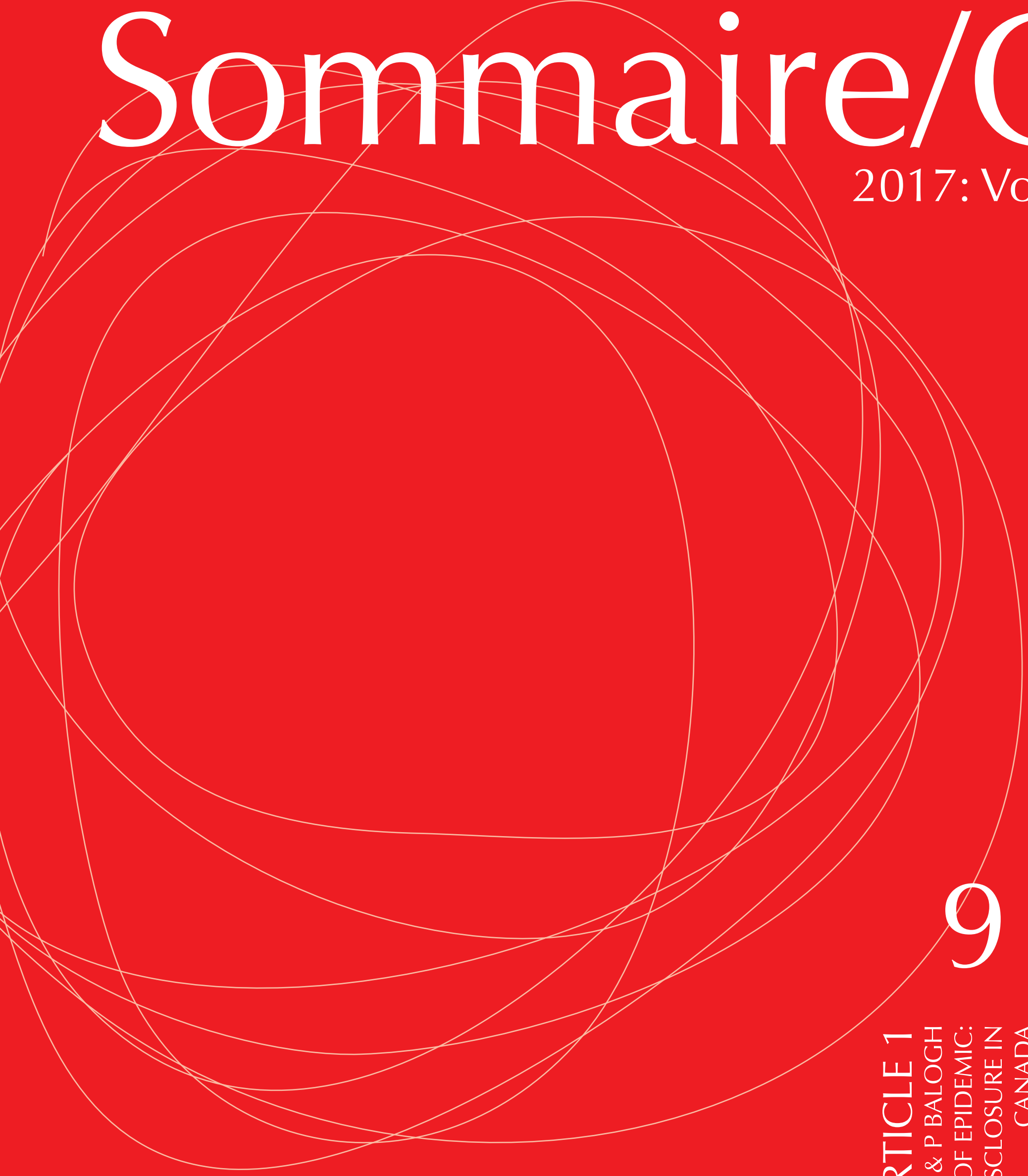
APORIA

LA REVUE EN SCIENCES INFIRMIÈRES • THE NURSING JOURNAL

2017 Volume 9, Numéro 1/ Volume 9, Issue 1. ISSN: 1918-1345

Sommaire/Content

2017: Vol.9, Numéro 1/Vol.9, Issue 1



Éditorial/Editorial

9 ARTICLE 1
JM KILTY, M ORSINI & P BALOGH
CRITICAL BIOETHICS IN THE TIME OF EPIDEMIC: THE CASE OF THE CRIMINALIZATION OF HIV/AIDS NONDISCLOSURE IN CANADA

19 ARTICLE 2
MPLABELLE & P MARTIN
DE LA THÉORIE POSTCOLONIALE EN SCIENCES INFIRMIÈRES : UNE MISE EN REGARD DE SES FONDEMENTS ET UNE ANALYSE CRITIQUE DU CONCEPT DE SÉCURITÉ CULTURELLE

Commentary 29

HIV Pre-Exposure Prophylaxis: Current Controversies and Questions

In most areas around the world, HIV transmission continues unabated, particularly among the groups already most-affected by this virus; e.g., men who have sex with men (MSM), persons who engage in injection drug use (IDU), and individuals who reside in or emigrate from regions where HIV is endemic.[1] To prevent such transmission, clinicians, policy workers, and prevention specialists have trialled and implemented many strategies, including behavioural counselling, treatment for sexually transmitted infections (STI), access to HIV testing, HIV viral load suppression, and, recently, the use of antiretroviral medications as pre-exposure prophylaxis (PrEP).[2] This new intervention, however, is not without controversy.

First, questions arise about what PrEP is, and the answer is simple: PrEP is a novel HIV prevention strategy that employs the well-established practice of having susceptible persons initiate anti-infective medication before exposure to a communicable disease to prevent acquisition of the targeted infection. This practice is used, for example, for influenza (Oseltamivir) or malaria (Chloroquine).[3] PrEP is thus not a new strategy; it is just a novel HIV prevention approach that allows HIV-negative persons to use HIV medications (specifically, single tablet fixed-dose Emtricitabine 200mg + Tenofovir DF 300mg [FTC/TDF]) so that, after exposure to HIV, the virus cannot replicate and cause irreversible infection in the person using PrEP.[4]

Second, questions abound about if PrEP works. The short answer is that PrEP is efficacious, but with varying effectiveness, likely because it requires that people take FTC/TDF one tablet per os (PO) daily. To explain further, in the iPrEx study, which involved 1224 MSM, a meagre 44% reduction in HIV transmission was observed in the FTC/TDF arm, compared to control arm, when all participants were analyzed.[5] When HIV transmission outcomes were stratified based on whether or not persons had detectable TDF in plasma, however, efficacy rose to 92%.[5] This suggests that while efficacious, PrEP is limited by the need to take daily medication.[5] Other studies have shown similar results,[6-8] supporting the conclusion that while PrEP can prevent HIV transmission, its ability to do so depends on daily medication use, and all of the complications and life circumstances that can undermine so-called perfect adherence.

One recent trial (IPERGAY),[9] consequently, explored if FTC/TDF could be taken only when required, rather than continuously. This research allotted participants to receive either placebo or FTC/TDF using the following schedule: two tablets 2 to 24 hours before sex, followed by one tablet every 24 hours for two days; if sexual contact occurred on consecutive days, participants were to take one tablet daily for the days they had sex, followed by one tablet every 24 hours for two days after the last sexual contact.[9] The study found an 86% reduction in seroconversion in the FTC/TDF arm, compared to placebo.[9] The IPERGAY participants, however, took a median of 15 FTC/TDF pills per month,[9] which is the same number of pills found to correspond with maximal HIV prevention outcomes in prior pharmacokinetic analyses of PrEP.[10] The IPERGAY authors thus cautioned that their "results cannot be extrapolated to persons taking a lower number of pills per month".[9 p2245] As such, while event-driven, or what the authors called "On Demand", PrEP may work, current data do not support it.[11] Research needs to explore if a lower pill number and/or frequency or a different dosing regimen could yield prevention outcomes that match continuous PrEP use with at least 15 tablets per month.[11]

