opportune time for exploring how charting practices can be modified to promote confidentiality, how HIV testing can be encouraged despite legal disincentives, and how the HIV criminalization trend can be reversed. While discussions currently exist about HIV disclosure laws from a legal, human rights, and population health perspective, little exists to guide clinical and research practices, and little focuses on how these laws may impede the development of therapeutic or caring relationships. This information is needed.

In closing, let us return to one of the founding principles of the helping/healing professions: first do no harm. In appreciating the significant nature of this statement, it is obvious that health care professionals and researchers (i.e., we) must protect HIV-positive patients and research participants from the strong arm of the law. This is required in an effort to help maintain the progress made in the field of HIV prevention over the last three decades. We should not return to the days when knowing one's HIV status was a social, economic, and personal liability, which outweighed the benefits of knowing one's HIV status. We should move forward, making knowledge, and not a lack thereof, powerful. If knowledge is power – as it is theorized – then let us ensure that it remains as such in the realm of HIV prevention. Let us challenge the current criminalization trend in HIV on ethical, legal, and public health grounds, and let us work toward decreasing HIV transmission without discouraging testing, without limiting confidentiality, and without creating further problems for people who are living with HIV.

Patrick O'Byrne
Editor

Abstract
The Canadian Immigration and Refugee Protection Act of 2001 outlines conditions under which individuals may be granted or denied admission to Canada. The Act stipulates that applications for residence will be rejected if their health is expected to generate excessive demand on Canadian health or social services. The purpose of this paper is to derive a statistical definition of excessive demand and to apply that threshold to persons with HIV who are seeking admission to Canada. The paper demonstrates that the current threshold used by Citizenship and Immigration Canada is much lower than the thresholds that may be derived statistically.

Key Words economic burden of disease, health economics, HIV/AIDS, immigration policy

When Does an Immigrant with HIV Represent an Excessive Demand on Canadian Health or Social Services?

PETER COYTE &
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Introduction

In 2005, the *Canada Communicable Disease Report* estimated that 58,000 people in Canada were living with HIV.[1] During that year it was estimated that between 2,300 and 4,600 new cases of HIV emerged, with the incidence rate relatively uniform since 2002.[2] The number of people worldwide living with HIV is approximately 33 million and increasing.[3] As the world HIV population expands, there is expected to be an increase in the number of HIV-positive immigrants applying for entry to Canada,[4] and accordingly, it is important to critically review federal immigration policies that affect such applicants.

The *Canadian Immigration and Refugee Protection Act* (IRPA) states in Section 38(1) that:

> A foreign national is inadmissible on health grounds if their health condition:
> (a) is likely to be a danger to public health;
> (b) is likely to be a danger to public safety; or
> (c) might reasonably be expected to cause excessive demand on health or social services.

While IRPA does not specifically mention HIV or related illnesses, Canada generally excludes people infected with HIV if they can be expected to place an "excessive demand" on publicly funded health or social services. It is important to note that entry restrictions to Canada based on HIV status do not apply to short-term visitors staying for less than six months.[5] This is indicative of the underlying assumption that HIV is not highly contagious and therefore is not reason in itself for a person to be denied entry to Canada. The extent to which an immigrant is likely to place an excessive burden on the health care system is indicated as the primary concern and is evaluated based on whether an applicant's projected annual health care costs would exceed the annual health care costs of an average Canadian,[4] which in 2007 was $4,867.40.[6] It is not specified what constitutes an 'average' Canadian, given the large within-group variation that exists among the general population, but it is likely that an HIV-positive person receiving antiretroviral treatment will incur expenses that exceed that threshold. While the law has resulted in denial of admission due to "excessive burden" to only 3.4% of all HIV-positive applicants between 2006 and 2007 (i.e. 36 of 1,050), the overwhelming majority of the HIV-positive applicants (94.7% or 994 of 1,050) were exempt from this condition as they were admitted as spouses or legal dependents under family-class sponsorship or as officially recognized refugees. Consequently, 64.3% of those HIV-positive applicants (i.e. 36 of 56) who were at potential risk of denial of admission due to the potential "excessive burden" attributable to their HIV status were denied admission between 2006 and 2007.

The purpose of this paper is twofold: first, to review the application of Canadian immigration law and jurisprudence as it pertains to persons with HIV and to place this review within a broader international context of restrictions on international mobility; and second, to derive a statistical definition of excessive demand and to apply that threshold to persons with HIV who are seeking admission to Canada. In Section 2.0, we review the application of Canadian immigration law as it pertains to persons with HIV. In Section 3.0, we review and assess the current threshold used to determine excessive demand on Canadian health or social services. Section 4.0 yields a synthesis of the clinical, epidemiological and economics literatures concerning the expected burden placed on health or social services by persons with HIV. In Section 5.0, we derive estimates of the economic burden of a new immigrant with HIV after stratifying for their underlying health state, age and sex at the time of admission. Section 6.0 affords a comparison between the thresholds derived to measure excessive demand with the expected economic burden that immigrants with HIV may place on Canadian health or social services in order to yield evidence-informed criteria for the determination of medical inadmissibility. We conclude with a brief summary of our findings.

Canadian and international experience with medical inadmissibility

While international standards do not prohibit the practice of screening prospective immigrants for communicable diseases prior to entry, the scope of restrictions on people with HIV is strictly constrained. According to the International Guidelines on HIV and Human Rights:

> The right to liberty of movement encompasses the rights of everyone lawfully within a territory of a State to liberty of movement within that State and the freedom to choose his/her residence, as well as the rights of nationals to enter and leave their own country….
> Where States prohibit people living with HIV from longer-term residency due to concerns about economic costs, States should not single out HIV, as opposed to comparable conditions, for such treatment and should establish that such costs would indeed be incurred in the case of the individual alien seeking residency.[7]

In the United Kingdom, Australia and the United States, it is common to deny admission to prospective immigrants with HIV. In the United Kingdom, denial of admission to HIV-positive immigration applicants has occurred on the basis that required treatments may be too expensive for the applicant to afford.[8] While a publicly funded National Health Service (NHS) allows citizens of the United Kingdom to seek health care treatment at minimal individual cost, the UK's immigration practice has been to stringently enforce its policy of medical inadmissibility to deter persons with HIV from engaging in 'treatment tourism'.[9]

In Australia, travelers wishing to stay temporarily in the country for short visits may do so but are required to sign a declaration of good health, or otherwise state the health problems with which they are currently living.[8] Based on the information provided, a person may be deemed inadmissible for even a temporary visit, although such cases are typically reserved for severe circumstances. In order to immigrate to Australia, each applicant must undergo HIV testing and if it is suspected that the cost of health care treatment will be excessive, or will subsequently deny Australian citizens access to limited health care resources, an applicant may be denied admission.[8]

In the United States, no person with HIV, in principle, may be admitted to the country as an immigrant.[8] Under exceptional circumstances a person may be admitted temporarily (30 days or less) to visit family, seek medical treatment or to conduct business.[8] While admission to the United States does not require one to undergo a medical examination, it is important to note that if a foreign national knowingly declares that he or she is HIV-negative and is found to have HIV in the United States after arrival, that person will be deported to his or her country of origin.[8]

Such strict international migration policies are not the global standard, however, as in both Denmark and Sweden there are few entry restrictions for HIV-positive persons.[8] Many Western countries have denied medical treatment to persons with HIV who are often from countries in which access to antiretroviral (ARV) treatment is not readily available.[10] Further, the incidences of deportation which have been noted in both the United States and the United Kingdom,[11] on the grounds that HIV-positive persons tend to place excessive demands on health care services, has been questioned on the basis of health as a human right, while the act of deportation itself has been deplored as 'immoral'[9] and 'unjustifiable'.[11]

The financial burden of HIV on the general population is evaluated at the level of the individual and is typically based on a metric involving the calculation of hospitalization costs, ARV and drug treatment expenses as well as the use of other health care services.[11] In a 2001 study conducted by Chen et al.,[12] concerning the per capita costs of HIV based on medication and hospitalization expenditures in the United States, it was found that disbursements for highly active ARV therapy were relatively constant at $10,500 USD across all CD4 cell count strata. However, patients with CD4 cell counts less than 50 cells/mm3 incurred costs that were 2.6 times greater than the total annual expenditures of patients with CD4 cell counts less than 350 cells/mm3.[12] The study concluded that an increase in disease severity was positively correlated with increased health care costs.[12] The implications of this finding suggest that the use of health care services by persons with HIV increases over time and needs to be considered in the evaluation of applicants seeking to migrate to countries such as Canada. At present, Citizenship and Immigration Canada (CIC) uses an Operational Processing Instruction manual to assess the eligibility of HIV-positive applicants that may enter Canada. The manual indicates that certain applicants may be Excessive Demand Exempt (EDE), according to Section 38(2) of the IRPA, in cases where one,

> (a) has been determined to be a member of the family class and to be the spouse, common-law partner or child of a sponsor within the meaning of the regulations;
> (b) has applied for a permanent resident visa as a Convention refugee or a person in similar circumstances;
> (c) is a protected person; or
> (d) is, where prescribed by the regulations, the spouse, common-law partner, child or other family member of a foreign national […]

Such applicants, as defined above, are assessed for entry based on whether or not they present a threat to public health or safety. Problematically, it is not clear from the IRPA guidelines what may constitute a public health or safety threat. Moreover, non-EDE applicants must undergo testing to determine their CD4 cell count. If the test indicates that an applicant has a CD4 cell count below 350 cells/mm3, ARVs are required based on Canadian guidelines.[13] In such cases, an applicant is said to represent an excessive demand irrespective of the source of finance for such mediations.[13] The interpretation of excessive demand also includes those who may in the future require ARVs to mitigate the progression of the disease, substantially decreasing the possibility that any HIV-positive person would be found admissible without a separate claim to entry under family-class sponsorship or as a refugee.[4]

While the cost of ARVs may be a long-term financial burden on the Canadian public health care system, the results of sustained ARV treatment have led to a decrease in the frequency and duration of hospitalizations by HIV-positive persons.[14] In addition, the methods used by CIC to determine whether an applicant represents an excessive burden fail to account for the productivity that any given person might generate within Canada after immigrating.[10] As CIC has affirmed, immigration plays "an increasingly important role in supporting Canada's economic prosperity and competitiveness" and immigration is "a key source of labour force growth in the future."[15] Indeed, immigrants arriving in Canada between 1991 and 2001 represented 70 percent of the decade's total net labour force growth, and notably accounted for 24 percent of the labour force growth of the health and social services sector during that period.[16] Moreover, immigration makes an enormous contribution to the pool of people in Canada with post-secondary qualifications. In 2006, among new immigrants 15 years of age and over, almost 42 % of economic immigrants to Canada held a university degree and a further 15.5% held some other form of post-secondary credentials such as a non-university diploma or trade certificate.[17] Therefore, the relative contribution of HIV-positive individuals to Canadian society needs to be evaluated in addition to the health care costs he or she may accrue in managing the progression of HIV in order to yield a comprehensive assessment of net cost (or net benefit) associated with each immigration applicant.

Furthermore, on October 21st, 2005, in a landmark decision made by the Supreme Court of Canada in the cases of *Hilewitz v. Minister of Citizenship and Immigration* and *de Jong v. Minister of Citizenship and Immigration*, it was decided that persons with disabilities could contribute valuably to Canadian society.[18] Supreme Court Justice Abella wrote the majority decision in which CIC was directed to evaluate immigration applications on an individualized basis, so as to incorporate into admissibility decision-making schemes the ability of each applicant to invest personal resources of time, money, and social support to sustain the livelihood of themselves or family members with disabilities.[18] The Supreme Court decision validated the concern that an objective metric for evaluating the eligibility of a prospective immigrant fails to account for important individualized circumstances, and it acknowledged the legitimate claim that an applicant's individual resources may offset the costs that would otherwise mean he or she would place an excessive burden on public costs in Canada. The *Hilewitz* decision concerned excessive demand in relation to social services; to date, no official court ruling has been made to extend the reasoning behind the *Hilewitz* decision to the context of health care services in Canada.

In sum, the literature suggests that fair treatment of people with HIV requires evidence-based policies at home and abroad. Immigration policies for persons with HIV will become increasingly important as legal, political and humanitarian concepts of access to health care services evolve. Presently, Canadian federal immigration policies reflect somewhat arbitrary and rigid standards for determining excessive demand for persons with HIV. These assessments are conducted without individualized assessments of those who are not exempt from IRPA's medical inadmissibility clause. Whether or not such standards serve to protect the Canadian health care system and the citizens of Canada has yet to be affirmed, given: the positive contributions HIV-positive persons may make to Canada; and the possibility that applicants' private financial and social resources may reduce their relative demand on publicly financed health care services.

Threshold for excessive demand on Canadian health or social services

The current threshold used to determine excessive demand on Canadian health or social services is assessed in this section in light of Canadian health expenditure characteristics.

Although the provision of health care is a provincial concern in Canada, the federal government has influenced the development of policy. Since January 1, 1971, all ten provinces and the territories have had public health insurance plans covering all necessary medical and hospital services. Since the federal government covers a substantial portion of all health expenditures, it has been able to establish certain criteria that the provinces and territories must meet if they were to qualify for their full share of federal transfers. Reasonable access by all residents to the full range of insured services without financial impediments to utilization captures the essence of the federal funding criteria.[19]

In 2007, average per capita Canadian health care expenditures were $4,867.40.[6] These expenditures included various categories of health service expenditures whether financed publicly or privately. While the public share accounts (in 2007) for 70.6% of total expenditures, most services are delivered privately. For example, physicians are generally self-employed, but reimbursed by provincial health insurance plans on a fee-for-service basis; while hospitals, which are owned and operated on a not-for-profit basis by various organizations, receive prospective global budgets from provincial governments to finance ambulatory and inpatient services.

To assess whether a potential immigrant represents an "excessive" demand on Canadian health or social services, a threshold is required as stipulated in the legislation. Current practice by CIC has been to set the annual cost threshold at approximately the same value as that for average per capita Canadian health care expenditures. However, that threshold is arbitrary and may be shown to be neither a reasonable nor statistically appropriate interpretation of the term "excessive" demand used in IRPA.