Third, questions about behavioural dis-inhibition have arisen: Will PrEP lead to less condom use? A meta-analysis of 18 studies found this may be true: "the use of PrEP for HIV infection was associated with increased risk of STI acquisition among MSM".[12 p2251] The maxim, *correlation does not equal causation*, however, is important here because at least three factors likely contributed to the identified association: (1) it is possible that people who use PrEP truly do use condoms less, increase their number of partners, and/or engage in more anal sex, etc., suggesting in this case that the risk for STIs might actually increase after PrEP initiation due to behavioural disinhibition; (2) it is equally possible that PrEP is used by persons who, before starting this intervention, were already at higher risk for STIs, meaning that increased STI diagnoses were simply the outcome of providing PrEP to appropriate target populations, which, as per the United States Centers for Disease Control (CDC), would be individuals with a "history of inconsistent or no condom use"[4 p11]; and/or (3) it may also be that more STI diagnoses among PrEP users is an artefact of frequent STI testing among such persons, which is possible because clinical practice guidelines[4] recommend STI testing at least every 6 months to obtain refills of FTC/TDF. Interestingly, option two is perhaps most likely, as, within the PrEP trials,[5,9,10,13,14] elevated rates of STIs were diagnosed among PrEP users before FTC/TDF initiation, and differences in STI diagnosis rates were usually not identified either after PrEP initiation or between the control and experimental arms of the PrEP trials. Nonetheless, these data irrefutably highlight that people who use PrEP should receive routine STI testing.[4]

Another important discussion point about PrEP and condoms is that, to date, all but the PROUD study[14] compared PrEP plus condoms and behavioural counselling *versus* condoms and behavioural counselling.[4] Most data about PrEP, therefore, do not arise from, to describe it colloquially, *bareback trials*, but from studies wherein the reported rates of condom use was often very high.[4] Notably, PROUD – as an open label study involving MSM who reported condomless anal sex in the previous 90 days – observed an 86% reduction in HIV seroconversion in the study arm, compared to the control arm.[14] However, some of the prevention benefits may have related to post-exposure prophylaxis: 12 participants receiving FTC/TDF used post-exposure prophylaxis a total of 14 times during the study.[14] Conversely, suggesting that PrEP may have been more effective than the published estimate is that, of the 3 participants who seroconverted and had been randomised to receive FTC/TDF, none had used the medication.[14] Until this study is replicated, however, it is likely best to follow the product monograph for FTC/TDF, which indicates that PrEP should only be considered "as part of a comprehensive prevention strategy that includes other prevention measures, such as safer sex practices … that includes consistent and correct use of condoms".[15 p13] Although it is possible that future studies will support that PrEP can effectively prevent HIV transmission in the absence of condoms, in the meantime, only one study has demonstrated this relationship.

Fourth, questions have arisen about the adverse effects associated with FTC/TDF use. Indubitably, these concerns are valid. In the available trials, while side effects were usually transient (often resolving in the first month) and uncommon (frequencies less than 10% compared to placebo), side effects were mostly gastrointestinal (abdominal cramping, nausea, emesis, diarrhea), neurological (headaches), and musculoskeletal (arthralgia).[4] Elevated serum creatinine levels also occurred among less than 8% of PrEP participants using FTC/TDF.[4] While infrequent and reversible after FTC/TDF discontinuation, the combination of these changes in serum creatinine, the potential sequelae of diminished renal function, and the ease of screening serum creatinine were sufficient to have guidelines recommend serum creatinine testing every three to six months during PrEP use, with FTC/TDF discontinuation (or non-initiation) in the event of a creatinine clearance less than 60mL/min, as calculated using the Cockcroft-Gault formula.[4] These that short-term adverse events should be discussed with patients before PrEP initiation.

Discussions about the long-term sequelae of PrEP should also occur. In contrast to the short-term issues, however, these are not well established. To date, PrEP studies have all been less than four years in duration.[4] As such, we can only speculate about what could occur based on data dating back to the year 2000 about the effects of these medications in HIV treatment trials and from post-marketing adverse event tracking of FTC and TDF (both as independent medications and in fixed-dose combination form).[16] According to the product monograph,[15] observed adverse events for TDF/FTC have included lipodystrophy, lactic acidosis and hepatomegaly (both more common among women), and pancreatitis. Whether or not these outcomes would occur among HIV-negative persons who use FTC/TDF for PrEP is unknown, and, as with short-term side effects, needs to be discussed with patients prior to PrEP initiation.

Similarly, bone mineral density should be considered. Studies involving HIV-positive persons who received FTC/TDF for HIV treatment observed 3-4% decreases in bone mineral density among some study participants.[4] Notably, the HIV-positive participants in these studies received combination therapy that included other antiretroviral agents, obfuscating the applicability of these results to HIV-negative persons using FTC/TDF as PrEP. Two PrEP trials[5,17] have since observed that (1) the decreases in bone mineral density among participants receiving FTC/TDF for PrEP were only approximately 1%, (2) this decline "during the first few months of PrEP either stabilized or returned to normal",[5 p39], and (3) there were no fragility fractures during the study periods. Based on these findings, the United States Centers for Disease Control (CDC) did not recommend bone mineral density screening as part of PrEP management, unless a patient had independent risk factors that would suggest bone mineral density screening.[4] As above, it might still be prudent to inform patients about this possible risk, noting that the observational periods used to assess fragility fractures in these two studies was only one to two years.

Fifth, important questions have been raised asking if PrEP is equitable. The simple answer is that PrEP is unattainable for many persons who require it the most.[18] While physicians and nurse practitioners in many jurisdictions have authority to prescribe antiretroviral medication, high costs associated with ongoing FTC/TDF use make PrEP unattainable for many. At $29.08 (CAD) per tablet, the base cost of TDF/FTC is approximately $873 per month, which rises to $975 per month, or $11,700 per annum, with pharmacy mark-up and dispensing fees.[19] At this cost, only patients with public or private insurance plans can generally access PrEP. While, in many areas of Canada, individuals with government plans (social assistance, disability, etc.) receive 100% coverage, those with private insurance may only receive partial coverage (approximately 80-90%), resulting in high monthly out-of-pocket expenses ($100-200); alternatively, people who are good candidates for PrEP may have low yearly maximum coverage (e.g., less than $5,000), or have high yearly deductibles, which could further limit accessibility. Consequently, regarding equity, it appears that PrEP is a luxury of the rich. It could thus, rather than decreasing HIV transmission at the population level, exacerbate inequities and leave many socially disadvantaged persons without access to an efficacious strategy that is available to those with more resources. That those who are affluent can use HIV medications to remain HIV-negative is even more ethically tenuous in light of the fact that, internationally, millions of people who are already HIV-positive are unable to afford HIV medications for lifesaving purposes.[20]

In closing, as the newest addition to the HIV prevention armamentarium, PrEP holds great promise to change the landscape of HIV transmission internationally. Available data suggest it can reduce HIV transmission by up to 92%, and that, despite often minor and transient side effects, it is overwhelmingly tolerable as a therapy.[4] This is not to say, however, that PrEP is without issue.[16] Adverse events have been reported, and the long-term negative sequelae of TDF/FTC use are unknown among HIV-negative persons.[4,16] Medication use is also problematic, as current regimens require daily pill use, which corresponds with decreased efficacy as many trial participants were unable to follow this regimen notwithstanding biweekly to monthly counselling.[4] How this will play out over a longer time period with less follow-up is uncertain, as current evidence suggests that upwards of 40% of persons who take medications have discontinued within one year of use.[21] Lastly, and most importantly, the cost of TDF/FTC makes it unattainable for many, particularly those of lower socioeconomic status who already bear the burden of many health problems, including HIV infection. This shortcoming cannot be overlooked, and warrants advocacy by nurses, frontline HIV prevention and policy workers, and the general public. An historical cornerstone of HIV prevention has been that this virus can affect everyone. It is time to ensure our prevention strategies are equally inclusive, and do not occur at the expense of the many persons who are either (1) at-risk but unable to afford PrEP and (2) presently unable to obtain HIV medications for treatment and lifesaving purposes. This is an ethical duty that, in light of available scientific evidence, applies to us all.

Patrick O'Byrne RN(EC) PhD

Production Editor / Associate Professor
Aporia – La revue en sciences infirmières /
University of Ottawa
School of Nursing

Lauren Orser RN BScN

Research Assistant
University of Ottawa
School of Nursing

References

1.UNAIDS. Fact Sheet November 2016. http://www.unaids.org/en/resources/fact-sheet.