We propose that "excessive" demand on Canadian health or social services be defined as a cost profile for a prospective immigrant that is *statistically* ***greater*** than that for Canadians. To establish this "excessive" demand threshold, a statistical test is used to determine how large costs need to be before a prospective immigrant "might reasonably be expected to cause "excessive" demand on health or social services" in accordance with Section 38(1) of the *Canadian Immigration and Refugee Protection Act* (IRPA) of 2001.

To operationalize this statistical test, the distribution of Canadian health care costs, the cost profile of a prospective immigrant, and the level of statistical significance all need to be established. Once acquired, tests may then be performed to assess whether the expected health care cost experience of an immigration applicant is the same as or is greater than that for Canadians. Specifically, a statistical test is constructed to determine how large costs might need to be before a prospective immigrant's cost profile is deemed to be "excessive", i.e. statistically different from that for a representative Canadian.

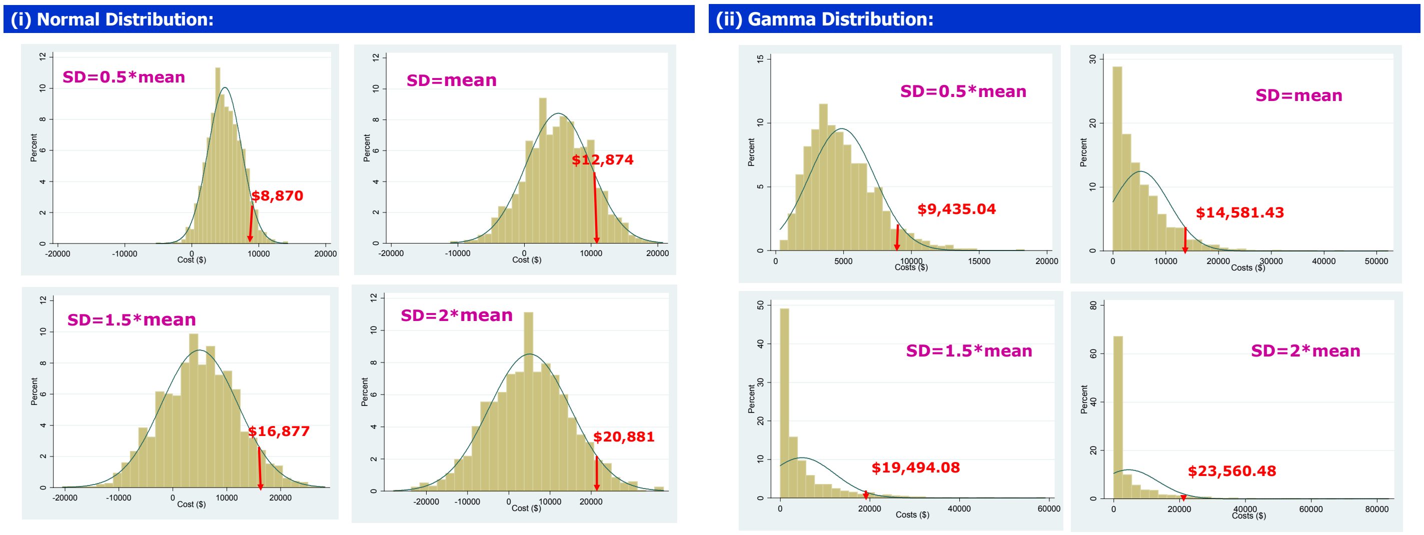
While average per capita health expenditures in Canada in 2007 were $4,867.40, there is a paucity of data on the distribution of such costs across all Canadians. It may be convenient to hypothesize that health care costs follow a normal (or bell-shaped) distribution; however, experience suggests that health care costs are non-negative and positively skewed, i.e. skewed towards the high end. A distribution that is consistent with such costs (i.e. non-negative and positively skewed) is a Gamma distribution. This distribution has been used previously in modeling health care costs,[20-23] and it is relatively simple to describe because it is defined in terms of scale and shape factors. These factors are the ratio of the variance of costs to average costs (s2/µ) and the ratio of squared average cost to the variance of costs (µ2/s2), respectively. Consequently, the Gamma distribution is essentially based on two parameters: average costs; and the relative variance in costs (i.e. the coefficient of variation which is defined as the ratio of the standard deviation of costs to its mean, s/µ). A low relative variance yields cost observations concentrated around average costs, while observations are more dispersed when the relative variance is high.

Once the cost distribution for Canadians and for a prospective immigrant have been established, the level of statistical significance used to test the null hypothesis that a prospective immigrant exhibits a cost profile that is the *same* as that for Canadians against the alternative that such costs are ***greater*** than those for Canadians needs to be established. While it is conventional in the research literature to use a 5% significance level (i.e. Fisher, 1925),[24] this level of significance is discretionary and depends on the confidence warranted in the test. Use of a 5% significance level implies that the statistical test correctly rejects the null hypothesis that a prospective immigrant has the same cost distribution as a Canadian 95% of the time. A less stringent requirement to be correct (i.e. only 90%) yields a significance level of 10%, while a more stringent requirement to be correct (i.e. 98%) yields a significance level of 2%. A less stringent requirement increases the chance that the null hypothesis is rejected when a prospective immigrant has the same cost distribution as a Canadian. Based on the distribution of costs for Canadians and for a prospective immigrant, the significance level invoked yields a unique "excessive" demand threshold as shown in Figures 1(i) and 1(ii).

Figures 1(i) and 1(ii) represent two sets of simulated distributions of Canadian health care expenditures when we know average per capita health care expenditures, but where assumptions are made about both their relative variance and proposed distribution. Figure 1(i) represents four possible normal (or bell-shaped) distributions for Canadian health care costs, while Figure 1(ii) offers equivalent Gamma distributions. The solid curves represent continuous probability density functions, while the bar charts represent the proportion of observations that fall within various intervals. The simulated distributions of health care costs become more dispersed when the relative variance increases from 0.5 to 2.0. The solid vertical lines represent the threshold of health care costs experienced by 5% or fewer Canadians. These upper values of health care costs are equivalent to the threshold used in hypothesis testing when a 5% significance level is considered. Moreover, these thresholds increase as the relative variance of costs increase.

Annual cost thresholds for excessive demand are reported in Table 1. These thresholds are dependent on the assumed cost distribution (normal or gamma), the relative variance of such costs (0, 0.5, 1, 1.5, or 2), and the significance level used to test the null hypothesis that an immigration applicant exhibits a cost profile that is the same as that for a Canadian or a cost profile that is higher. Three findings may be summarized. First, the Gamma distribution generally results

Figure 1: Annual cost thresholds for excessive demand (i) for a normal distribution; and (ii) for a gamma distribution reported in Table 1.


(i) Normal Distribution:

(ii) Gamma Distribution:

in a larger cost threshold than that obtained when using a normal distribution. This occurs because the Gamma distribution yields only positive values for health expenditures and incorporates a positive skew to such costs. In contrast, non-positive costs are possible under a normal distribution, with the distribution of costs symmetric around the mean of such costs. Second, for both the normal and the gamma distribution, and for each invoked level of statistical significance, the annual cost threshold for excessive demand consistently increases with the relative variance in costs. Only when the relative variance in costs is zero, i.e. all Canadians incur the same annual costs for health care, would the threshold be the same as that currently used by CIC. In all other instances, the cost threshold is higher. Finally, the annual cost threshold for "excessive" demand increases with a more stringent requirement for hypothesis testing, i.e. where the invoked significance level is lower. (If the statistical test is designed to be more likely to be correct in rejecting the null hypothesis that a prospective immigrant has the same cost profile as a Canadian, then the threshold needs to be higher.)

Table 1 yields wide variations in the cost threshold that may be used to determine "excessive" demand. Thresholds vary from a low of $4,867.40 (the current threshold used by CIC) when the relative variance of costs is zero to a threshold of $36,739.56, which is almost eight-fold greater. While there are circumstances in which each threshold is appropriate, there is compelling evidence to support a Gamma distribution in contrast to a Normal distribution. Moreover, for those who have studied the distribution of health care costs they have tended to invoke a Gamma distribution and have used unity as the relative variance of costs.[20-23] Moreover, use of a conventional level of statistical significance of 5%, yields a health care cost threshold for "excessive" demand as $14,581.43, as reported in Table 1. If a potential immigrant were to exhibit a cost profile yielding higher costs, then the hypothesis that that potential immigrant had a cost profile that is the same as that for a representative Canadian would be rejected. Consequently, this is how we interpret, in a statistical sense, the meaning of "excessive" demand within Section 38(1) of IRPA, i.e. statistically different from that for a representative Canadian.

Potential economic burden on health or social services by persons with HIV

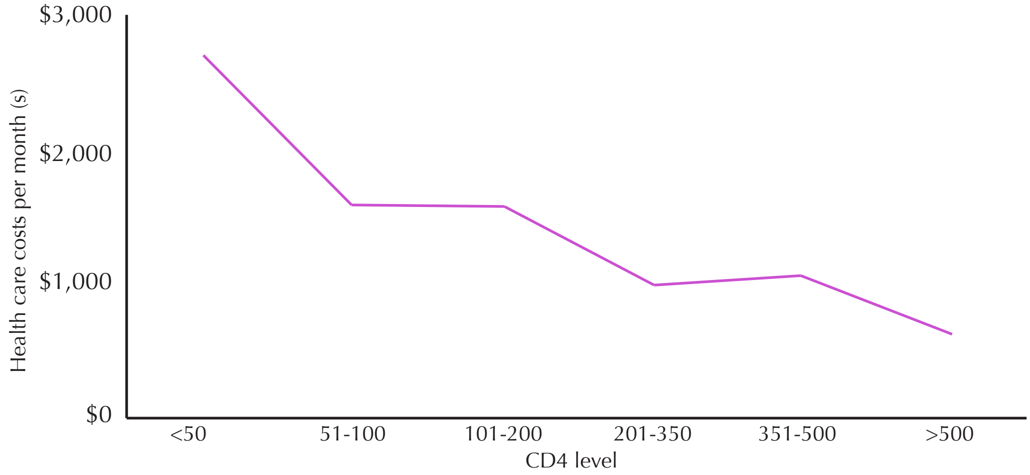
This Section reports on a synthesis of the clinical, epidemiological and economics literatures concerning the economic burden placed on health or social services by persons with HIV. In reviewing data for inclusion in our assessment of the relationship between disease progression and health care costs, studies reviewed in a publication by Levy et al.[25] were used. Only nine studies met three inclusion criteria: (i) peer-reviewed publication in English; (ii) original, patient-level data yielding mean monthly or annual direct estimates of medical costs of treating people with HIV, where anti-retroviral medication was included as routine clinical practice even when CD4 cell counts were over 500 cells/mm3; and (iii) medical cost estimates stratified by CD4 cell counts. A recent Canadian study, which was not included in the review by Levy et al, yields slightly lower cost estimates than those reported below.[26] Data from the studies reported by Levy et al were extracted from either the original article or directly from the author(s). Monthly health care costs in 2007 US dollars were presented after stratification by CD4 cell count categories as shown in Figure 2. A wide range of cost components were captured, including inpatient, outpatient, laboratory, and medication costs.

There is a general tendency for health care costs to increase with disease progression, but our confidence in some of the point estimates are limited by the underlying sample size. Specifically, while there are only 71 and 385 patients captured for the CD4 cell count categories 51-100 cells/mm3 and 201-350 cells/mm3, respectively, all other cost estimates were based on samples of more than 23,000 patients.

Table 1: Annual cost thresholds for "excessive" demand contingent on the distribution of costs, the relative variance in costs, and significance levels

		Cost Threshold in 2007					
		Normal distribution			Gamma distribution		
		2%	5%	10%	2%	5%	10%
Relative variance (or coefficient of variation)	0	4,867.40	4,867.40	4,867.40	4,867.40	4,867.40	4,867.40
	0.5	9,866.22	8,870.84	7,987.40	11,054.01	9,435.04	8,129.51
	1	14,865.04	12,874.27	11,107.41	19,041.38	14,581.43	11,207.60
	1.5	19,863.86	16,877.71	14,227.41	27,879.94	19,494.08	13,483.14
	2	24,862.68	20,881.15	17,347.41	36,739.56	23,560.48	14,609.86

Figure 2: Disease progression and average monthly health care costs in 2007 (US$)



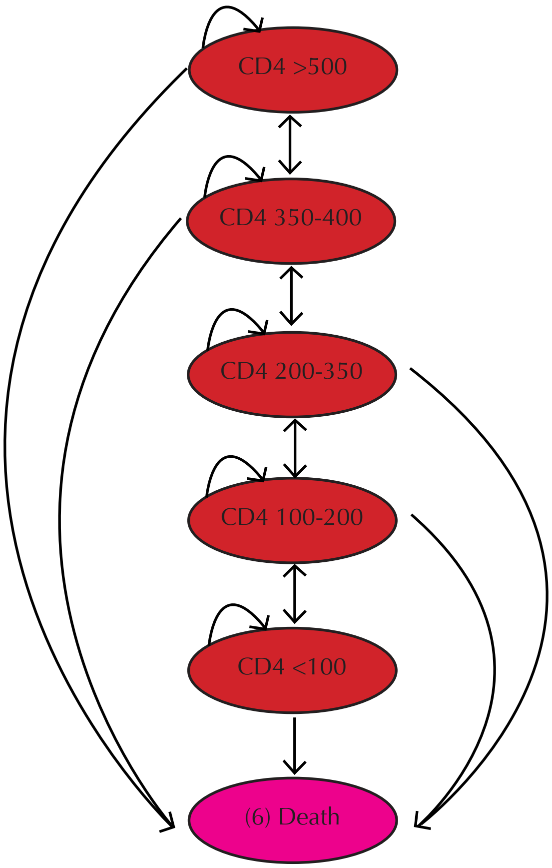
The economic burden of persons with HIV over various time horizons

Estimates of the economic burden of new immigrants with HIV are derived over three different time horizons (5-years, 10-years, and their remaining lifetime) after stratifying for underlying health state, age and sex at the time of admission to Canada.

In order to derive estimates of the economic burden a Markov model was developed, as shown in Figure 3 that describes the transition of a cohort of immigrants with HIV through various health states, here defined as CD4 cell count categories.