2.Public Health Agency of Canada. Canadian Guidelines on Sexually Transmitted Infections – HIV. http://www.phac-aspc.gc.ca/std-mts/sti-its/cgsti-ldcits/section-5-8-eng.php.

3.Anti-Infective Review Panel. Anti-Infective Guidelines for Community-Acquired Infections. Toronto: MUMS Guidelines.

4.United States Centers of Disease Control and Prevention. Preexposure Prophylaxis for the Prevention of HIV Infection in the United States: A clinical Practice Guideline. https://www.cdc.gov/hiv/pdf/prepguidelines2014.pdf.

5.Grant RM, et al. Preexposure chemoprophylaxis for HIV prevention in men who have sex with men. N Eng J Med 2010; 363(27):2587-99.

6.Baeten JM, et al. Antiretroviral prophylaxis for HIV prevention in heterosexual men and women. N Engl J Med 2012;367(5):399-410.

7.Murnane PM, et al. Efficacy of preexposure prophylaxis for HIV-1 prevention among high-risk heterosexuals: subgroup analyses from a randomized trial. AIDS 2013;27(13):2155-60.

8.Thigpen MC, et al. Antiretroviral preexposure prophylaxis for heterosexual HIV transmission in Botswana. N Engl J Med 2012;367(5):423-34.

9.Molina JM, et al. On-demand PrEP in men at risk for HIV-1 infection. New Eng J Med 2015; 373(23):2237-46.

10.Grant RM, et al. Uptake of PrEP, sexual practices, & HIV incidence in men & transgender women who have sex with men: a cohort study. Lancet Inf Dis 2014; 14:820-9.

11.Mermin J. CDC Statement on IPERGAY Trial of Pre-Exposure Prophylaxis (PrEP) for HIV Prevention among Men Who Have Sex with Men. https://aidsinfo.nih.gov/news/1541/cdc-statement-on-ipergay-trial-of-pre-exposure-prophylaxis--prep--for-hiv-prevention-among-men-who-have-sex-with-men.

12.Kojima N, Davey DJ, Lausner JD. Pre-exposure prophylaxis for HIV infection and new sexually transmitted infections among men who have sex with men. AIDS 2016; 39:2251-2.

13.Dolling DI, et al. An analysis of baseline data from the PROUD study: an open-label randomised trial of pre-exposure prophylaxis. Trials 2016; 17:163.

14.McCormack S, et al. Pre-exposure prophylaxis to prevent the acquisition of HIV-1 infection (PROUD): effectiveness results from the pilot phase of a pragmatic open-label randomised trial. Lancet 2016: 387:53-60.

15.Gilead Sciences, Inc. Product Monograph – TRUVADA (emtricitabine/tenofovir disproxil fumarate 200mg / 300mg). http://www.gilead.ca/pdf/ca/truvada_pm_english.pdf.

16.Saag MS, et al. Efficacy and safety of emtricitabine vs stavudine in combination therapy in antiretroviral-naïve patients: a randomized trial. JAMA 2004; 292(2): 180-9.

17.Mulligan K, et al. Effects of emtricitabine/tenofovir on bone mineral density in seronegative men from 4 continents: DEXA results of the global iPrEx study. Paper presented at:18th Conference on Retroviruses and Opportunistic Infections 2011; Boston, Massachusetts.

18.Weeks C. High cost of HIV drugs creates 'huge equity gap'. Globe & Mail 2015; Dec 1. http://www.theglobeandmail.com/life/health-and-fitness/health/anti-retroviral-drug-can-almost-completely-eliminate-risk-of-hiv-transmission-says-study/article27539562/.

19.Ontario. Truvada. https://www.formulary.health.gov.on.ca/formulary/results.xhtml?q=truvada&type=2.

20.Mayer KH, Beyrer C. Antiretroviral chemoprophlaxis: PROUD & pragmatism. Lancet 2016; 387:6-7.

21.Blaschke TF, et al. Adherence to medictions: insights arising from studies on the unreliable link between prescribed and actual drug dosing histories. Ann Rev Pharacol Toxicol 2012; 52:275-301.

1

Abstract
This article highlights the ethically uncertain and emotionally charged climate that governs the criminalization of HIV nondisclosure in Canada. Focusing on AIDS Service Organizations (ASO), we suggest that interlocutors perform critical work that helps people living with HIV/AIDS make sense of their rights and responsibilities. Semi-structured interviews with 62 ASO staff across Canada revealed this shifting landscape of HIV advocacy in the age of criminalizing HIV nondisclosure. Drawing on a critical bioethics approach that is informed by considering the role of emotion in decision-making, this article critiques the liberal model of the rational actor that is central to traditional discussions of bioethics and law. Our findings suggest that ASO workers have varying degrees of knowledge about the intricacies of legal duties of disclosure, which affect how they balance their own emotions and thoughts about nondisclosure with their professional duties to provide support and counselling. Ultimately, we argue that critical bioethics in the context of criminalization commands us to appreciate the inherently affective nature of the environment in which bioethical decisions are made.

Key Words criminalization, HIV/AIDS nondisclosure, critical bioethics, emotion, medico-legal borderland

Critical bioethics in the time of epidemic: The case of the criminalization of HIV/AIDS nondisclosure in Canada

JENNIFER M. KILTY, MICHAEL ORSINI & PÉTER BALOGH

Introduction

From calls for mandatory testing to imposing quarantine, HIV/AIDS has evoked intense ethical debate since its discovery in the early 1980s. During those early years, attention centered on groups that were vilified as moral threats to public health, namely sex workers, injection drug users, and gay men. While great strides have been made with respect to the scientific understanding of HIV/AIDS since that time, the ethical debates that engulf it are no less perplexing today. Arguably, the criminalization of HIV/AIDS nondisclosure is one of the most ethically contentious issues to arise in recent years. The subject of lurid media coverage, efforts to punish HIV-positive individuals for exposing their sexual partners to HIV have been loudly denounced by activists and advocates, many of whom insist that criminalization increases stigma, frustrates public health efforts that encourage testing, and signals a regressive return to the moral panic climate of the early years of the AIDS epidemic.[1-5]

Expanding on the promising conceptual framework offered by critical bioethics,[6,7] we explore the *emotionally charged* and *ethically uncertain* climate of the criminalization of HIV nondisclosure in Canada. We suggest that a critical bioethics for HIV/AIDS must include considerations of "bioethics on the ground," which Heimer conceives as the ways in which the "more inchoate moral sentiments of ethics on the ground get transformed into decisions and courses of action... These on-the-spot decisions about particular instances often cumulate over time into routinized but not fully codified ways of doing things".[8 p374] By including considerations of on-the-spot decisions, critical bioethics can better contemplate the emotional nature of bioethical decision-making, in contrast to the liberal approach that reproduces problematic assumptions about the so-called rational actor and views individuals as not "fully autonomous when ruled by emotions or bodily urges".[7 p3] We argue that it is essential to consider the role of emotions in disclosure and in disclosure counselling and by extension, bioethical decision-making. In fact, one of the most important objectives of this article is to critique the conventional model of the rational actor that is normative in the fields of bioethics and law.

Showcasing how emotions give meaning, in her definitive cultural history of HIV/AIDS, Paula Treichler describes AIDS as both a "transmissible lethal disease and an epidemic of meanings or signification".[9 p1] Evoking intensely divisive political, social, cultural and emotional responses, epidemics of signification reveal crises of meaning. In order to appreciate what HIV/AIDS means in our current age, Treichler suggests we need, "a comprehensive mapping and analysis of these multiple meanings… (T)hese may rest upon 'facts,' which in turn may rest upon […] deeply entrenched cultural narratives...".[9 p287] Criminalization may be understood as "an epidemic of signification" grafted onto the broader HIV/AIDS epidemic. While the epidemic language of urgency (e.g., Silence=Death) that animated the HIV/AIDS movement in North America in the 1980s has somewhat dissipated, criminalization carries with it a discursive force that reinscribes HIV/AIDS as a contemporary problem to be feared.

Debates about criminalization reinforce the exceptional nature of HIV/AIDS in industrialized contexts, despite the fact that it is increasingly framed as a chronic, manageable condition. Smith and Whiteside documented the history of AIDS exceptionalism and found that in developed countries HIV/AIDS is gradually being integrated into more general public health frameworks that address a range of blood-borne diseases.[10] We are interested in how this paradox of HIV/AIDS exceptionalism is related to efforts to promote tolerance and de-stigmatization amidst an ongoing discourse of HIV/AIDS rooted in fear, shame and disgust. We suggest that the meanings attached to HIV/AIDS are shifting in the wake of scientific advancements and legal judgments that together are creating an *ethically uncertain* climate. More specifically, we are interested in how criminalization is promoting the unanticipated expansion of bioethical concerns in the advocacy field. This discussion builds on existing research that identifies some of the similarly knotty ethical challenges public health nurses face in their HIV-related work. For example, nurses have been found to employ varied strategies in trying to balance their duties to warn and protect. In some cases, they provide robust discussions of the limits of confidentiality, especially given the possibility that whatever their patients reveal during post-test counselling might be subject to subpoena in a court of law.[11,12] In other instances, however, they reason that it might be unnecessarily burdensome to inform their patients about the risks associated with disclosure in the course of counselling unless they are asked directly. As Sanders notes, this model "relies on clients to arrive prepared with questions about what statements can later harm them in a legal context. The expectation of a rational and informed mindset perhaps does not adequately acknowledge that some recently diagnosed HIV-positive clients present for counseling feeling distraught and unfocused as opposed to rational and level-headed".[11 p258]

To set the stage for this discussion, we begin by reviewing some of the key court decisions that structure the criminalization debate in Canada, paying close attention to the ways they showcase the medical and juridical complexity that can foster bioethical uncertainty. This is followed by a brief description of the methodology and then a section that outlines the theoretical framework employed for this research. In the final section, we use empirical material to demonstrate how a critical bioethics framework can be enriched by considering the role of emotions in the articulation of bioethical decision-making, which challenges the traditional conception of the rational actor that informs the fields of both bioethics and law.

Medico-legal borderland and the creation of bioethical uncertainty

Timmermans and Gabe use the term "medico-legal borderland" to describe how medical and legal discourses, institutions, and powers intersect to constitute new forms of knowledge about particular identities and ways to govern and regulate them.[13] While criminalization occurs in a number of countries, including the U.S., the U.K. and New Zealand, it has been especially prominent in Canada. Approximately 180 individuals have been charged with HIV nondisclosure during a sexual encounter, with the province of Ontario representing nearly half of all cases.[14] From the landmark *Cuerrier* decision in 1998 to the jointly heard *D.C.* and *Mabior* cases in 2012, the Supreme Court of Canada (SCC) has grappled with the medico-legal borderland regarding the duty to disclose one's HIV status to a sexual partner. *Cuerrier* set criteria for determining whether consent was fraudulently attained: the accused must have knowledge that they are

HIV positive and of how HIV/AIDS is transmitted and must either lie about or fail to disclose their sero-status; there must be a "significant risk of serious bodily harm" as a result of the accused's dishonesty;[15 para.128] and the Crown must prove that the complainant would not have consented to sexual activity had they been aware the accused was HIV positive. Canadian lower courts struggled to interpret what constitutes significant risk,[3] leading to contradictory verdicts and juridical uncertainty. For example, *Edwards* was found not guilty of aggravated assault and sexual assault because the court did not consider oral sex as constituting a significant risk;[16] yet, other oral sex cases have led to guilty verdicts.[3] Adding to the climate of scientific uncertainty, *Trott* was found guilty when he had unprotected anal sex, despite the fact that he was the receiver or "bottom," which carries a much lower risk of transmission than if he had been the "top" or insertive partner.[17]

In 2012, the SCC jointly heard submissions from *Mabior* and *D.C.* and ruled that significant risk of serious bodily harm should be read as "a realistic possibility of transmission of HIV".[18 para.94] However, like *Cuerrier* before them, both of these cases pertained to penetrative vaginal sex only; the lower courts have yet to rule on the realistic possibility test for cases involving anal (higher risk of transmission) and oral sex (lower risk of transmission). The Court determined that the risk of transmission could be reduced so as to justify nondisclosure only when the HIV-positive individual carries a low or undetectable viral load (typically considered 50 copies or less of HIV per cubic ml of blood) and a condom is used, thereby setting an even more stringent requirement for disclosure than *Cuerrier*. The SCC's inclusion of a low or undetectable viral load in its judgment illustrates how the medico-legal borderland adds another layer of bioethical uncertainty to the nondisclosure debate. The Court failed to consider for how long a particular viral load test should be considered legally valid, although it is common medical practice to test every three to four months when an individual is undergoing antiretroviral treatment (ART) until the viral load count has been suppressed to low or undetectable levels and every six months thereafter. Tests can be more frequent at the start of treatment or when there is a change in treatment. That said, some individuals receiving ART and who achieve long-term suppression of their viral load to undetectable levels may exhibit periodic, temporary viral load blips. Blips are small increases (between approximately 50 and 1000 copies/ml), that can last for up to three weeks, which means they are easy to miss on routine viral load testing. Currently, there are insufficient data to speculate on the magnitude of transmission risk related to viral load blips.[19]

This brief survey of key Canadian cases demonstrates how the evolution of medico-legal knowledge has contributed to a climate of bioethical uncertainty for the HIV/AIDS community in Canada. The medical and legal questions raised by nondisclosure are far from clear-cut and while they may speak to traditional liberal principles central to bioethics such as autonomy, nonmaleficence and justice, they also underscore the need to account for the role of emotions in structuring the environment in which bioethical decisions are made.

Methodology

After receiving approval from our university's Research Ethics Board, we conducted 62 semi-structured interviews with frontline workers in Canada's ASO community. Interviews were conducted in two phases between early 2014 and the fall of 2015. To recruit potential interview candidates, we contacted the Executive Directors at ASOs across the country, who then forwarded our information sheet to staff. Using snowball sampling, we were able to increase the number and diversity of interviewees through networking. In-person interviews were conducted in all ten provinces and primarily took place in offices at ASOs or other work-related locations. On-site interviews allowed us to undertake observations of the similarities and differences among the various ASO environments, as well as to engage with community members and collect informational and educational materials that the ASOs offer to their clients.

The majority of participants can be categorized as frontline workers who support and advocate for people living with or at risk for acquiring HIV/AIDS. Participants also included the Executive Directors of some of the organizations, social workers, administrators, as well as nurses and doctors connected to ASOs and who work exclusively within the HIV/AIDS community. Slightly more women than men were interviewed (55% women versus 45% men), which reflects the fact that women more commonly work in the helping professions. The interviews were recorded digitally, transcribed verbatim, and then coded and analyzed using critical discourse analysis – a method that links discourse to broader social and political contexts and institutional systems.[20,21] The main limitation of this study is that we only interviewed ASO staff. While some participants self-identified as HIV positive – they volunteered this information as we chose not to ask individuals to share their serostatus – it would have strengthened our results to have interviewed PLWHA directly about their emotions toward disclosure and criminalization. We endeavour to do so in the next phase of our research agenda. To be clear, however, the main objective of the study was to explore the increasing role that AIDS service organizations play in decision making vis-à-vis disclosure.

Theoretical framework: Toward a critical bioethics of the criminalization of HIV/AIDS nondisclosure

Critical bioethics can help us to analyze how the current climate of uncertainty in terms of medical, juridical, and bioethical knowledge is (re)shaping our understandings of HIV/AIDS and the collective commitments to curtail new transmissions. While bioethicists were slow to take seriously the ethics of infectious disease,[22,23] we suggest that Canada's experience with criminalization offers an opportunity to engage a more sustained debate about this changing ethical landscape vis-à-vis HIV/AIDS. Building on previous research that highlights the experiential knowledge of PLWHA,[1,3,24-27] we train our analytical lens on those interlocutors in the ASO community who assist individuals with questions about how to conduct themselves in this *emotionally charged* and *ethically uncertain* climate. As Heimer explains in her ethnographic study of HIV clinics, a "bioethics on the ground" is interested in the spaces in between what we officially know and understand about bioethics and what is experienced in the everyday.[8]

Criminalization is *emotionally charged* as nondisclosure cases typically lead to feelings of anger, fear, guilt, shame, and disgust.[2,26-27] Individuals charged with failing to disclose their status are often portrayed in the media as morally reprehensible, while their partners are cast as unwitting victims. Like many areas in the field of bioethics, the criminalization of HIV nondisclosure is *ethically uncertain* because legal and scientific knowledge about HIV transmission is constantly shifting, making it difficult and unclear for ASOs and PLWHA to determine what might constitute ethically and/or legally appropriate sexual conduct. Moreover, one might judge that it is immoral to withhold one's HIV positive status, yet simultaneously reject the notion that the act of nondisclosure itself should be criminalized. As noted, the field is also uncertain because the Supreme Court of Canada has ruled exclusively on cases involving vaginal sex. The evolving nature of knowledge about the risks associated with different forms of sexual activity means that complex legal questions and bioethical decisions occur in a vacuum within the medico-legal borderland. For example, should exposure to HIV be as ethically and legally proscribed as actual transmission? What if a condom is used and there is no intent to transmit HIV?