In Figure 3, a cohort of immigrants is classified into initial health states according to their CD4 count measured at the time of application for admission to Canada. Transitions between health states are assessed on an annual basis. Potential health state transitions are: death; progression to a lower CD4 cell count health state; disease improvement to a higher CD4 cell count health state; or the status quo in which individuals remain in their current health state. The

Figure 3: Health-state transition for the Markov Model



model tracks the proportion of individuals in each health state after each cycle. Transitions are based on conditional probabilities that depend on age, sex, and CD4 cell count. Table 2 reports transition probabilities for each CD4 cell count category were drawn from the literature as referenced.

Economic burden estimates for immigrant applicants with HIV depend crucially on the projected trajectory of disease, the anticipated incidence of mortality, health care cost estimates stratified by CD4 cell count categories, the rate at which future care costs are discounted to present values, and the time horizon over which cost are assessed. To derive economic burden estimates for each immigration applicant with HIV, costing weights (as discussed above) and reported in 2007 Canadian dollars in Table 3, are applied to each health state as represented by CD4 cell count categories.

Because standard practice in the economic evaluation requires adjustment for the timing of costs, the analysis follows current practice and invokes a discount rate of 3 percent to convert the annual stream of expected health care costs to present valve terms.[29] Moreover, in order to assess the economic burden of immigrants with HIV, three separate time horizons are considered, 5-years, 10-years, and lifetime for both men and women using mortality rates derived from Canadian life tables.[30]

Application of the Markov model yields estimates of the economic burden of new immigrants with HIV that depend on: the time horizon used to assess the impact on health care costs (5-years, 10-years, and the remaining lifetime); baseline CD4 cell count; and the age and sex of individuals at the time of admission to Canada. These estimates are reported in Tables 4(i)-4(iii).

There are four notable findings regarding the economic burden of new immigrants. First, the economic burden of immigration applicants increases with disease progression, i.e. the burden is larger if immigration applicants have smaller CD4 cell counts, indicating more serious symptoms. This occurs because such immigrants present a higher cost profile than other immigrants. Second, the burden increases when the time horizon over which health care costs are assessed increases. This occurs because more years are included in the assessment of the burden on health or social services. Third, the burden is greater for women than for men, and particularly so if the time horizon for assessment is longer. This occurs because women face a lower mortality rate, and consequently a longer life expectancy. Forth, the burden falls with the age of the immigration applicant, because older immigrants face a higher mortality rate than younger immigrants.

Table 2: Transitional probabilities used in the Markov Model for immigration applicants with HIV

Input Parameters	Values	Source
Transition probabilities from “CD4 > 500” state		
Annual risk of having "CD4 350-500"	7.59%	#27
Relative risk of death	5.00	#28
Transition probabilities from “CD4 350-500” state		
Annual risk of having "CD4 200-350"	6.92%	#27
Annual risk of recovering to "CD4 > 500"	2.71%	#27
Relative risk of death	7.00	#28
Transition probabilities from “CD4 200-350” state		
Annual risk of having "CD4 100-200"	3.13%	#27
Annual risk of recovering to "CD4 350-500"	2.71%	#28
Relative risk of death	9.00	#28
Transition probabilities from “CD4 100-200” state		
Annual risk of having "CD4 < 100"	1.79%	#27
Annual risk of recovering to "CD4 200-350"	1.22%	#27
Relative risk of death	13.00	#28
Transition probabilities from “CD4 < 100” state		
Annual risk of recovering to "CD4 100-200"	1.22%	#27
Relative risk of death	20.00	#28

Table 4: Present value of health care expenditures in 2007 for
(i) Immigration Applicants aged 30 years with HIV;
(ii) Immigration Applicants aged 40 years with HIV;
(iii) Immigration Applicants aged 50 years with HIV.

Table 4(i)	Males			Females		
Baseline CD4	5-Year	10-Year	Lifetime	5-Year	10-Year	Lifetime
>500	$36,151	$71,384	$183,612	$36,339	$72,263	$205,176
351-500	$55,945	$100,969	$222,100	$56,320	$102,503	$247,959
201-350	$55,562	$104,361	$233,254	$56,055	$106,477	$264,464
101-200	$85,181	$155,631	$311,042	$86,263	$160,089	$356,852
<100	$142,023	$248,953	$437,669	$144,725	$259,282	$508,296

Table 4(ii)	Males			Females		
Baseline CD4	5-Year	10-Year	Lifetime	5-Year	10-Year	Lifetime
>500	$35,871	$69,725	$144,155	$36,117	$71,024	$165,621
351-500	$55,393	$98,151	$175,847	$55,881	$100,374	$201,258
201-350	$54,836	$100,494	$179,028	$55,476	$103,536	$208,807
101-200	$83,599	$147,659	$234,983	$84,995	$153,932	$277,205
<100	$138,115	$231,178	$326,926	$141,565	$245,214	$390,022

Table 4(iii)	Males			Females		
Baseline CD4	5-Year	10-Year	Lifetime	5-Year	10-Year	Lifetime
>500	$35,005	$65,028	$102,997	$35,541	$67,872	$124,277
351-500	$53,687	$90,283	$126,832	$54,742	$95,027	$152,061
201-350	$52,608	$89,965	$122,940	$53,983	$96,265	$151,367
101-200	$78,807	$126,838	$156,726	$81,754	$139,139	$195,700
<100	$126,522	$187,344	$211,688	$133,610	$212,772	$268,164

Table 5: Thresholds for the present value of health care costs by age, sex, and time horizon discounted in advance at 3% in 2007 ($14,581.43)

	Males			Females		
Age	5-Year	10-Year	Lifetime	5-Year	10-Year	Lifetime
30 years	$67,085	$124,283	$361,909	$67,149	$124,544	$378,274
40 years	$66,990	$123,794	$323,314	$67,074	$124,182	$343,459
50 years	$66,692	$122,325	$274,821	$66,877	$123,229	$299,380

Inadmissibility depends on an applicant's characteristics and time horizon

Thresholds used to define excessive demand are reported in this Section and applied to estimates of the economic burden of persons with HIV in order to identify which immigration applicants may be deemed to be inadmissible on medical grounds. In Section 3.0, we demonstrated that the current annual cost threshold used by CIC to determine whether an applicant is likely to pose "excessive" demand ($4,867.40) is too low, and that there might be justification under some circumstances for a threshold that is almost eight-fold greater at $36,739.56. Under these extreme positions either all individuals with HIV would be denied admission or all would be accepted. In Section 3.0, we proposed a middle position that we felt was a statistically more appropriate annual cost threshold at $14,581.43 (or three-fold greater than the current CIC threshold). Application to various assessment periods and to Canadian mortality rates yields Table 5. This Table reports the present value of cost thresholds (in 2007 Canadian dollars) for representative Canadians based on their age, sex, and the time horizon for assessment. Consequently, in order to assess whether immigrant applicants present a cost profile that is higher than that for a matched representative Canadian warrants a comparison between the figure in each cell in Table 5 and an appropriate figure from Tables 4(i)-4(iii).

Comparison between the figures in Tables 4(i)-4(iii) and Table 5 yields the shaded regions in Tables 4(i)-4(iii). These shaded regions identify individuals who do not represent an excessive burden on Canadian health or social services. Classification as medically inadmissible depends on the unique characteristics of each potential immigrant including their age, sex and baseline CD4 cell count as well as on the time horizon over which an applicant is assessed to impact health or social services.

The baseline CD4 cell count category, at which immigration applicants with HIV are deemed to represent an excessive burden on Canadian health or social care, falls as the time horizon for assessment increases. Specifically, a five-year or ten-year time horizon generally warrants individuals with CD4 cell counts <200 cells/mm3 to be deemed inadmissible, while a lifetime horizon provides for admission to all except for women and men aged 30 and 40 years with CD4 cell counts <100 cells/mm3. These finding occurs because persons with HIV are at a greater risk of death than the general population which lowers the present value of their potential economic burden when the time horizon increases. Similarly, as women have greater life expectancies than men, their potential economic burden on Canadian health or social care is accordingly greater. While this does not make a difference in Table 4 when comparisons are made every ten years, it would make a difference if the age intervals were finer. Moreover, as the age of the applicant increases, their remaining life expectancy falls. This decline lowers their potential economic burden on health or social services, and accordingly, lowers the CD4 cell count threshold at which potential immigrants may be classified as being medically inadmissible. This effect is only noticeable when a lifetime time horizon is used whereby the threshold for being deemed medically inadmissible drops for women and men aged 40 to 50 from CD4 cell counts <100 cells/mm3 to include all women and men irrespective of their CD4 cell count when aged 50 years. These are interesting age and sex related differences and suggest that women or younger applicants face a slightly greater likelihood of being deemed medically inadmissible than men or older applicants.

Conclusions and limitations

There is a paucity of studies assessing thresholds used by immigration officials in the determination of medical inadmissibility. Despite the need for evidence informed immigration policy, and the findings contained in this paper, a number of limitations warrant discussion. First, the definition of "excessive" demand is inherently subjective. While this paper has offered a statistical definition of "excessive" demand, the paper has demonstrated that the precise threshold is discretionary; it depends on the confidence warranted in the test that a prospective immigrant has a cost profile that is the same as that for Canadians. A more stringent confidence requirement (i.e. that we are correct in rejecting this hypothesis) than the customarily 5% significance level, warrants a higher threshold. Second, while we have shown how the statistical threshold used to determine "excessive" demand depends on the underlying distribution of health care costs, unless precise estimates of that distribution are acquired the resulting threshold will always be an approximation. Third, present value estimates of the economic burden of illness are limited by the available literature and the sophistication in the modeling of the underlying health conditions. This is also true in the context of HIV and is crucially dependent not just on the unit cost of specific CD4 cell count health states, but also in the transition from one health state to another. We should never forget that the estimates reported herein are just point estimates, and furthermore, are dependent on current medical practices in the settings that yielded the original data. Fourth, in order to engineer an assessment of which HIV-positive individuals would be deemed to be medically inadmissible, consideration of the trajectory of costs for both HIV-positive individuals and those for Canadians were converted to present value terms for particular assessment horizons. Variation in underlying assumptions concerning discounting practices, disease progression and relative rates of mortality influence the findings and should be considered in a comprehensive assessment of current policy. Finally, in order to have a balanced assessment of the costs and contributions of a prospective immigrant, there should also be an assessment of the potential contributions of a new immigrant.

Notwithstanding the limitations, three substantive findings are offered in this paper. First, the current cost threshold used by CIC in assessing whether an applicant is likely to pose "excessive" demand on Canadian health or social services is too low. A statistically more appropriate threshold is three-fold greater at $14,581.43. Second, there is a close relationship between disease progression (measured by CD4 cell counts) and health care costs, with annual costs increasing from under C$8,000 for CD4 >500 cells/mm3 to over C$35,000 for CD4 <100 cells/mm3. Third, application of these cost estimates to a revised cost threshold for inadmissibility indicates that classification depends on individual characteristics, including age, sex and baseline CD4 cell count as well as on the time horizon over which each applicant's projected demand for health or social services is assessed. "Excessive" demand is more likely to occur for applicants with low CD4 cell counts and a shorter time horizon for assessment (i.e., 5-years versus their lifetime). Women and younger applicants are slightly more likely to be deemed inadmissible than men and older immigration applicants.

Our findings suggest that the adjudication guidelines and policies used by CIC warrant urgent review so that they are informed by the existing clinical, epidemiological and economics evidence, and that they conform to an appropriate statistical interpretation of "excessive" demand. In the absence of this review, current policy results in immigration denial on medical inadmissibility grounds and the consequent loss to Canadian society of some gifted individuals.

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Abstract
For researchers working within a critique of capitalism and its relation to knowledge production, it is problematic to use traditional research methodologies endemic to the very system being critiqued unless they are somehow altered. This article investigates the potential of schizoanalysis to provide conceptual tools for such an approach. Developed through the collaborative work of Deleuze and Guattari, schizoanalysis operates from the organic principle that knowledge is an indivisible part of the way we live in the world. However, schizoanalysis is not a research methodology; it inserts itself into research methodologies, warps them, and reproduces itself through them.

Key Words Deleuze & Guattari, horizontalist methodologies, militant research, relationality, schizoanalysis

SCHIZOANALYSIS AND COLLABORATIVE CRITICAL RESEARCH

ERIKA BIDDLE

Introduction

According to sociologist Michel Maffesoli, "the attempt to organize our systems from one defined point is futile".[1] In the past two decades, in the health sciences and on other institutional fronts, new forms of community-based participatory research (CBPR) have emerged, calling for partnerships between community members and researchers to facilitate a more synergistic approach to projects involving human subjects, particularly those who are underserved. However well-intentioned these efforts may be, there is the spectre of capital at hand in these initiatives, which are often administered through organizations heavily funded by the state. From antecedent methodologies, they maintain the subject as the focus of study by an institutional researcher/observer and involve the perpetuation of evidence-based practices that demand replicable results. This observer/observed divide is inscribed with hierarchy and the understanding of knowledge as something static to be acquired and possessed.

This inheritance from traditional methodologies is fundamentally problematic for a horizontalist practice that emphasizes intra-subjective transformation (becoming-other) over relations *between* subjects. This paper investigates the potential of schizoanalysis to provide an alternative to traditional research methodologies. Schizoanalysis was developed through the collaborative work of French 'anti-psychiatrist' Félix Guattari and philosopher Gilles Deleuze. It has been used to effect change in education (from militant research to primary-school teaching and proliferate net-based learning environments); health care (radical nursing, e.g., revolts against "best evidence" practices); art (especially avant-garde and interventionist/tactical media practices); and grassroots activist organising.

In contrast with traditional research methodologies, schizoanalysis is overtly 'political'. It is a critique of power-knowledge in the vein of Michel Foucault, who exposed the power dynamics that suffuse knowledge as systems of capitalist production. In this criticism, knowledge is lived rather than something to be possessed. As we are all participants in the production of a reality that is never static, but always becoming, with schizoanalysis the hierarchy of the observer/observed is wiped out. Along with creating radical alternatives, schizoanalysis can be seen as a way of subverting or 'perverting' traditional methodologies for the purpose of critical engagement, rather than a methodology in itself.

The emergence of schizoanalysis

Schizoanalysis is a method that emerged out of the collaboration between Félix Guattari and Gilles Deleuze in *Anti-Oedipus: Capitalism and Schizophrenia*, Vol. 1. At the time, Deleuze was well known among the Parisian intelligentsia for his scholarly work on Kant, Spinoza and Nietzsche, and for his radicalization of film theory. Guattari was active in the psychoanalytic arena, with his practice falling left of the reigning heterodox Lacanian alternative to Freud. He was also well known among French radicals for his role in mobilizing the events of May 1968, when a campus insurrection at the University of Paris at Nanterre spread wildcat sympathy strikes throughout France that paralyzed the country, and for a brief moment seemed to herald a genuine social revolution. In the wake of the failed revolt there was a surge of theoretical writings from French authors inspired by the potential of the event; the body of texts they produced became referred to thereafter as '*la pensée soixante-huit*' ['68 thought]. Deleuze and Guattari are two of the leading theorists of this group of writers, and their collective output has become the canon for much contemporary critical theory.

Deleuze and Guattari were interested in creating possibilities for radical individual autonomy in a repressive world. Situated in the political aftermath of May 1968, *Anti-Oedipus* draws upon Deleuze's commitment to an immanent ontology, the position of the social and political at the core of being, and the affirmation of difference over transcendental hierarchy, as well as Guattari's psychotherapeutic critique of the Freudian and Lacanian dependence on totalizing, referential myths (such as Oedipus, the great Other and the unconscious structured as language) for rearticulation and interpretation of all subjective histories via productive dissensus.

They are both theorists of difference; the kind of theory that is productive of change. Deleuze published *Difference and Repetition* in 1968 and his philosophical work on difference is roughly contiguous with Jacques Derrida's work on *différance* as a critique of structuralist theories of language. Their ideas are also contemporaneous with Jean-François Lyotard's rejection of totalizing narratives through his work on postmodernism. Nevertheless, their work is distinctly not about language: it is about praxis. In Bruno Latour's *We Have Never Been Modern*, a central aspect of his thesis is the rejection of postmodernism as a version of linguistic constructionism, whereby either the discursive or material is privileged in the construction of knowledge.[2] Deleuze and Guattari's approach to knowledge, however, entails the intimate integration, interaction, intervention and subterfuge of the material and the discursive in every aspect of its constitution for the purpose of effecting change to the *socius* and not to reify representation.

Their works together were prepared as field guides, not polemics. *Anti-Oedipus* was their first collaborative effort to find a 'method' for provoking preexisting groups or arrangements to actively question their composition as such. This project continued in their follow-up volume, *A Thousand Plateaus* (1980) – where the critical activities grouped under the term "schizoanalysis" are given individual names, including: "rhizomatics", "nomadology", "deterritorialization", and "micropolitics" to highlight the various forms of intervention they make possible.

Schizoanalysis as a research methodology?

Schizoanaylsis encompasses an axis for "theory and action", with no fixed form or technique. But can schizoanalysis even be considered a research methodology, let alone a 'credible' one? Deleuze and Guattari would resist any declaration of credibility. Brian Massumi notes in his foreword to *A Thousand Plateaus*,[3] paraphrasing Deleuze, that "legitimate philosophy is the handiwork of 'bureaucrats' of pure reason who speak in 'the shadow of the despot' and are in historical complicity with the State".[ix] Any such charge of legitimacy in the domain of research methodologies – a regime of 'molar' truth – would draw the same criticism. Their 'methodology' is to reject the authority and tradition of method – "the received view of the world", the application of a finite and structured way of doing things, the logic of the assembly line applied to the production of human psycho-simulacra – and to accede to the infinitude of morphic desire, so that change and movement can occur.

There are no hierarchical dyads or reductionist comparisons in schizoanalysis, only differences produced by entities mutually embedded in a network. Each entity takes part in the enacting of mutable component entities, and is 'always becoming'. The possibility of change is always immanent, it is the positive force recognized as 'potential'. The prospect of cold, hard data collection and analysis from a detached entity is anathema to schizoanalysis as a lived methodology. "The multiple must be made".[4, p6]

The following is a sketch of what applied schizoanalysis could look like:

To begin, researchers are situated within the analytic body, and are neither central nor authoritative. The aim is to produce an 'interactive group dynamic'.[4] This undermines the traditional authoritarian/hierarchical relationship between analyst and analysand (or, the interviewer and interviewee). For schizoanalysis the process should be collective, and not governed by professionals and experts.

The mode of inquiry is playful, does not conform to logical reasoning, and promotes intellectual creativity. The researchers engage with the analytic bodies in everyday life through a process of connections and interactions. Ideas develop out of these very assemblages. Unlike more conventional research methods, schizoanalysis allows the inclusion of the researchers' voices; it is more interested in 'rendering visibility' than 'reproducing visibility'. It is about the production of possibilities (of social change), not mere expression. Expression, the collective operative goal of research methodologies, is the primary enemy as it poses a meaning outside of and detached from the process and hence blocks the process.

Schizoanalysis tends towards the experimental production of concepts, referred to by Deleuze and Guattari as 'lines of flight' (resistance). It is an experiential exercise in organization and self-direction of collective social arrangements involving intuitive, practical and reflective processes.

Applied to the almost-imperceptible matter of what makes us act, feel, and think, schizoanalysis as a research method is capable of producing warm bodies of data because it is not simply a reflective, theoretical exercise, but an experiment in organization and self-direction of collective social arrangements, producing new forms of self-organization, self-management, self-direction, etc. It endlessly generates possibilities rather than providing limits, constantly reorganizing these possibilities into new productive constellations, making delineation and distinction irrelevant. It works from the inside-out, rather than the outside-in – as even the most immersive ethnography does.

Schizoanalysis was conceived as an "open system"; there is no final word.[3] What schizoanalysis proposes is that desiring machines and their assemblages are NOT to be interpreted; implausible readings may overlap, intersect, conflict, and are positively multiplicities. It was towards this end that Deleuze and Guattari developed (in *A Thousand Plateaus*) their theory of the rhizome. In botany, 'rhizome' describes a system of roots that expands horizontally and underground. It has become shorthand for radical democratization. In this instance, it is also a riff on Noam Chomsky's tree-based linguistic model for meaning-making. The six principles of the rhizome as listed by Deleuze and Guattari are: connection, heterogeneity, multiplicity, asignifying rupture, cartography, decalomania (the condition of infinite flexibility, adaptability and resistance to rigidity). When used as a research tool, the rhizome allows for multiple nonhierarchical interventions in data representation and interpretation wherein no one is the subject, everyone is a subjectivity.

Schizoanalysis in action: Guattari's 'the patients' club'

> [T]he ministerial guardians having never given up on the idea of establishing certain norms for them [the patients] despite the fact that their true value consists in the inventiveness they show outside of the established frameworks. – Félix Guattari [5, p200]

What Deleuze and Guattari are attempting to provide with schizoanalysis is a strategy for mobilizing latent potentials of resistance within (and possibly beyond) existing institutions of social production, as they are located within capitalism, and other such hegemonic systems of organization. In *Chaosophy*, Guattari recounts an experience he had at Jean Oury's La Borde, a clinic devoted to studies in antipsychiatry and investigations into group therapy. La Borde was well known for its experimental approach to psychiatric care, including 'communalism'; at the time, this allowed for an unheard of degree of humanity for institutionalized patients. Guattari himself said he was shocked at the "familiar, friendly, human" [5, p188] aspect of the patients and the staff. Although Guattari does not provide a date for this experience, in his foreword to *A Thousand Plateaus*, Massumi places Guattari's early investigations into the "subject-group" as early as 1960.[3, p13; 6]

Oury invited Guattari to spearhead an experiment in developing an intrahospital committee – 'the Patients' Club' – a radical reorganization of the institution with the gradual goal of desegregating the doctor-patient relationship as much as that between medical staff and service personnel. This experiment was essentially schizoanalysis' first practice. Its goal being to mobilize the sick and the care personnel, it entailed "an internal mini-revolution". [5, p190] All service work was integrated with medical work – for example, the administration of medications, patient assessments, and the cleaning of toilets – for a radically dehierarchizing reorganization of duties. According to Guattari's recount of the experiment, the doctors appreciated the enriched encounters and dialogue they had with the patients and although the service employees were initially reluctant to resume the additional responsibilities, Guattari writes, within a few months time, "the clinic's institutional landscape would change radically". [5, p190] The organization of the staff got more complex and 'rhizomatic' as tasks became more differentiated and activities within the institutional machine became more multiple. Although it may seem contra to schizoanalysis' ethos of 'no bosses, no masters', a group of supervisors was implemented to assess the dissonances and flows of the reorganization.

Guattari does not clarify the role of the directorial group, but instead he stresses that the experiment served to produce new subjectivities in each of the participants. He writes: "The supervisors created by the 'rotations', guided by the 'schedule', and actively participating in the 'information meetings', gradually became, with training, very different people from what they had been upon arrival at the clinic. Not only did they familiarize themselves with the world of madness… [and] not only did they learn new techniques, but their whole way of seeing and living was modified. More specifically, they shed that protective armor with which so many nurses, educators, and social workers guard themselves against an alterity that unsettles them… it was the same with the psychotic patients… they discovered a whole new relationship to the world". [5, p192] Guattari argues that intervention into the psyche of the psychotic, the doctor, and the service worker is one and the same not by way of some "projective equivalent" [5, p192] to the individual body or the individual self, but is pragmatically situated in collective daily life.

The experiment at La Borde, effectively an experiment in 'deterritorializing' the flows and patterns of daily life in the institution, redirected the dreary and empty repetition of medical roles into a productive, internal, communal re-creation of something virtually larger than the institution. Guattari writes, "It was not simply a matter of calling psychiatry into question, but also pedagogy…. As I see it, all social segments should undergo, step by step, a veritable molecular revolution, i.e., a permanent reinvention. In no way did I suggest extending the experiment of La Borde to the whole of society, no single model being materially transposable in this way. Yet it seemed to me that subjectivity, at any stage of the *socius* worth considering, did not occur by itself, but was produced by certain conditions, and that these conditions could be modified through procedures in a way that would channel it in a more creative direction". [5, p194] This experiment in the radical democratization of psychiatric care resulted in change within the wider social field. As Guattari concludes, by working day to day in this fashion with its community of doctors, service staff, and patients, La Borde found itself involved in wider global issues of "health, pedagogy, prison conditions, femininity, architecture, urbanism". [5, p195]

It is important to note, as Guattari mentioned above, that 'no single model of schizoanalysis is transposable'. Every experiment in schizoanalysis is a one-off with unduplicatable results. Each new configuration, situation, 'assemblage' is unique, and as such, each approach to it will be different. As a method, this allows for a great deal of flexibility and possibility, but not much in terms of direction or certainty of results. However, what this method does allow for is self-awareness of the ethics of positionality, reflexive criticism that provokes action, fluidity and experimentation, creative situation-based thinking and tangibly productive results.

Schizoanalysis: becoming militant research, collective theorization

> We think of our practice as a double movement: to create ways of being militants that escape the political certainties established a priori and embrace politics as research (in this case it would be 'research militancy'), and at the same time, to invent forms of thinking and producing concepts that reject academic procedures, breaking away from the image of an object to be known and putting at the center subjective experience (in this case, it would be 'militant research').
> – Colectivo Situaciones [7]

Methodology is traditionally a structured form of obtaining knowledge, based on the subject/object divide. Knowledge is something that is acquired, possessed; it is the property of the researcher or the institution. In other words, traditional methodologies reproduce the capitalist private property relationship in the epistemic sphere, thereby reifying knowledge. Schizoanalysis allows for the effective elimination of the subject/object divide inherent in other research methods as is appropriate in the epistemological overhaul of the scientific method brought about by quantum mechanics. There is no Archimedean point outside the system from which to observe it. The observer is within the system, and affects the observed by the questions the observer puts to it and is in turn affected by it. Observation is never neutral.

According to Deleuze and Guattari, we are all participants in the production of a reality that is never fixed, but always becoming. In outlining their work together, they describe their theories as a 'toolbox of concepts' and we "are all handymen: each with his little machines and each with his little toolbox".[8, p1] Schizoanalysis operates from the understanding that knowledge is not just something written on the page, stored in a hard drive, processed through a system, and given currency in an institution, but an indivisible part of the way we live in the world. Knowledge is being or becoming. Ludwig Wittgenstein said of language in his critique of the parallel reification of it performed by analytic philosophy, that it implies a 'whole form of life'. Knowledge too is part and parcel of a whole form of life, and forms of life are knowledge.

If the way we live is a form of knowing, then research into it must also be lived. This is the takeoff point for schizoanalysis. The de-reification of knowledge is itself political, but schizoanalysis takes things further by not simply accepting things as they are but seeking to be productive of change. It is a question of 'ethos': a researcher working within a critique of capitalism and its relation to knowledge production cannot use traditional research methodologies which are a part of the very system that is being critiqued unless they are somehow altered – like a recombinant virus – through schizoanalysis. Just like viruses are not living organisms in and of themselves, they need to insert themselves into living cells, schizoanalysis is not a research methodology in and of itself. It needs to insert itself into other research methodologies, warp them, and reproduce itself through them.

Should schizoanalysis be framed as a qualitative methodology or is it analogous to a methodology? It would seem that given Deleuze and Guattari's political commitments and view of knowledge/view of the world that 'methodology' is impossible. Their political-epistemic commitments are linked to other critical theorists of power-knowledge, and anti-capitalist, anti-authoritarian, anti-oppressive struggles, a sphere that rejects traditional ways of forming and understanding knowledge as infused with power politics and other forms of hierarchy. Writing from within that sphere, existing methodologies cannot simply be adopted, so schizoanalysis is part of the search for a radical alternative.

In the academic context, this search for a radical alternative has developed into an emergent field known as "militant research".[9] Militant research is indebted to Deleuze and Guattari's schizoanalytic practice of mapping transversal linkages between subjectivities, which stresses collective theorization and action as an alternative to the methods "at hand" in the Heideggerean sense. As such, militant research is not a specialized task, nor a process that only involves those who are traditionally thought of as researchers or academics. Militant research starts from the understandings, experiences, and relations generated through organizing, as both a method of political action and as a form of knowledge. It is a configuration of investigation and social research that expands possibilities for political action from the perspective of the theorist within and part of the multiple and overlapping cycles and circuits of struggle. Like schizoanalysis, militant research is deeply ethical (but not a meta-ethics). It involves making one's own rules and yet employs empathy towards reaching mutually shared goals. Militant research, with its close praxical relationship to schizoanalysis, holds potential for academics and researchers with ties to social movements, for engaged intellectual work, and especially for those trying to do radical work within institutional frameworks such as the university, the hospital, etc.