We complement the critical bioethics framework with specific attention to the role of emotions and to its profoundly gendered context, which have received comparatively little attention in the bioethics literature.[28] To date, Canada's experience with the vexing ethical-legal issues related to the criminalization of HIV nondisclosure suggests the need to rethink the core concepts of autonomy, nonmaleficence, beneficence, and justice that traditionally underpin the field of bioethics. For example, we challenge the notions of beneficence and justice as they pertain to the criminalization of HIV nondisclosure, wherein most cases there is no willful intent to transmit HIV. The main benefit is an emotional one for victims who feel hurt or angry and desirous of punishment. There is no evidence that criminalization operates as a deterrent, but rather that it may instead hinder public health by encouraging people to avoid testing.[1,3-5] The risks at the individual and societal levels are disproportionate to the benefits when we consider that the accused faces a lengthy (and costly) period of time in prison should they be convicted. Moreover, while using a condom to protect one's sexual partner might fulfill the principle of nonmaleficence, not to mention demonstrating an ethic of care, this nonetheless fails to meet the rigid legal requirements imposed by the realistic possibility test. Finally, the notion of autonomy, or self-determination, needs to account for the complex decision-making environment faced by individuals who are legally required to disclose their HIV status. The idea of the "thoughtful chooser"[29] who can act on the basis of their individual preferences or interests masks the admittedly provisional, uncertain and imperfect knowledge upon which individuals must act.

As Battin et al. note in their critique of conventional bioethics, what typically gets left out of discussions that adopt the notion of the rational actor is the dualism of being both a victim and a vector of the disease.[29] Their victim-vector approach proposes the notion of the "way station self," a self who is both vulnerable to disease but also a potential threat to others. In its zeal to present both sides of the picture, however, the idea of patient as both victim and vector can reproduce some of the heavy-handed language that has characterized failed responses to public health concerns in the past. For example, identifying someone as a vector of disease, whether as 'Patient Zero' in the case of Quebec flight attendant Gaëtan Dugas or as an 'AIDS predator' in the criminological imaginary, does little to appreciate the troubled history that marginalized populations affected by HIV have experienced at the hands of well-meaning public health experts. Moreover, a singular focus on victimhood in terms of vulnerability to disease neglects the reality that vulnerability to disease is structured by a host of factors beyond an individual's control. Feminist theorists such as Patricia Hill Collins rightly discuss the importance of paying attention to the intersectional "matrices of oppression."[30] This is a particularly important framework for considering the different situations of women in relationships that are potentially characterized by violence and who are justifiably concerned about disclosing to their sexual partners out of fear of violent reprisals.

To address these concerns, we adopt Hedgecoe's view that a critical bioethics must move beyond the traditional model of the individual rational actor that dominates the field.[6] While we do not discount the value of the core bioethics concepts or principles, we argue that constructions of the individual as an always-already rational actor who is solely responsible for exposure to and onward transmission of HIV, neglects the complex intersection of different actors and discourses in bioethical conversations around HIV. Moreover, this approach fails to consider the effects of the history of the HIV/AIDS response in North America, which has not been particularly kind to PLWHA; given this history, it is not surprising that individuals might find it difficult and even dangerous to openly disclose their HIV status.[2,26, 31]

Hedgecoe identified three potential elements in his articulation of a critical bioethics. First, he suggests that critical bioethics must be "theory challenging," specifically incorporating social science insights in ways that illuminate the social worlds of bioethics via "the sociological imagination".[32] Our respective training in criminology, law, public policy, and political science influences the perspective we advance here. The second feature of critical bioethics is reflexivity. Echoing Hill Collins,[30] Hedgecoe explains that, "who we are in terms of class, ethnicity, profession, religion, sexuality, education and experience of medical settings (how many times we have had surgery for example) shape our instinctive and intellectual responses to biomedical technologies".[6 p138] As applied to the criminalization of nondisclosure, reflexivity also involves attention to how affect and emotion shape cultural interpretations of and socio-political responses to HIV risk and responsibility. Our approach reflects a growing interest in grounding the study of bioethics in recognition of how social processes mediate individual action,[23,33] it also dovetails with how solidarity amongst different groups might affect the context of decision-making. For example, according to Prainsack and Buyx:

> In its most bare-bone form, solidarity signifies shared practices reflecting a collective commitment to carry 'costs' (financial, social, emotional, or otherwise) to assist others. It is important to note that solidarity is understood here as a practice and not merely as an inner sentiment or an abstract value. Solidarity requires actions. Motivations and feelings such as empathy etc. are not sufficient to satisfy this understanding of solidarity, unless they manifest themselves in acts.[34 p46]

Given the historic solidarity between the ASO community and PLWHA we were interested in how the personal emotions of ASO staff members toward the criminalization of HIV/AIDS nondisclosure and the affective climate of frontline HIV/AIDS advocacy comes to shape the content and messaging of the counsel offered to PLWHA and of the ways in which staff conduct their day-to-day work.

Finally, Hedgecoe counsels that a critical bioethics must be "empirically rooted."[6] This article connects questions about risk and responsibility in the age of criminalization to the situated knowledge of the HIV/AIDS community, which includes individuals living with and at risk of HIV, as well as individuals working in the ASO sector. Our study findings demonstrate that the emotionally charged and ethically uncertain climate resulting from criminalization are being felt well beyond the direct daily encounters between individuals living with HIV and their actual or potential sexual partners. In the next section, we discuss the value of incorporating emotions into critical bioethics and use our empirical data to demonstrate how emotions are affecting frontline ASO work in Canada.

Results & Discussion: Incorporating Emotion into Critical Bioethics

The emotional turn has been felt throughout the social sciences, humanities, and law.[35-38] A central theme in some of the literature concerns the need to destabilize the separation of emotion from reason. If reason and emotions are inextricably linked such that rationality requires emotion, then it is unhelpful to pit feeling and emotion against cognition and reason.[39] Complex emotions such as compassion, disgust, fear and anger "express explicit principles that we hold, or mere intuitions that we have never fully articulated".[40 p17] Moreover, we attach certain moral ideas to our ability to express different emotions; for example, we might feel shameful about expressing anger, or indeed righteous.

Appreciating the role of emotions in bioethics led us to focus on advocates working in the ASO community to understand how they might challenge or reproduce dominant *feeling rules*, a concept first coined by Hochschild, and more recently explored by Gould, to reveal the ways in which rituals and conventions capture, document, and codify felt experience.[37,41] Unlike other rules, feeling rules "do not apply to action but to what is often taken as a precursor to action".[41 p564] Hochschild distinguishes a feeling rule – "our sense of what we can expect to feel in a given situation" – from rules that reflect "our sense of what we *should feel* in that situation".[41 p564] Anderson invokes Raymond Williams' concept "structures of feeling" to describe "forms of affective presence that disclose self, others and the world in particular ways. Structures of feeling mediate life by exerting 'palpable pressures' and setting 'effective limits on experience and on action'.[42 p106] When a PLWHA understands that HIV commonly evinces fear, disgust and stigma, these emotions become structures of feeling that can influence bioethical decision-making surrounding disclosure.