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Abstract
Nursing practices can attract concern, even criticism, when watched from the bedside, or read from fieldwork transcripts by nurse-researchers investigating patients' communication of pain. However, a secondary analysis, via a discourse analysis with Foucault's work on governmentality, allowed for a reading of how pain was governed and this provided another perspective. In these findings, the nurses' position is constructed by patients as both 'good' and 'busy', regardless of the responsiveness of nurses to patients' pain. The patients' position was that of a 'good' patient if they were 'active'; that is, undertaking self-surveillance in relation to their pain and actively working toward their recovery. Their pain was constructed on a linear and numerical scale, to which all complied. Important to all this is the examination, a disciplinary procedure with invisible but powerful effects, so powerful that the patient's body is rendered docile.

Key Words disciplinary power, Foucault, governmentality, pain

Governing Post-Operative Pain: The Construction of 'Good and Active' Patients, 'Good and Busy' Nurses and the Production of Docile Bodies

ALICIA EVANS

Background

This paper reports the findings of a secondary analysis of field-notes written as part of a primary study that investigated nurses' responses to patients' self-report of post-operative pain. These field-notes caused concern when first read by a group of nurse researchers, including myself. Although there were examples of nurses being responsive to patients' complaints of pain, there were many examples where it seemed that the nurse was somehow deaf, or just not responsive, to what the patient said about their pain. For example, when a patient complained that his indwelling-catheter was very painful, the nurse replied 'Shouldn't be' and left the room. The primary analysis was thematic in nature and also involved an analysis of time spent at the bedside. The secondary analysis, conducted concurrently, was undertaken in order to consider if a different theoretical and methodological approach to the field-notes could provide alternative understandings of the nurses' practice.

Considering my own position as a nurse-researcher reading the field-notes from the primary study, I was middle-aged and some years removed from the bedside nursing practice of post-operative patients. Perhaps my recollection of post-operative nursing was somewhat romanticized, as if the nursing of a previous era was somehow less problematic.[1] Or maybe I held fast to an image of nursing, described by Allen as that of the nurse providing individualised, unmediated care; an image that contrasts with the everyday practice of nurses.[2]

Either way, inherent in my concern was an assumption that nursing is a caring practice where the nurse should respond well to the patient's complaint of pain. This notion of the 'caring' nurse ignores not only the context of nursing practice, but also the disciplinary power of the nursing position, as theorised by Foucault[3] in relation to the disciplines; something I will discuss a little later in this paper.

This dominant and idealised view of the nurse as 'caring' is also problematic for the nurse, for when they fail to live up to the ideal image, so-called problems of practice can too easily become fore-grounded. These 'practice problems' can even call up notions of 'good' and 'bad' practice, with no regard for how the nurse's agency (the capacity for choice) is intertwined with structure (the conditions of practice and organisational work).[4]

At the complex site of the hospital, advances in technology have brought about changes in the way both nurses and doctors practice.[1] Also changed is how the hospital functions in contemporary times. The efficient flow of patients through the hospital becomes important,[5,6] so much so that health establishments can now resemble industrial assembly lines.[7] These assembly lines keep running regardless of circumstances and nurses are central to this, indeed it is one way nurses exercise their power, even though they might at the same time acknowledge how much their practice has changed as a result of economic and health care reforms.[8]

Another change to the health area has been the introduction of the patient satisfaction survey. It might be speculated that here the patient is situated as an active participant in the judgement of quality health care; apparently determined by their level of satisfaction with that health care. In Rankin's[9] analysis of a patient satisfaction survey, she found that the way the survey was constructed shaped responses in ways that silenced some of the patient's experience and could distort accounts of care and treatment given.

At the same time as these and other changes have occurred in the hospital setting, and in the context of reduced financial funding, there is still an expectation that nurses will maintain high standards and provide 'good' nursing care.[8] As well as providing 'good' nursing care, nurses help to shape the subjectivity of the patient such that standards for the 'good' patient are established.[8] Indeed nurses, via an exercise of power, help to shape both individual and collective behaviour.[10] This is achieved by the way nurses conduct themselves, for it is via the nurses' conduct that patients are assisted with their initiation into the clinical domain. Nurses' conduct helps patients to come to know what is expected of them in their own conduct and how to present themselves so as to continue to be considered 'clinically appropriate'.[5]

This can be considered as nurses' use of disciplinary methods; the way, since the seventeenth and eighteenth century, the methods of the disciplines have overtaken slavery as a way to control the body of the other, with similar effects of utility but with both less cost and violence (3). The docile body is produced via the disciplinary method, one that uses the rather simple instruments of "hierarchical observation, normalizing judgement and their combination in a procedure that is specific to it, the examination".[3, p170]

One of the ways that patients' conduct is shaped is via an expectation that they take individual responsibility for their health; an expectation arising out of a trend that has taken hold in the Western world and has its roots in the association between illness and sin. This takes form today, in liberal democracies, as victim blaming.[11] This is achieved via notions of the 'good citizen', that is, a citizen who is an active participant in both economic and social life. This active and thus 'good' citizen is expected to be independent, responsible and self-reliant. Not only this, as risks are apparently known, citizens are expected to make rational decisions about their life and health so that risks are avoided. Thus the chronically ill person is positioned, via this discourse, as one who has failed as a 'good' citizen because they have somehow failed to make the right choices, have failed morally and are now somehow culpable in relation to their ill-health.[11]

This onus on the citizen to be active and participate resonates with notions of governmentality, where the subject is not only governed by the conduct of others but comes to govern their own conduct by surveying and monitoring their own bodies, thoughts and actions.[12] Thus there have been some significant changes, over recent decades, to concepts that govern health care. These changes provide a backdrop from which to notice and bring into sharp relief, the prevailing discourses that are operational in health care today.

Conceptual framework

The French philosopher Michel Foucault introduced the concept of 'governmentality' to consider a broader reading of the notion of governance. He considered the practice of governing from a historical perspective; from the sovereign's relation to their principality, via the idea of the art of government to today's notion of political science.[13]

More specifically, during the Middle Ages and classical antiquity, questions of government concerned how the ruling sovereign conducted themselves, the exercise of their power, how to secure both the respect and acceptance of their subjects, obedience to and love of God, *etc*. The idea of 'the art of government' arose from the middle of the sixteenth to the end of the eighteenth century. This 'art of government' broadened the notion of governing beyond just the concerns of a sovereign to include the government of oneself, of others, of souls, of how to govern and whom the people would accept governing them etc. The problematics of government brought up further questions: how to be ruled, how strictly to rule, what methods to use and to what end? Then, during the eighteenth century an idea arose that challenged the art of government: political science. With this came techniques of government that acted on the population.[12]

Foucault's concept of 'governmentality' encompassed a number of ideas. Among them is the notion of how power is predominantly organised in the Western world, that is, in a complex way and via institutions, analyses, procedures etc, with the population as the target and 'political economy' as the form of knowledge.[13] From his historical analysis of government, Foucault further theorised governmentality in relation to how human behaviour is directed by procedures and techniques.[13] For Foucault, his interest in government is in relation to how it is practised[14] and is considered in a broad way, including the government of the state and of the household, how children and souls are governed for example, and how one governs oneself.[13] When government involves the governance of others, it has been referred to as 'the conduct of conduct' and consideration is given to how the other's conduct is shaped by practices that guide and affect that conduct.[14]

Thus Foucault's[12] concept of governmentality can bear relevance to how nurses (and other clinicians) might govern the conduct of patients in their care. It can also include how patients govern their own selves in the institution of the hospital.

Methodology

The aim of the study was to undertake a secondary analysis of data. The data was originally collected for a study that aimed to explore communication processes between patients and clinicians in relation to patients' post-operative pain and to describe the patients' experience and perception of their pain. The study from which the data arose will hitherto be referred to as the primary study.

The primary study design was a naturalistic, observational methodology with field observations, semi-structured interviews and pain assessments. The study involved an investigation of pain characteristics as communicated by patients, and nurses' responses to both the communication of pain by patients and pain-related activity. The sampling in the primary study was purposive. Fifty patients were recruited from an acute metropolitan private hospital in Australia. This sample consisted of 25 women and 25 men, with twenty five being under 65 and twenty five being 65 and over. The patients had undergone either orthopaedic, abdominal or thoracic surgery and were between day one and three post-operatively. They were all able to speak the English language and consecutive patients, who met the inclusion criteria, were invited to participate. The observation periods were of four hours duration, per patient.

The data from the primary study was analysed according to the research design for that study. However, in order to consider this data in a different way, and given that a text was available for analysis in the form of field-notes and interview transcripts, a discourse analysis was conducted for the secondary analysis. The theoretical perspective of the discourse analysis was informed by the work of Foucault, as this brought to the study a capacity to focus on practices rather than people, institutions or ideologies.[15] Thus the analysis focused on the practices of participants and these practices were interrogated via the research questions. In this instance the practices were those of nurses in relation to patients' expression of post-operative pain and of patients' expression of their pain. However, consistent with Foucault's[16] work, the nurses were not considered to be individuals with free-will but rather considered to occupy subject positions made available by the prevailing discourses operating at the site of this hospital. The patients were also considered to occupy subject positions produced by prevailing discourses

Also important was the way Foucault, in his work, asked 'how' rather than 'why' things came about[15] and this influenced the way the research questions were shaped for this study. That is, the research questions for the secondary analysis were: How is the subject position of the nurse constructed? How is the subject position of the patient constructed? How is the discursive object of pain constructed? How is pain governed? If anything is rendered silent, how is this brought about?

As there is no set way of conducting a discourse analysis,[17] the data analysis for this study involved the consideration of the research questions in the light of Foucault's[12,13] work on governmentality and the interrogation of the participants' practices, as represented in the field-notes, in relation to these questions. This was not undertaken in any formalised way but rather involved reading and re-reading the data-as-text and theoretical texts (field-notes, interview transcripts and Foucault's theory). The language of participants was also considered in relation to what it might disclose about their assumptions, and how subject positions and pain were discursively constructed.

Findings

The 'good' and 'busy' nurses

The analysis found that the nurse is predominantly constructed from the patient accounts as 'good' and 'busy'. For example, said one patient in response to a question from the Research Assistant as to whether the staff listened to them: "Oh yes, they are doing a marvellous job; they are very busy … the nurses are very busy. The girls; they have been so good" (010). Another patient says "Oh, absolutely. They [the nurses] are good" and in reply to a question about how well the nurses had listened to their reports of pain, says: "Oh yes … they have got me extra pills when I have been in pain. I think if anyone listens to you, it's the nurses' (028). Another patient replies to the same question with "Oh, excellent; they have been excellent" (200).

These predominant glowing reports of nurses seemed, at times (and only at times), at odds with the field-notes reporting the events unfolding in front of the Research Assistant. For it seemed that regardless of what the nurses did, as represented in the transcripts, they maintained their place as 'good' and 'busy', as far as the patients were concerned. The most striking example of this is illustrated by the following extract. An anaesthetist is visiting the patient on the first post-operative morning and seems concerned about the level of pain the patient currently has and the pain she apparently experienced overnight:

> Anaesthetist: [to the nurse] - I thought 'Oh, all the patients must be really terrific' last night because there's no phone calls. There's usually heaps of phone calls on epidural day. [To the patient] – Well, I'm really sorry. I can't do anything about it if I don't know. I can't sleep in the room with the patient… and if the nurses don't ring me, I don't know what's going on. …
>
> Patient: They [the nurses] were very busy last night.
>
> Anaesthetist: Yeah. Okay.
>
> Nurse: That's where the morning shift come on and obviously…[to the patient] – Has it gotten more sore in the last hour or so?
>
> Patient: Oh, yeah. I rang the bell at quarter to seven and no one came till half past.
>
> Anaesthetist: Just as well you weren't choking or something isn't it!.... [After some further conversation the anaesthetist leaves]…
>
> [A little later…Patient to nurse:] …because I couldn't get anybody to come in.
>
> Nurse: Yeah.
>
> Patient: And it was just getting worse.
>
> Nurse: Yeah. I apologise for that.
>
> Patient: They were just very busy.
>
> [Later the surgeon comes.] Surgeon: You okay? Pain?
>
> Patient: Frightful night last night. They were very busy last night" (199).

Another example, given by the following extract, is one of the rare occasions when the nurses are criticised, and even so, the patient moves to defend the nurses against his own criticism.

> Patient: She [the nurse] said 'Well, I could give you a bolus [of analgesia]. I'll check on it' or something. But, again, I think she forgot but again I don't remember. I forget whether it was day or night. She came back and hadn't done it. And then she finally did it. She may have gotten, well, the minute you walk out that door, there's someone gunna grab you. So it's not really a critical thing. I'm not trying to criticise them. It's just a statement that it depends on who you have (107).

The patient goes on to say, upon direct questioning, that the nurses don't often come back to see if the analgesia has relieved the pain. He says: "Well one or two, a couple have that I can remember. No, I think that once they've given it to you they've moved on to something else. But I think maybe that's because they're so busy". In any case, he adds, "I'm not reliable at the moment because I'll drift off to sleep" (107).

Occasionally there was some resistance to this dominant subject position of 'good' and 'busy' nurse. For example, when asked if the nurses always listened to their reports of pain one patient said "Oh they do and they don't …Oh they go away and forget to give you the tablet"(138). This resistance though, as noted in this extract, did not extend to all the nurses, but rather, placed some as different to others. This was apparent with the few other notable resistances to the positioning of nurses as 'good' and 'busy'. When a nurse did not live up to this constructed position, they were seen as exceptions to the rule, as is illustrated here.

> A patient comments on how well the nurses have listened: "Oh they've all been very good. Everyone's been marvellous. The night nurse was great. [Whispers] – The other one that came in was a bit off-hand but you get that with nurses; don't know what to say there" (146). To the patients then, the nurses were busy, good, marvellous people and if a nurse could be faulted, she or he was marked as an exception.