In adapting the notion of feeling rules to the bioethical field of HIV/AIDS and criminalization, we are interested in what is considered appropriate to feel in the ASO environment vis-à-vis criminalization, and whether this affects the kinds of discussions that take place regarding nondisclosure. Of course, HIV/AIDS advocacy has never been devoid of emotion; consider, for example, the long-standing tradition of activism popularized by the AIDS Coalition to Unleash Power that legitimized anger as a collectively felt emotion.[37] While staff might be encouraged to act professionally, which requires working 'at a distance' when dealing with clients who seek their counsel, such professionalism might be frowned upon in a community built on relationships of trust, love, and feeling. What are the implications of appearing to be unfeeling? In some cases, the inability of staff members to express empathy or compassion can contribute to feelings of shame among clients.

Members of the ASO community are not simply expected to provide reliable or "objective" information and counsel to PLWHA. Instead, they must grapple with the need to reconcile "on the ground" bioethical decision-making with the ever shifting and uncertain terrain created by criminalizing HIV nondisclosure. Subsequently, bioethical decision-making on the ground may depart from what would be considered legally responsible conduct. For example, like many of the participants we interviewed, Andrew reported that his understanding of what constitutes responsible sexual conduct is often challenged by the day-to-day realities of exercising professional ethics:

> I've got guys who are concerned about going and getting tested for HIV because they're afraid that the test results will be shared with their wives at home who have no idea they have this lifestyle [Men who have sex with men]. So for me, that's a hard one for me on my personal values test, in that cheating is cheating, and if you're engaging in risky sexual behaviours behind your partner's back without their knowledge and not getting tested to ensure that you're not putting them at risk, I find that very difficult to wade through, and it's a bit of a minefield, but you have to really tiptoe.

Andrew's statement that ASO staff must "tiptoe" as they "wade through a minefield" reveals how many different circumstances and individual emotional responses (e.g. their own, the client's, as well as those of the client's partner, family and community) they must consider when counselling about disclosure. Moreover, they must do so without revealing any personal judgments they may hold regarding the individual's behaviour in order to try to ensure that the service user maintains contact with the ASO. On the other hand, bioethical uncertainties that challenge personal ethics can lead to personal soul searching and frustration:

> I'll talk to one of my other peers about stuff and say, "I just need to talk to you. I need to vent this shit out of here. This guy's just driving me crazy. His test has come back positive. He doesn't want to tell his wife, but he's not sleeping with his wife, so really, does he need to tell his wife?"

The collision of professional ethics, feelings of solidarity with PLWHA, and personal emotions and morals created other bioethical conundrums for ASO staff. Most notably, participants raised concerns about counselling service users to disclose when the client is known to be in a violent relationship or might be at risk of violence if they disclose. Counselling clients to engage in blanket, universal disclosure to all of their sexual partners reflects ASO workers' fear of criminalization but it goes beyond the requirements of the legal obligation set by the 'realistic possibility test' and it may simultaneously increase the potential for risk and harm to clients. Indeed, while most ASO staff members are philosophically opposed to criminalization, traditional bioethical principles are often of little help when trying to respond to legitimate, on-the-ground issues faced by people living with HIV. Reflecting this common concern, one frontline worker stated:

> I go back to the client being afraid to tell their parent or being afraid to tell their spouse or their pimp, and I know they're going to end up having sex with them. And knowing that the condom might not work [Pauses] that's my hardest part because there's nothing I can say. I have to – I understand why. I'm sorry, but if I'm going to get the bejesus beaten out of me because I now have HIV, I'm not going to want to tell people. I get that.

The AIDS movement's success in challenging medical and scientific authority was an important factor driving our interest in exploring the ways in which new, bioethical considerations emerging from shifting medical and legal discourses are reshaping the contours of HIV/AIDS advocacy. These questions often surface with respect to the emotional labour advocates are required to perform in order to translate complex ethical-medico-legal knowledge into accessible language to their clients, all the while trying to maintain some, but not too much, professional distance. For example, while ASO staff may understand that the risk of transmission varies by sex and by sexual position and activity, the legal precedents set by the SCC rulings, which only considered heterosexual penetrative vaginal sex, complicate their efforts to provide clear advice and counselling regarding the duty to disclose. Mary Anne summed up the issue this way:

> I honestly don't understand [the criminalization of HIV nondisclosure]. I think that's the biggest problem – is I don't understand, and when I don't understand, I get agitated, and I get angry. And I'm sorry. My clients – all of them – even the ones on the street that are working the street – are not bad people. That's just there but for the grace of God go you or I. (…) Not being a lawyer and not understanding the fine print of everything and coming from the just common sense model of everything, a lot of times, I end up being tongue-tied because I don't want to say the wrong thing to you.

Mary Anne's narrative illustrates what many participants noted – that the legal requirement to disclose one's HIV status to all sexual partners is not as straightforward as law's rational actor might suggest. While legal norms assume that the rational actor has access to all available information and takes the most beneficent and just course of action, self-determined reasoning (reflecting the bioethical principle of autonomy) is highly influenced by emotions, structural power relations and socio-cultural context. This means that in some situations, decisions to disregard the law do not reflect irrational or purposively reckless behaviour, but rather the messiness inherent in complex, emotional decision-making. Consequently, such decisions must be read with an eye to the affective economy that emotional and power relations engender, rather than what is assumed by the objective calculus of the rational actor identified in the fields of bioethics and law. For a woman in a violent relationship, the decision to forestall disclosure – while risking criminalization (a harmful cost) – may help to prevent victimization (a potentially life-saving benefit).

The law creates feelings of uncertainty, apprehension, anger and fear, not only for PLWHA but also for the broader ASO community that is charged with communicating accurate, reliable information and counsel. Reflecting upon how stigma and discrimination make many PLWHA reluctant to universally disclose and the dangers this may pose in cases where soured relationships perpetuate vengeful calls for criminalization, as was the case in *R. v. D.C.*, one participant averred:

> And I totally get why they're not – stigma, the discrimination, all the shit that comes with disclosing one's HIV status when – until this disease isn't criminalized, we're fucked around disclosure. People will not do it so long as they're afraid they're going to be charged somewhere down the road. He said, she said – we've seen too many cases in the courts of I disclosed. Five years later, we divorced. Now, the dick's charging me. What the fuck?

Given the climate of fear around disclosure that criminalization exacerbates, some PLWHA have gone to great lengths to ensure that their disclosure is documented and preserved. While Medina reported that some ASO staff counsel clients to store used condoms in the freezer as proof that they practiced safer sex should they be criminally charged,[31] a number of interview participants relayed that some of their clients are drawing up disclosure contracts for their sexual partners to sign. Exemplifying solidarity with other PLWHA, one participant noted that he has used this approach himself and that he recommends his clients use disclosure contracts as a method of legal protection:

> As an educational measure to the guys I talk to who are disclosing their status, I encourage them to keep all conversations – so ideally, get a witness in the bar to the fact that you disclosed your HIV status to buddy who wants to take you home. Good luck with that. Have a document at home that says, and make them sign it. There was a time when I actually had one in my home – a document that I signed that I made people sign: I told you I was HIV-positive; this is what we're going to do, this is da, da, da, da. You agree, blah, blah, blah. End of discussion.

The bioethical challenges associated with the criminalization of HIV/AIDS nondisclosure are rooted in the context of medico-legal uncertainty that characterizes the environment within which members of the ASO community work and PLWHA live. We suggest that these bioethical challenges mobilize strongly felt emotional responses because they target highly stigmatized and vulnerable groups. Rooted in emotions of disgust and fear of the 'dangerous other',[2] criminalization fosters the problematic and inaccurate view that PLWHA who choose not to disclose are consciously trying to transmit HIV to others. As a result, criminalization maintains and even augments the stigma that has long been attached to HIV/AIDS and effectively dehumanizes PLWHA. Given that the legal system channels cultural emotions,[35,38] it is unsurprising that socio-legal scholars have identified trends indicative of the re-emotionalization of law in two arenas: "the emotionalization of public discourse about crime and criminal justice, and the implementation of sanctions in the criminal justice system that are explicitly based on—or designed to arouse—emotions".[43 p301]

Conclusion

This article highlights some of the bioethical challenges unfolding in the wake of a changing HIV epidemic. While the use of the criminal law to punish PLWHA has been roundly criticized as poor public policy, less attention has centered on how the intersection of public health and criminal law is reconstituting the HIV-positive subject as an always-already, potential sexual predator.

Advancing a critical bioethics approach to study the criminalization of HIV nondisclosure, we focused our attention on how counsel regarding the duty to disclose is being considered in the ASO context. While the field of bioethics forces us to confront uncertainty, not knowing how our individual decisions will directly affect others, and over what course, means that we are rarely "rationally" accessing comprehensive information about the risks and benefits associated with our actions. Subsequently, there is much to be gleaned from investigating the environments in which these difficult decisions are made. While Battin et al. are correct to suggest that we possess "embedded agency", we need to unpack the environment in which the individual is embedded to examine how it contributes to defining what it means to behave responsibly or ethically in the age of epidemic.[29 p89]

Having established that both medical and legal knowledge related to HIV are ever-evolving and are contributing to an environment of bioethical uncertainty, we view the ASO community as a collective of key actors who translate these uncertain knowledges to PLWHA and perform their own emotional labour in the process. By examining how ASOs communicate shifting medical and legal knowledge to PLWHAs, we hope to shed light on how bioethical decision-making might be structured not only by a range of interlocking oppressions related to gender, race/ethnicity, class and sexuality, but also by affect and emotion. Adding emotions and affects to our analytic lens enabled us to challenge the problematic conceptualization of the rational actor that is located in bioethics and law,[5,6,29] especially in light of the (re)emotionalization of law.[36,38,43] We argue that the vexing moral and legal questions that are emerging as a result of the criminalization of HIV/AIDS nondisclosure and that are faced by PLWHA and ASO workers alike are mediated by a range of conscious and unconscious emotions and affects. This finding suggests that scholars working in the field of bioethics must move beyond the traditional principles of autonomy, nonmaleficence, beneficence and justice and begin to consider the ways in which emotions shape bioethical decision-making 'on the ground' and therefore in varying intersectional and socio-cultural contexts. Finally, establishing the importance of everyday bioethical decision-making – Heimer's bioethics on the ground – in the advocacy field can contribute to valorizing the emotionally challenging work performed by these advocates.[8]

References

1.Adam BD, Elliott R, Husbands W, Murray J, Maxwell J. Effects of the criminalization of HIV transmission in Cuerrier on men reporting unprotected sex with men. Canadian Journal of Law & Society 2008; 23:143-59.

2.Kilty JM. Dangerous liaisons, a tale of two cases: Constructing women accused of HIV/AIDS non-disclosure as threats to the (inter)national body politic In: Kilty JM (ed). Within the Confines: Women and the Law in Canada. Toronto: Canadian Scholars Press Inc., 2014:271-92.

3.Mykhalovskiy E. The problem of 'significant risk': Exploring the public health impact of criminalizing HIV non-disclosure. Social Science & Medicine 2011; 73:668-75.

4.O'Byrne P. Criminal law and public health practice: Are the Canadian HIV disclosure laws an effective HIV prevention strategy? Sexuality Research and Social Policy 2012; 9:70-9.

5.Mykhalovskiy E. The Public Health Implications of HIV Criminalization: Past, Current, and Future Research Directions. Critical Public Health 2015; 25, 4:373-85.

6.Hedgecoe AM. Critical bioethics: Beyond the social science critique of applied ethics. Bioethics 2004; 18:120-43.

7.Murray SJ, Holmes D. Introduction: Towards a critical bioethics. In: Murray SJ, Holmes D (eds). Critical Interventions in the Ethics of Healthcare. Palo Alto: Ashgate, 2009; 1-11.

8.Heimer CA. 'Wicked' ethics: Compliance work and the practice of ethics in HIV research. Social Science & Medicine 2013; 98:371-8.

9.Treichler PA. AIDS, homophobia and biomedical discourse: An epidemic of signification. Cultural Studies of Science Education 1987; 1:263-305.

10.Smith JH, Whiteside A. The history of AIDS exceptionalism. Journal of the International AIDS Society 2010; 13:1-8.

11.Sanders C. Discussing the limits of confidentiality: The impact of criminalizing HIV nondisclosure on public health nurses' counseling practices. Public Health Ethics 2014; 7:253-60.

12.Sanders C. Examining Public Health Nurses' Documentary Practices: The Impact of Criminalizing HIV non-disclosure on Inscription Styles. Critical Public Health 2015; 25, 4:398-409.

13.Timmermans S, Gabe J. Partners in Health, Partners in Crime: Exploring the Boundaries of Criminology and Sociology of Health and Illness. Oxford, UK: Blackwell, 2003.

14.Global Network of People Living with HIV (GNP+) and HIV Justice Network (HIVJN). Advancing HIV Justice 2: Building Momentum in Global Advocacy Against HIV Criminalisation. Amsterdam and London: GNP+ and HIVJN, 2016. Available from: http://www.hivjustice.net/advancing2/.

15.R v. Cuerrier, [1998] 2 SCR 371; [1996] BCJ No 2229 (QL), 83 BCAC 295; (1995), 26 WCB (2d) 378.

16.R v. Edwards, [2001] N.S.J. No. 221, 2001 N.S.R. (2d) 107.

17.R v. Trott, [2008] BCCA 463; 2008 BCSC Doc. 24402.

18.R v. Mabior, 2012 SCC 47; [2010] MJ No 308, 2010 MBCA 93; [2008] MBQB 201, 230 Man R (2d) 184.

19.Attia S, Egger M, Müller M, Zwahlen M, Low N. Sexual transmission of HIV according to viral load and antiretroviral therapy: Systematic review and meta-analysis. AIDS 2009; 23: 1397–1404.

20.Fairclough N. Critical Discourse Analysis: The Critical Study of Language. Harlow: Longman, 1995.

21.van Dijk TA. Discourse and Power. Basingstoke: Palgrave Macmillan, 2008.

22.Schuklenk U. AIDS: Bioethics and public policy. New Review of Bioethics 2003; 1:127–44.

23. Tausig M, Selgelid MJ, Subedi S, Subedi J. Taking sociology seriously: A new approach to the bioethical problems of infectious disease. Sociology of Health & Illness 2006; 28:838–49.

24.Dodds C, Keogh P. Criminal prosecutions for HIV transmission: People living with HIV respond. International Journal of STD & AIDS 2006; 17:315-8.

25.Galletly CL, DiFranceisco W, Pinkerton SD. 'HIV-positive persons' awareness and understanding of their state's criminal HIV disclosure law. AIDS and Behavior 2009; 13: 1262-9.

26.Klitzman R, Kirshenbaum S, Kittel L, Morin S, Daya S, Mastrogiacomo M, Rotheram-Borus MJ. Naming names: Perceptions of name-based HIV reporting, partner notification, and criminalization of non-disclosure among persons living with HIV. Sexuality Research & Social Policy 2004; 1:38-57.

27.O'Leary A, Wolitski RJ. Moral agency and the sexual transmission of HIV. Psychological Bulletin 2009; 135:478-94.

28.Robichaud AL. Healing and feeling: The clinical ontology of emotion. Bioethics 2003; 17:59-68.

29.Battin MP, Francis LP, Jacobson JA, Smith CB. The Patient as Victim and Vector: Ethics and Infectious Disease. Oxford: Oxford University Press, 2009.

30.Collins PH. Gender, black feminism, and black political economy. Annals of the American Academy of Political and Social Science 2000; 568:41-53.

31.Medina C. Supporting people living with HIV/AIDS (PHAs) through the web of non-disclosure. Workshop organized by AIDS Committee of Ottawa 2013 Feb.

32.de Vries R, Turner L, Orfali K, Bosk C. (2006). Social science and bioethics: The way forward. Sociology of Health & Illness 2006; 28:665–77.

33.Twine R. Constructing critical bioethics by deconstructing culture/nature dualism. Medicine, Health Care & Philosophy 2005; 8:285-95.

34.Prainsack B, Buyx A. Solidarity: Reflections on an Emerging Concept in Bioethics. Wiltshire, UK: Nuffield Council of Bioethics, 2011.

35.Ahmed S. The Cultural Politics of Emotion. London: Routledge, 2004.

36.Bandes SA. Victims, closure and the sociology of emotion. Law and Contemporary Problems 2009; 72:1-26.

37.Gould D. Moving Politics: Emotion and ACT UP's Fight Against AIDS. Chicago, IL: University of Chicago Press, 2009.

38.Nussbaum MC. Hiding from Humanity: Disgust, Shame and the Law. Princeton, NJ: Princeton University Press, 2004.