The 'good' and 'active' patients

While the nurses were discursively constructed, so the patients were constructed also. The notion of 'goodness', that was pervasive in the construction of nurses, was also pervasive in relation to the patient construction. For example, one patient said "I don't think I'll be very good for the study. I am not good with pain … I am not a good one to ask about that because I am a woos [sook] " (010). Another patient didn't like to talk about pain but said "but it's there constantly, isn't it, to talk about … otherwise you can't tell anybody how you feel because you're not a good patient then" (161). This last patient illustrates something of a resistance to the notion of a 'good' patient in as much as he voices some distance from this subject position.

Another illustration of the idea of 'good' involved in the construction of the patient is given by the following extract, where a patient is telling the Research Assistant that she had severe pain and had spoken to the surgeon.

> Patient: Mr [surgeon] said 'You came good too quickly'. Or words to that effect. Do you know what I mean? I can't remember exactly what he said now, but I know what he meant. That somehow I was good too soon…" (189).

So there are notions of a 'good' patient, one who is not a sook with pain, who tells how the pain is for them. However, it's important not to come 'good' too quickly. A surgeon tells another patient:

> …Okay, we're going to give you some pain killers and we're going to get you up … won't be an easy day today, I warn you, but the quicker you're going, the better. Overall, it's good for you, but also it reduces the risk of blood clots (077).

So, not only does making the patient physically active reduce the risk of blood clots, for other un-stated reasons it's 'good' for the patient to get them going. An active patient is a good patient. Another doctor says: "We can't have you languishing in pain – you can't do things" (107). The analgesia therefore is related to getting the patient active, up and about, doing things. The patient is got going: working toward their recovery and discharge out of hospital: "the quicker you're going, the better". Another example:

> Surgeon: How did you go yesterday?
>
> Patient: Yes. Tough day. Felt a bit washed out.
>
> Surgeon: You had your Endone [analgesia] this a.m.? [Patient nods]. And the ice? Yes, good. The aim is to get up and going (055).

A good patient, one who tolerates and reports pain, also works actively toward their own discharge, not only in a physical sense, but also, as will be argued in the next section of this paper, in the way they survey their bodies in order to report their pain.

The discursive object of pain as linear and apparently measurable

Whilst both nurses and patients are constructed in language, so too is pain, that is, as a discursive object. In the study reported on here, pain is constructed, predominantly, as something that can attract a numerical rating of one to ten. The patients were positioned as the ones who could assign their pain the appropriate number. For example:

> The patient says he has pain.
>
> Nurse: What would the pain be out of 10?
>
> Patient: Right up there; about an 8 (209).
>
> Nurse: How bad is your pain?
>
> Patient: 5 out of 10 (161).

Indeed so widespread was this practice of the patient report of pain via this numerical measurement, that even the primary study's semi-structured interview guide included the question 'What is your current pain? (0-10)'.

However, although this was the dominant way pain was constructed, sometimes something escaped from this and it was far removed from notions of measurement. For example one patient said "Don't mind a bit of pain if you know someone cares about you" (163). Another patient told the Research Assistant that her pain was due to her being tired and missing her family in South America (276). These two examples stand as resistance to the dominant way pain is constructed.

Discussion

One of the striking aspects of the findings is the extent to which the patients excused mistakes and oversights made by nurses, by positioning them as 'good' and 'busy' even when it meant that they were in pain longer. The patients did not complain when the response to their pain was suboptimal. In a sense this could be explained as collusion by the patients with the nurses, reminiscent of the way Goffman[18] argues that audiences, such as hospital patients, can sometimes collude with the staff, excusing their mistakes, as part of a protective practice, where performers are protected by their audience.

Collusion by an audience occurs particularly at times when the performers are under inspection and is part of how social encounters are structured.[18] In my analysis of the study, the doctors and even the research assistant may have been constructed by the patients as inspectors of nurses' work. This front stage of the nurses' performance, the bedside of the patient, is a site where patients watch the nurses perform and tactfully move to protect them from any mistakes picked up by the inspection of doctors, research assistants or others. This was remarkable though, given that the collusion resulted in minimising complaint about their own pain relief.

Moreover, in relation to this concept of inspectors of nursing work, it was Foucault who argued that at the end of the eighteenth century the hospital was organised so as to become an apparatus of examination, epitomized by the doctor's visit.[3] More than two hundred years later, the anaesthetist (in the field notes) visits a patient and, from their examination, moves to overtly (and not so delicately) admonish the nurse. Clearly here, the doctor is an inspector of nurses' work. In this inspection, the nurse, as supervisor of the patient, becomes supervised by the doctor. Hierarchical observation functions in this way,[3] with the doctor supervised by a medical superintendant, who is supervised by a hospital manager, and so on. While it might be disconcerting for nurses to consider that their work is supervised by doctors and not a more senior nurse, the findings from this study clearly disclose a medical supervision to which the nurse is subjected.

Another way to consider how it comes about that patients do not complain about sub-optimal pain relief, is in relation to how the patients are governed in the hospital and then come to govern themselves. The nurses, by their conduct, make it clear to the patients that they (the patients) are in the hands of those around them and their body is now constructed according to medical and nursing discourses.[5] This is a form of disciplinary power and an example of this is the nurse's examination of the patient in relation to their pain; an examination that illustrates the invisible way that disciplinary power operates. The one with the power (the nurse) is not on show, rather the one to whom power is exercised over (the patient) is on constant display, and in such a way that they are transformed from a subject to an object.[3]

Although the patient's body is in pain after being surgically opened and manipulated, the patient does not scream out, cursing and spitting, writhing and sobbing with pain. Rather, they take their own bodies as objects, survey their pain and report it in neat, orderly numbers from one to ten. Watched on all sides, by nurses, other staff, other patients, visitors and visiting doctors, the patient ends up rendering their own body as docile in conformance with the prevailing disciplinary methods of examination, an examination that entails a gaze of constant surveillance and a normalizing judgement.[3]

However, this rendering of their body as docile, and thus compliant to how it is taken as object, is not something the patient necessarily intends to do, rather it is the way the silent power of the health disciplines shape the patient's conduct so that not only do they conform in a manner that suits the way health professionals' work, they take on the gaze and examine themselves as if they were the health professional. They end up governing themselves.[12] There were, of course, some instances of resistance to this dominant mode of governance. However, even if resisting a docile position, it becomes rather difficult for the patient to complain about sub-optimal pain relief, for in doing so they could not only be rendered a 'bad' patient, but might find that it becomes harder to be heard.

The study findings reported here show that sometimes patients profess loudly and strongly about the 'goodness' of the care they receive, regardless of what those witness to that care might think of it. Rankin[9] found this also. Her aunt's ideas about the care and treatment she received as a patient were at times at odds with her own expert view of her aunt's care and treatment. Thus, this renders a nonsense (non-sense) the idea that the measurement of patient satisfaction somehow equates with the measurement of the quality of health care.

A further consideration in relation to these findings, is how the subject position of the patient is reminiscent of Galvin's[11] argument that the 'good citizen', in contemporary times, equates with the idea of an active citizen. In my analysis of the study, the 'good' patient is also an 'active' patient and one who will work their way toward discharge, surveying their body for pain, reporting it on a numerical scale, and taking analgesia, not so they will be comfortable but so they can be physically active. This is, as Galvin argues, an era when patients are expected to make rational choices based on the information provided to them about health and risks. The rational choice expected of the patient, in the study reported here, is that they participate actively in their own treatment.

The production of this 'good and active' citizen/patient can be brought about via a technology of the self, as proposed by Foucault.[19] The patient, by themselves or with the help of the nurses and doctors (and other hospital staff no doubt), transforms the way they present, their thoughts and actions, so as to attain something. This that might be attained could be thought of as 'goodness'; they become a 'very good' patient. This technology of the self then, works together with the disciplinary power to produce the 'good and active' patient.

In this paper, while attempting neither to idealise nor denigrate nursing practice, but rather to consider how responses to pain are produced, it is worth also considering how, as Purkis[4] argues, the nurse practices within an organisational context that is intertwined with their agency. There are discourses, other than the disciplinary ones, that shape available subject positions for nurses. The administrative discourse, with its imperative to move patients quickly through the hospital[5, 6] as if they were on an industrial assembly line[7] is also apparent in the study findings.

Limitations of the study

There were two main limitations of the study. The first was that the study field was, in Goffman's[18] terms, only the front-stage of nursing practice. Due to this, there was no way of knowing what was occurring back-stage for the nurses. It is possible that the back-stage work was having an effect on the front-stage work, particularly given the changes to the functioning of the hospital in recent times, as was outlined in the background section of this paper.

The second limitation was that the primary study design did not establish the conditions for the research assistant to be reflexive regarding their position in the field. It is therefore not clear how the research assistant's position in the field had a bearing on the research findings. For example, as noted in the transcripts, on one occasion the research assistant stopped the audio-tape because the patient was going to talk about 'an unfortunate event' with medical staff. What then is stopped, and what is given permission to continue, would have been worthy of consideration in relation to the research assistant's position in the field.

Conclusion

The 'good and busy' nurse was the dominant subject position for nurses in this study. This construction was heavily defended by patients who protected the nurses when their performance came under inspection, even when their own pain relief was the concern. These 'good and busy' nurses inducted the patients into their dominant subject position as 'good and active' patients, and doctors also played a role in this. The dominant construction of pain was via an apparently quantifiable and a linear scale that worked to silence patients own associations with pain. This simple 'instrument', an apparently efficient way to think about pain, renders something as complex and plural as human responses to pain to a number from one to ten. Patients weren't people who entered hospital with their own life circumstances, experiences and associations with pain. This would be far too messy for an institution dedicated to the efficient processing of patients toward discharge. Comfort is not important – movement is.

Patient satisfaction is also apparently important in the contemporary hospital, yet patients do not necessarily respond to instances of 'poor service' by complaining, as customers are inclined to do. In this study, those with some knowledge of health care (nurse-researchers and the anaesthetist) could locate instances of suboptimal practice by nurses (and for that matter of some doctors' responses) in relation to patients' complaints of pain. Yet the patients themselves did not complain, thus highlighting the complexity of the site of health care, and rendering as a nonsense the notion that patient satisfaction somehow equates with quality health care.

Rather than being rendered 'satisfied' the patient is rendered 'docile' by the power of the disciplinary processes. This is produced via the examination, one so powerful that all parties participate in it, even patients. They come to construct and govern their own pain in the same way as the nurses and doctors construct and govern their pain, and in doing so take their own selves as objects.

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Résumé
Parmi les réactions néfastes de la thérapie antirétrovirale, le syndrome de la lipodystrophie est une condition débilitante qui afflige les personnes vivant avec le VIH/sida et ce, tant sur le plan physique que psychosocial. Cette recherche qualitative avait pour but de décrire le processus de transformations corporelles auquel font face les femmes et d'explorer les répercussions psychosociales de cette condition qui se manifeste progressivement au cours du traitement.

Mots clés corps, femmes, lipodystrophie, SIDA, thérapie antirétrovirale, VIH

Femmes vivant avec le VIH/sida et lipodystrophie : vers une compréhension qualitative du processus de transformations corporelles

MARILOU GAGNON

Introduction

Dans les pays industrialisés, la thérapie antirétrovirale est la pierre angulaire de la gestion clinique du VIH et de la prévention des conditions pathologiques associées au syndrome d'immunodéficience acquise (SIDA). Grâce à la trithérapie, la majorité des personnes qui vivent avec le VIH dans ces pays ont un système immunitaire stable et une charge virale indétectable (copies du virus en quantité minimale dans le sang). Alors que ce traitement démontre une efficacité indéniable (et quantifiable) chez la plupart des patients, il provoque de nombreux effets secondaires et des complications qui affectent négativement la qualité de vie de ceux-ci. En effet, chaque agent antirétroviral engendre une panoplie de réactions adverses ; ces réactions peuvent varier d'une personne à l'autre et se manifestent selon divers niveaux d'intensité. Parmi cette panoplie de réactions adverses qui affectent les personnes vivant avec le VIH/sida, le syndrome de la lipodystrophie est la plus spectaculaire. L'apparition de cette condition dite « secondaire » commande impérativement une réflexion quant à la *plus-value* du traitement trithérapeutique offert aux personnes vivant avec le VIH/sida.

Problématique de recherche

Le « syndrome de la lipodystrophie » a été décrit pour la première fois en 1998 dans le cadre d'une étude transversale dont l'objectif était de documenter et de préciser les changements corporels qui se manifestaient chez un nombre croissant de personnes sous thérapie antirétrovirale.[1] Nous savons désormais que le syndrome de la lipodystrophie repose sur une redistribution anormale du tissu adipeux à des endroits spécifiques du corps et que cette condition provoque des changements corporels irréversibles. En général, la lipodystrophie se manifeste de façon progressive dans le temps et est responsable d'une variété de changements corporels, dont la perte de tissus adipeux au niveau du visage, des extrémités, des fesses et du tronc; l'apparition du réseau veineux sous-cutanée (surtout sur les jambes et les bras) et de la structure osseuse du visage; l'accumulation de tissus adipeux au niveau intra-abdominal et dans la région dorso-cervicale; la gynécomastie unilatérale ou bilatérale; l'apparition de lipomes uniques, multiples ou disséminés et le remplissage des sites sus-claviculaires et enfin, l'accumulation de tissus adipeux dans la partie antérieure du cou.[2]

À ce jour, le diagnostic de la lipodystrophie repose sur l'expérience subjective de la personne qui rapporte des changements corporels et les signes documentés par le médecin lors de l'examen physique.[2] Le manque de consensus scientifique entourant cette condition influence profondément la reconnaissance du problème et sa prise en charge. Dans certains cas, le manque de paramètres « objectifs » pour mesurer la transformation du corps entraîne la banalisation des changements corporels et la minimisation des expériences décrites par les personnes vivant avec le VIH/sida. En raison de la variabilité des symptômes qui se manifestent chez les personnes qui souffrent de lipodystrophie et des connaissances insuffisantes sur l'étiologie des changements corporels, Baril et ses collègues notent « de grands écarts de prévalence, d'incidence et de gravité rapportés à ce jour dans les différentes cohortes ».[2]

Compte tenu des définitions variables du syndrome de la lipodystrophie, il est difficile de déterminer la prévalence de ce syndrome chez les personnes vivant avec le VIH/sida et d'évaluer la fréquence de certains changements corporels au sein de cette population. Comme le soulignent Grinspoon et Carr, la prévalence de cette condition varie de 11 % à 83 % selon la définition utilisée et les caractéristiques de la population étudiée.[3] Tout comme les autres sphères de recherche dans le domaine du VIH/sida, l'étude des complications métaboliques (incluant le syndrome de la lipodystrophie) est principalement centrée sur des populations masculines.[4] Cependant, quelques études démontrent que les femmes vivant avec le VIH/sida souffrent plus fréquemment du syndrome de la lipodystrophie que les hommes.[5-6] De plus, de nombreux chercheurs rapportent que les femmes présentent un risque accru de développer la lipodystrophie et de subir des changements corporels sévères.[7-12] En effet, il semble que les femmes vivant avec le VIH/sida possèdent un facteur de risque supplémentaire, une sorte de prédisposition au syndrome de la lipodystrophie.[13-15]

Depuis la « découverte » de la lipodystrophie en 1998, les travaux de recherche dans le domaine du VIH/sida visent à décrire la pathogénie des changements corporels et déterminer leur étiologie pour proposer éventuellement des critères qui permettraient aux médecins de poser un diagnostic et de dresser un portrait clinique de cette condition. On compte plusieurs études qui explorent les répercussions de la lipodystrophie et démontrent des corrélations importantes entre les changements corporels et des difficultés spécifiques à la prise du traitement, la qualité de vie, l'image corporelle, la vie sociale, la productivité, la santé mentale, la santé physique, la santé sexuelle et le bien-être des personnes vivant avec le VIH/sida. On suggère notamment que la lipodystrophie comporte un lourd fardeau social et que les changements corporels deviennent une source de stigmatisation importante pour les personnes vivant avec le VIH/sida. Pourtant, peu de chercheurs explorent cette condition à partir du point de vue des personnes vivant avec le VIH/sida. Les études qualitatives qui exposent les expériences vécues par rapport aux changements corporels signalent la nécessité de mieux comprendre les dimensions psychosociales de la lipodystrophie.[16-20]

La problématique de cette recherche porte sur le processus de transformations corporelles et fait référence aux expériences des femmes qui souffrent de lipodystrophie. Bien que les publications recensées pour cette étude puissent nous éclairer en regard de la problématique exposée, la perspective des femmes qui vivent avec des changements corporels n'a fait l'objet, à notre connaissance, d'aucune recherche. De manière générale, les femmes vivant avec le VIH/sida sont exclues de la recherche quantitative qui porte sur le syndrome de la lipodystrophie et elles constituent une minorité invisible au sein des études qualitatives qui explorent les répercussions psychosociales de cette condition. Il nous semble important de décrire et de comprendre le parcours de ces femmes qui subissent d'importantes transformations corporelles attribuables à la thérapie antirétrovirale. En effet, nous croyons que l'étude de ce phénomène constitue une étape fondamentale dans la compréhension des enjeux auxquels font face les femmes vivant avec le VIH/sida qui sont aux prises avec un traitement qui provoque des changements corporels importants et irréversibles.

Méthode

Au courant de la période estivale 2008, dix-neuf participantes ont été rencontrées en entrevue individuelle (Tableaux 1 et 2). Le recrutement s'est poursuivi aussi longtemps que de nouvelles données émergeaient lors des entrevues soit jusqu'à ce que la saturation des données ait été atteinte (après 14 entrevues). Par la suite, nous avons rencontré cinq autres participantes afin de préciser et d'enrichir les thèmes récurrents qui avaient été isolés lors des premières entrevues. L'analyse des données s'est déroulée selon les étapes et principes méthodologiques de la théorisation ancrée et plus particulièrement, la démarche analytique proposée par Paillé, qui se veut une adaptation rigoureuse, mais conviviale de la méthode de recherche proposée par Strauss et Corbin.[21-22] Paillé propose une méthode pragmatique constituant une méthode d'analyse des données sous forme d'étapes successives à savoir : la codification, la catégorisation, la mise en relation, l'intégration, la modélisation et, enfin, la théorisation.

Résultats

Selon le cadre méthodologique de la théorisation ancrée, la démarche analytique a permis de construire quatre catégories mutuellement exclusives à partir des données recueillies (Figure 1). Il est à noter que la catégorie intitulée « transformations corporelles » constitue la catégorie centrale du phénomène à l'étude, le lieu d'un processus fondamental auquel se greffent les autres catégories.

Tableau 1. Caractéristiques sociodémographiques des 19 participantes

Catégorie		# de personnes
Âge		Moyenne : 45 ans
Langue	Français	14
	Anglais	5
Source de revenu	Emploi	1
	Assistance sociale	16
	Invalidité	2
Origine ethnique	Caucasienne	12
	Africaine	5
	Latine	2

Tableau 2. Portrait clinique des 19 participantes

Catégorie		# de personnes
Année du diagnostic (VIH)	1990-1995	6
	1996-2000	7
	2001-2006	6
Année du 1er traitement	1990-1995	3
	1996-2000	7
	2001-2006	9
Taux de CD4+ (cellules/µl)	>350 (cellules/µl)	9
	< 350 (cellules/µl)	4
	Inconnu	6
Charge virale (copies/ml)	< 50 copies/ml	13
	> 50 copies/ml	2
	Inconnu	4

Catégorie 1 – Complexe médico-pharmaceutique

À partir de nos résultats, le complexe médico-pharmaceutique fait référence à la complémentarité des dispositifs médical et pharmaceutique dans la prise en charge des personnes vivant avec le VIH/sida. Cette recherche nous a permis de constater que le complexe médico-pharmaceutique exerce un pouvoir considérable sur les attitudes, les comportements, mais aussi sur le corps des femmes vivant avec le VIH/sida. Dans le cadre de cette étude, les participantes soulignent à quel point le complexe médico-pharmaceutique est omniprésent dans leurs vies et plus particulièrement, dans leurs expériences avec la maladie, le traitement et les changements corporels. Au moment des entrevues, elles décrivent leurs expériences en fonction des relations de pouvoir qui modulent la rencontre médicale et influencent les décisions entourant la thérapie antirétrovirale.

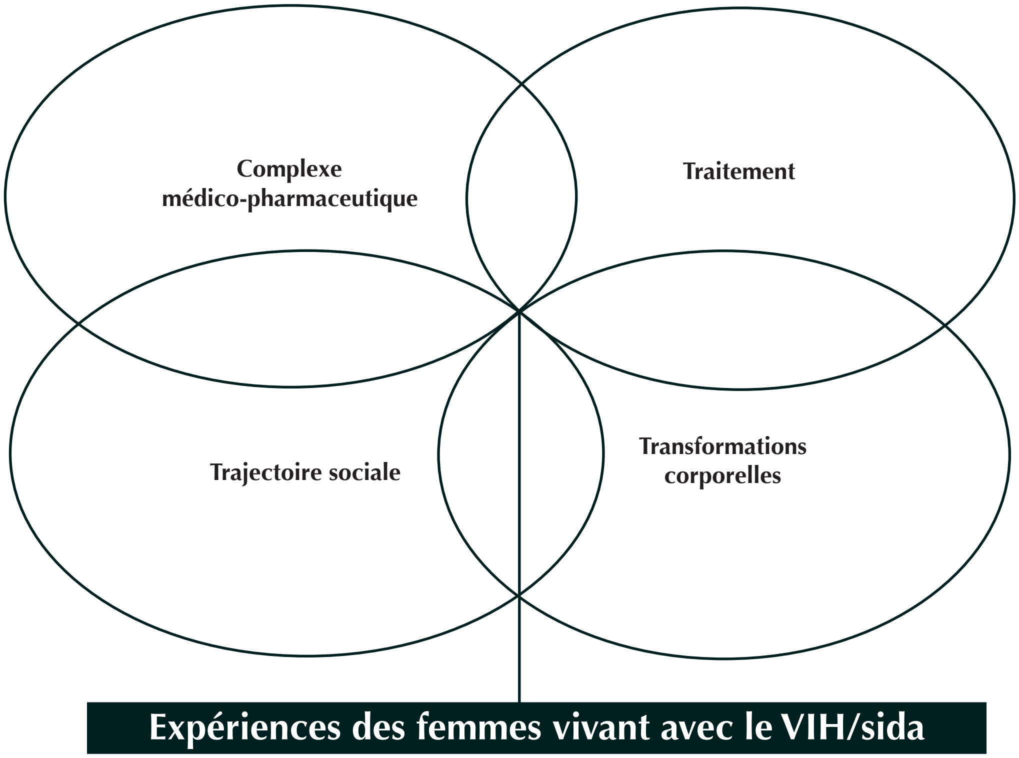
> On dit toujours que les choses importantes dans la communauté c'est de dire aux gens comment interagir avec leur médecin. Qu'ils ont le droit de questionner, qu'ils ont le droit de dire non, que la prise de médicament est un choix éclairé entre le médecin et soi-même. Regarde-moi, ça m'a pris quand même un an pour pouvoir changer mon traitement alors que tout le temps je disais « Je veux changer de médicament ». J'ai dû changer de médecin finalement. C'est quand même fou et pourtant, je suis quelqu'un qui n'a pas de problème à m'affirmer, MAIS à partir du moment où le médecin m'a dit « Non, tu ne peux pas faire ça», qu'est-ce que je dis moi? (Participante 1).

À cet égard, elles considèrent que le médecin, à titre d'expert, exerce un contrôle décisif sur la reconnaissance de la lipodystrophie au plan clinique. Cependant, nos données suggèrent que la reconnaissance de cette condition par les médecins de nos participantes se fait rare. En fait, ces données suggèrent que les médecins contestent la présence de la lipodystrophie et se désengagent face aux effets débilitants de celle-ci. Dans le cadre de cette recherche, les participantes partagent également leurs expériences avec le dispositif pharmaceutique et formulent une critique sévère de la relation entre ce dispositif, qui répond à une logique foncièrement commerciale et économique, et le dispositif médical, censé prendre en charge les personnes vivant avec le VIH/sida.

Catégorie 2 - Traitement

La deuxième catégorie construite à partir des données empiriques de la recherche renvoie aux expériences de nos participantes avec la thérapie antirétrovirale. Ainsi,

Figure 1. Catégories



chaque participante raconte les événements ayant mené à l'introduction de la thérapie antirétrovirale dans leur vie et expose la période de transition qui accompagne ce traitement. Que ce soit à titre de traitement salvateur ou de traitement précoce, la thérapie antirétrovirale est décrite comme un traitement obligé face à la menace constante du virus. Privilège ou droit? L'introduction à la thérapie antirétrovirale soulève des enjeux importants quant à l'accessibilité de ce traitement pour les femmes vivant avec le VIH/sida. Cette catégorie trace également les expériences différentes, mais étrangement semblables, de femmes qui décrivent leur parcours avec la thérapie antirétrovirale - un parcours en dents de scie, marqué par de nombreux effets secondaires, des modifications de traitement, des arrêts de traitement et des complications de toutes sortes.

Nous sommes d'avis que le cheminement de nos participantes influence profondément leur représentation du traitement antirétroviral comme étant à la fois un remède et un poison – une substance qui a la capacité d'être bénéfique et dommageable simultanément.

> L'effet bénéfique du traitement est que l'évolution du virus soit diminuée ou arrêtée. Bon d'accord, ce bénéfice est que ça diminue l'évolution du virus, mais que ça ne détruise pas le corps humain, sinon ça n'a pas de sens. Pourquoi continuer à prendre les médicaments si ça détruit le corps, donc ça n'a pas de sens (Participante 2).

Nos résultats démontrent que le rapport corps-technologie engendre des émotions particulièrement difficiles chez les femmes vivant avec le VIH/sida qui décrivent le traitement à la fois comme un remède et un poison; une substance qui combat le virus avec une telle puissance que le corps entier s'en trouve affecté. Ces tensions expliquent pourquoi la plupart des participantes disent devoir mettre les effets indésirables du traitement et les changements corporels « en perspective », ce qui équivaut à soupeser ceux-ci en en fonction d'un continuum vie-mort. Lorsque les participantes interviewées dans le cadre de cette recherche parlent du traitement, le désir de vivre et le refus de mourir refont surface pour contrebalancer les effets néfastes de la thérapie antirétrovirale. À la lumière de ces données, nous sommes d'avis que la thérapie antirétrovirale, présentée actuellement comme un remède « miracle », provoque des effets secondaires si dévastateurs que cet adjectif (miracle) constitue en fait un euphémisme. Or, les retombées positives, donc thérapeutiques, de la thérapie antirétrovirale (et plus particulièrement sa capacité d'augmenter le taux de CD4+ et de supprimer la charge virale) refont toujours surface dans le discours des participantes.

Catégorie 3 – Transformations corporelles

Des quatre catégories identifiées lors de notre analyse, les transformations corporelles constituent la catégorie centrale du phénomène à l'étude. Cette catégorie explore le processus au cours duquel le corps se transforme sous l'effet de la thérapie antirétrovirale. En effet, ce processus signale le passage vers un nouveau corps; un corps qui prend forme progressivement.

> C'est arrivé très vite. Mon corps a changé en moins de 6 mois. Ça n'a pas pris beaucoup de temps et les changements étaient très rapides. Mon corps a changé très vite comme ça, mais des fois… Tu ne te rends pas compte que ton corps a changé énormément… Mais quand tu achètes, admettons un pantalon, une chemise, une jupe et des choses comme ça, tu commences à voir que tu es grosse, mais tu penses que tu es grosse, mais dans le fond ce n'est pas juste le ventre qui est gros, mais les jambes commencent à être plus minces (Participante 3).

Cette recherche nous a permis de constater que le processus de transformations corporelles repose sur un ensemble de phénomènes qui se manifestent suivant trois phases : *normalisation*, *problématisation*, *pathologisation*. En référence aux résultats de recherche, il est donc possible de décrire la transformation corporelle des participantes à l'aide de ces trois phases distinctes.

La phase 1 se caractérise par la normalisation des premiers signes de la lipodystrophie et leur compatibilité avec le répertoire des changements corporels « normaux » de la femme. La transformation subtile et vraisemblablement naturelle du corps ne permet pas d'envisager une explication alternative. Pendant la phase 2, on assiste alors à une problématisation de la transformation corporelle qui motive les participantes à chercher des explications alternatives. Cette démarche leur permet de formuler leur propre hypothèse par rapport aux changements corporels et de considérer la thérapie antirétrovirale comme un, et peut-être même le seul, élément déclencheur du processus de transformations. Pendant la phase 2, les participantes recherchent donc divers moyens de mettre un terme à l'incertitude qui entoure la phase de problématisation, alors que cette incertitude persiste tant et aussi longtemps que leur hypothèse personnelle n'est pas mise à l'épreuve et validée par une instance médicale. Finalement, la phase 3 engendre une prise de conscience quant aux dommages physiques générés par la prise d'antirétroviraux. Les participantes ne peuvent que constater les dommages permanents faits au corps et exprimer la souffrance qui les afflige.

> Alors, c'est vraiment difficile parce que c'est une lutte tous les jours pour nous. Les médicaments, oui c'est pour vivre, mais en même temps, c'est la mort (Participante 3).

Les résultats de l'étude montrent d'une part, la détresse (physique et mentale) engendrée par ce corps métamorphosé et attestent, d'autre part, des stratégies de résistance manifestées par ces femmes qui contestent l'in/corporation des antirétroviraux et le pouvoir exercé par le complexe médico-pharmaceutique sur leurs corps. Par ailleurs, la souffrance est une dimension fondamentale de la transformation corporelle qui, par définition, provoque une modification permanente du corps et dépouille la personne de tout contrôle sur sa morphologie.

> Mais je me dis que OUI, la lipodystrophie peut avoir un impact au niveau du suicide. (…) Ça ne me surprendrait pas qu'il y ait plus de suicides un moment donné. Parce que tu viens que tu ne t'acceptes plus, tu es … tu es laide. Tu es laide (Participante 4).

Les participantes considèrent que le processus de transformations corporelles provoque une souffrance mentale considérable. Au moment de l'entrevue, ces dernières soulignent à quel point les changements corporels ont un impact dévastateur sur leur vie. De plus, on note que le corps transformé occasionne un sentiment de dégoût et une sensation d'étrangeté, voire d'aliénation, qui bouleverse les participantes qui ne peuvent tolérer l'image projetée par leur propre corps.

> Je me sens … Je me sens vraiment laide. Quand je me regarde dans le miroir, je n'aime pas ce que je vois (Participante 5).

Par ailleurs, comme le soulignent nos participantes, la souffrance qui se manifeste avec la lipodystrophie possède aussi une composante physique. En effet, le corps lipodystrophié est profondément déstructuré et disproportionné par la redistribution des tissus adipeux. Ainsi, il nous faut comprendre que la transformation corporelle engendre des douleurs physiques qui portent atteintes à la santé globale des participantes et à leur participation dans la société.

Catégorie 4 – Trajectoire sociale

La quatrième catégorie construite à partir des données empiriques de la recherche renvoie à la trajectoire sociale des participantes. Elle trace les différentes expériences de visibilité qui relèvent de la transformation corporelle et qui marquent profondément cette trajectoire sociale. Nos résultats suggèrent que l'expérience sociale des participantes influence profondément la représentation du corps comme étant visiblement différente. Cette recherche nous a également permis de constater qu'à l'intérieur du domaine social, le corps agit à titre de point de repère pour définir une personne. Suivant cette perspective, toutes différences corporelles qui se détachent du répertoire de changements corporels « normaux » constituent un stigmate et entraînent un questionnement persistant quant à la nature de cette différence. En référence aux résultats de recherche, il est possible de tracer la trajectoire sociale des participantes à l'aide de trois dimensions distinctes, soit le corps en tant que symbole, le stigmate, et le camouflage.

Les participantes considèrent que les changements corporels transforment profondément leur apparence physique et par conséquent, la façon dont leur corps (en tant que symbole) est interprété par les autres. Au moment de l'entrevue, ces dernières offrent plusieurs scénarios tirés de leur quotidien pour illustrer cette dimension sociale de la transformation corporelle. Dans l'ensemble, elles soulignent que le corps lipodystrophié peut être interprété comme un signe de maladie (incluant le VIH), de maternité, de vieillesse, de comportements sains ou de comportements déviants.

> Parfois, le monde dans l'autobus me laissait leur place, mais je disais « Non, non c'est beau. » Un moment donné, j'étais tellement tannée que je disais, « Oui, oui, je suis enceinte de 6 mois ». J'étais vraiment écoeurée (Participante 6).

Au vue de nos résultats, nous considérons que le corps lipodystrophié est un symbole *extra-ordinaire* qui sème le doute par sa différence et sa visibilité, deux éléments qui comportent un effet symbolique additif. Il est donc essentiel de comprendre en quoi cet effet additif entraîne une relecture du corps lipodystrophié qui, à défaut de signaler une condition physique « normale », devient une source de stigmatisation sans équivoque.

Lorsqu'elles décrivent leur trajectoire sociale, les participantes distinguent deux types de stigmate : le stigmate lié au corps et le stigmate lié au statut sérologique. Le *stigmate lié au corps* repose sur une démarche identificatoire qui permet d'exclure les changements corporels du répertoire des changements corporels « normaux », de questionner la nature de la transformation corporelle et d'assigner un statut social inférieur à la personne qui affiche le symbole de la différence. Ce type de stigmate fait surtout référence à la rencontre sociale, soit aux interactions qui prennent place à l'intérieur du système microsocial. Lorsqu'elles font référence à la rencontre sociale, les participantes désignent les interactions qui se déroulent au quotidien avec des personnes de leur entourage qui sont en mesure de noter la différence physique, d'exprimer des doutes quant à la nature de la transformation corporelle et de classifier rapidement le corps lipodystrophié comme étant visiblement anormal.

> Il a eu de gros changements dans mon corps. J'ai rencontré un de mes amis et il m'a dit, « Oh! mon dieu, qu'est-ce qui est arrivé avec toi? Tu as changé complètement, ton visage a changé, ton corps a changé. » C'est vraiment gênant parce que tu ne sais plus quoi dire, quoi faire… Tu dois changer de sujet tout le temps… Ce sont des situations très difficiles, surtout quand je rencontre des gens qui me connaissaient quand j'étais normale (Participante 3).

Le *stigmate lié au VIH* repose sur une démarche discriminatoire qui permet d'exclure la personne déviante du groupe dominant, d'établir un lien entre la personne déviante et une série d'attributs négatifs, et de déployer des actions qui témoignent de la désapprobation, du rejet, de la discrimination des personnes jugées socialement inférieures. Ce type de stigmate fait surtout référence à la position des personnes séropositives dans le système macrosocial et à la construction socioculturelle du VIH/sida à la fois comme une forme de déviance et une menace biologique pour la collectivité.

> Oui. J'ai une certaine crainte. Il faut dire que le VIH n'est pas une maladie comme les autres. Ça te fait perdre un peu de dignité (Participante 7).

Cette recherche nous a permis de constater que la visibilité du stigmate et la peur du dévoilement sont des thèmes récurrents parmi les témoignages des participantes. Afin de se rendre invisible (ou visiblement normale) et d'éviter la stigmatisation, la majorité d'entres elles ont recourt au camouflage – le camouflage de leur corps et de leur statut sérologique. En ce sens, le camouflage est une stratégie défensive et protectrice qui s'emploie au quotidien pour masquer la différence et tenter de passer inaperçue en société. Cette stratégie fait surtout référence aux risques, tant au plan personnel que social, que comportent la rencontre sociale pour les femmes qui souffrent de lipodystrophie.

> Il y a des milieux que je fréquente et il y a des milieux que je ne fréquente plus. Pour éviter les discussions et pour éviter que ça tire en longueur et qu'on me pose beaucoup de questions. C'est ça. (…) Pour essayer de me couvrir un peu, de me cacher un peu. Que les gens ne me posent pas de questions. Certaines personnes me posent des questions, donc je les évite (Participante 2).

Nos résultats indiquent que le camouflage est un mécanisme qui n'est pas nécessaire, voire désirable, dans un contexte social où le dévoilement est possible et acceptable. Nous sommes donc d'avis que le camouflage se déploie dans des contextes où le dévoilement est risqué et où les préjudices associés au VIH/sida sont véhiculés.

Discussion

Dans le cadre de cette recherche, nous avons repéré certains jeux de vérité et de pouvoir au travers desquels les femmes qui souffrent lipodystrophie situent leurs expériences avec les professionnels de la santé, notamment les médecins spécialistes. Nous constatons que la reconnaissance des changements corporels, et leurs répercussions psychosociales est une préoccupation majeure pour les femmes qui ont participé à cette étude. De plus, à la lumière de nos résultats de recherche, nous estimons que cette reconnaissance est excessivement rare, car elle suppose trois types de corrélation, soit une première corrélation entre les savoirs locaux et les savoirs experts, une deuxième corrélation entre la « vérité » des personnes qui subissent de graves transformations corporelles et celle de leur médecin traitant, et une troisième corrélation entre le pouvoir des femmes vivant avec le VIH/sida et celui de la médecine qui, à la fois comme dispositif et comme profession, exerce un pouvoir considérable sur les corps individuels et collectifs. Les témoignages de nos participantes par rapport à la lipodystrophie font écho à des enjeux beaucoup plus larges comme, par exemple, la disqualification des savoirs locaux au profit des savoirs experts, la production de vérités à propos du corps et de règles qui déterminent ce qui est tenu pour vérité, et la « disciplinarisation » des femmes qui souffrent de changements corporels.

Les résultats de cette recherche montrent que la thérapie antirétrovirale est un instrument excessivement efficace pour influencer les attitudes et modeler les comportements des femmes vivant avec le VIH/sida. Or, la prise en charge des femmes vivant avec le VIH/sida par la thérapie antirétrovirale répond ici aux écrits théoriques de Michel Foucault sur le gouvernement (à la fois populationnel et individuel) des corps et des conduites. La rencontre médicale, telle que décrite dans nos résultats de recherche, contribue à la surveillance, la régulation, la normalisation et la conformation des femmes qui subissent de graves transformations corporelles à cause de la thérapie antirétrovirale. Cette étude montre que la lipodystrophie intensifie ces technologies de gouvernement des corps puisque la manifestation progressive des changements corporels alimente la résistance de ces femmes qui remettent en question le bon fonctionnement de la thérapie antirétrovirale, de même que leur désir de poursuivre un traitement aussi dommageable pour le corps. Dans le cadre de cette recherche, nous avons également pu constater que ces formes de gouvernement contribuent à la colère et à la détresse des participantes qui sont encourager à revoir leurs attitudes « négatives » et à adopter certains comportements, afin que les objectifs précis du traitement soient atteints et que les recommandations en vigueur dans les milieux cliniques soient respectées.

Nous avons également décrit les répercussions psychosociales de la lipodystrophie pour encourager les professionnels de la santé, les chercheurs, les dirigeants de compagnies pharmaceutiques, les décideurs publics et les intervenants du milieu communautaire à penser autrement et à adapter leurs pratiques en regard de cette condition débilitante qui affecte des milliers de personnes vivant avec le VIH/sida. Ce faisant, les résultats de cette étude montrent que la lipodystrophie n'est pas la transformation banale de caractéristiques physiques, mais bien la reconfiguration définitive de la personne en entier et de son statut social. Nous estimons que les répercussions psychosociales de la lipodystrophie sont à comprendre dans un cadre sociologique où le rapport au monde et le rapport à soi-même passent par le corps. C'est dans ce cadre que nous invitons les professionnels de la santé à comprendre la détresse des personnes vivant avec le VIH/sida qui subissent de graves transformations corporelles, alors que les pharmacothérapies antirétrovirales leur permettent de vivre plus longtemps. Le corps lipodystrophié doit être présenté comme un lieu de souffrance, de douleur, de différenciation et de persécution. Nous espérons que ce projet de recherche contribuera à renouveler les attitudes, les discours et les pratiques qui se rapportent à la lipodystrophie. Il ne suffit pas, à notre avis, de noter les transformations corporelles que subissent les personnes vivant avec le VIH/sida et de constater en silence les ravages du traitement sur leurs corps pour assurer une réponse professionnelle éthique. Ainsi, nous interpellons tous les professionnels de la santé à revoir leur engagement par rapport à la lipodystrophie et par conséquent leur contribution à la santé des personnes vivant avec le VIH/sida.

Conclusion

La pertinence de cette recherche pour les sciences infirmières ne fait aucun doute et ses implications pour la pratique professionnelle sont considérables. En effet, notre projet vise le développement de la recherche critique en sciences infirmières et la construction d'un corpus de connaissances au regard de l'axe personne-santé-soins-environnement. Il fait aussi appel au mandat social de la profession infirmière et, plus particulièrement, au lien qui existe entre la recherche critique et la production de savoirs infirmiers politiques. Nous sommes d'avis que la problématique comporte des implications pour la formation professionnelle des infirmières et des infirmiers qui reconnaissent l'importance d'une compréhension globale des expériences relatives à la santé et à la maladie. Nous croyons également que notre objet de recherche dépasse le cadre du VIH/sida et que nos conclusions pourront éclairer, voire transformer, les pratiques infirmières dans divers milieux de soins en plus de problématiser, dans certains cas, la notion « d'observance au traitement ».

Ce projet de recherche contribue de façon considérable à la production de savoirs infirmiers qui visent à comprendre l'expérience des personnes atteintes du VIH/sida et sous trithérapie. En ce sens, nous croyons que ce projet participe directement au développement de la pratique infirmière en favorisant une meilleure compréhension des enjeux psychosociaux qui caractérisent le syndrome de la lipodystrophie, ainsi que des expériences vécues par les femmes vivant avec le VIH/sida en réponse aux changements corporels. Nous invitons les infirmières et les infirmiers qui se spécialisent dans les soins aux personnes vivant avec le VIH/sida de proposer des interventions précises et de mettre en place les pratiques nécessaires pour répondre aux besoins de leur clientèle. Ces résultats de recherche pourront également influencer les interventions des autres professionnels de la santé et des travailleurs communautaires qui oeuvrent dans le domaine du VIH/sida. Mais plus encore, nous estimons que ce projet de recherche participe à l'émancipation de femmes dont la parole est souvent discréditée par certains représentants du complexe médico-pharmaceutique.

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