39.Orsini M, Wiebe S. Between hope and fear: Comparing the emotional landscapes of autism activism in Canada and the U.S. In: Turgeon L, Wallner J, Papillon M, White S (eds). Comparing Canada. Vancouver: UBC Press, 2014; 147-67.

40.Jasper JM. Emotions and the microfoundations of politics: Rethinking ends and means'. In: Clarke S, Hoggett P, Thompson S (eds). Emotion, Politics and Society. London: Palgrave-Macmillan, 2006;14-30.

41.Hochschild A. Emotion work, feeling rules, and social structure. American Journal of Sociology, 1979; 85:551-75.

42. Anderson B. Encountering Affect: Capacities, Apparatuses, Conditions. London: Routledge, 2014.

43.Karstedt S. Emotions and criminal justice. Theoretical Criminology 2002; 6:299–317.

Acknowledgements
This research was supported by a Catalyst Grant (Ethics) from the Canadian Institutes of Health Research [grant number 220829-190399-2001]. We wish to acknowledge the numerous AIDS Service Organizations whose staff members agreed to participate in this research.

To contact the authors:
Jennifer M. Kilty, Ph.D.
Associate Professor & Associate Chair
University of Ottawa
Department of Criminology
120 University Private, FSS 14030
Ottawa, Ontario
K1N 6N5
Canada
Email: jkilty@uOttawa.ca

Michael Orsini, Ph.D.
Full Professor
University of Ottawa
Faculty of Social Sciences

Péter Balogh, Ph.D.
Part-Time Professor
University of Ottawa
Faculty of Social Sciences

2

Résumé
Fortement influencée par la théorie poststructuraliste et ayant elle-même exercée une indéniable influence sur la théorie féministe, la théorie postcoloniale suscite de plus en plus d'intérêt au sein de la discipline infirmière. Sa base descriptive et normative, le lien intime que cette théorie entretient avec la pratique, ainsi que les possibilités qu'elle offre de donner une voix aux personnes en situation de vulnérabilité, ne sont d'ailleurs pas étranger à l'attention qui lui est accordée en recherche infirmière. Dans cet article, nous explorerons les fondements de la théorie postcoloniale en nous appuyant sur les travaux de théoriciens des sciences sociales et des sciences infirmières. Nous discuterons de sa pertinence pour la discipline et de ses applications, notamment par le biais d'une analyse critique du concept de sécurité culturelle. Nous proposerons également une application du concept dans un contexte de maternité chez les femmes immigrantes.

Mots-clés émancipation, praxis, recherche infirmière, sécurité culturelle, théorie postcoloniale

De la théorie postcoloniale en sciences infirmières : une mise en regard de ses fondements et une analyse critique du concept de sécurité culturelle

MARIE-PIER LABELLE & PATRICK MARTIN

Introduction

La pertinence de la théorie postcoloniale pour la recherche et la pratique infirmière a, au cours des dernières années, fait l'objet de plusieurs écrits au sein de la discipline. Des auteurs se sont positionnés quant à sa valeur ajoutée dans le développement du savoir infirmier, notamment parce que les actions transformationnelles dont elle peut devenir le catalyseur s'inscrivent de plein fouet dans une pratique infirmière émancipatrice. Fortement influencée par la théorie poststructuraliste et ayant elle-même exercée une indéniable influence sur la théorie féministe, celle-ci permet la mise en regard du statu quo social par l'investigation des facteurs structurels qui interagissent avec la culture pour moduler les expériences vécues des individus.[1] De par son caractère réflexif et ses attributs émancipateurs, nous croyons que la théorie postcoloniale gagne à être mieux connue des infirmières. Ainsi, dans cet article, nous explorerons les fondements de la théorie postcoloniale en nous appuyant sur les travaux de théoriciens des sciences sociales et des sciences infirmières. Nous effectuerons par la suite une analyse critique du concept de *sécurité culturelle* en discutant de sa pertinence pour la discipline et de ses applications en recherche infirmière, particulièrement dans un contexte de maternité chez des femmes immigrantes.

Genèse de la théorie postcoloniale

Il importe de connaître l'origine du terme «postcolonial» afin de bien se situer par rapport au contexte dans lequel il est utilisé. Le terme postcolonial présente une double acceptation et une double orthographe. D'un point de vue chronologique, il s'écrit avec un trait d'union pour désigner ce qui vient après la colonisation. D'un point de vue épistémologique, il s'écrit sans trait d'union, au sens critique de l'État colonial et de ses effets délétères. Le préfixe *post* suggère à la fois la clôture d'une ère historique et à la fois un mouvement au-delà de cette limite.[2] La période postcoloniale «a été marquée» en Europe et en Amérique par l'arrivée massive d'immigrants de colonies ou d'anciennes colonies ce qui a ajouté une masse substantielle de « minorités » visibles dans les pays occidentaux et qui a augmenté considérablement la diaspora postcoloniale.[3] Les minorités dites « visibles » font partie intégrante de notre société qui se veut pluraliste et il est important de fournir des soins qui répondent à leurs besoins afin de favoriser l'émancipation de ces populations à travers leurs expériences de santé sans perpétuer leur exclusion et leur discrimination. Au cours des dernières décennies, en sciences infirmières et au sein d'autres disciplines de la santé, on assiste à l'émergence de différents termes tels que la *diversité culturelle*, la *sensibilité culturelle*, la *compétence culturelle* et la *sécurité culturelle*. Ces concepts relativement récents renvoient tous à une intention d'offrir des soins qui répondent aux besoins de la clientèle immigrante. L'émergence de ces concepts montrent l'intérêt de la discipline infirmière à favoriser la compréhension des divers groupes ethniques,[4] car ces derniers permettent de mieux comprendre comment la conception de la «race», la notion de l'*Autre* et les cultures ont été construites selon des contextes historiques et coloniaux particuliers. L'*Autre* étant écrit avec une lettre majuscule pour dénoter une catégorie spécifique de personnes qui ne sont pas occidentales, vu comme des subalternes à travers un processus de racialisation et d'essentialisme culturel.[5] Par ailleurs, il est à noter que le mot «blanc», dans le cadre de cet article, sera utilisé pour désigner le fait que la couleur de la peau est fréquemment associée – lorsqu'elle est blanche – à la domination et aux rapports coloniaux.

École de pensée

Aussi connue sous le vocable anglophone « *colonial discourse analysis* », et en français sous les termes « études postcoloniales» ou « postcolonialisme », la théorie postcoloniale est également associée à diverses écoles de pensée.[6] Cette théorie que l'on associe à la théorie critique ne peut pas être définie en une seule et unique entité théorique mais plutôt comme une famille de théories qui est conceptualisée et opérationnalisée selon la position sociale du chercheur.[7]

L'école que l'on peut considérer comme étant à l'origine de cette théorie s'est érigée autour des idées mises de l'avant par Edward Saïd[8] dans son livre *Orientalism*. Le colonialisme avait certes déjà été étudié avant la lecture qu'en fera Said, mais celui-ci fut le premier à aller au-delà d'une critique marxiste orthodoxe, une critique qui avait tendance à mettre l'accent sur la soumission des sujets subalternes à des facteurs économiques.[9] *Orientalisme* expose le processus politique du colonialisme. Il montre également comment la pensée scientifique, qui gouverne les populations orientales, est perçue et étudiée par les scientifiques occidentaux.[10] Saïd réfère ainsi au concept de l'*Orientalisme* pour expliquer le discours hégémonique qui gouverne la science occidentale et les stéréotypes que cette science génère pour les gens de l'Orient.[11] En mobilisant ce concept, il décrit la domination et l'acculturation du monde oriental par le monde occidental. Said est le premier auteur à investiguer les effets du colonialisme à travers une analyse de discours. Contrairement à d'autres études qui discutaient de la logique économique et politique du pouvoir, Said a orienté son travail sur la relation entre le savoir et le pouvoir en s'inspirant de Foucault. La façon critique dont il articule les préceptes de la théorie postcoloniale offre une vision du monde, en marge de l'eurocentrisme, brandissant la représentation des pratiques qui reproduisent la logique de la subordination qui perdure au XXIe siècle. *Orientalisme* se veut une œuvre révélatrice de la connexion entre les processus épistémologiques de la production du savoir et la domination coloniale.[4] La notion de pouvoir-savoir que Foucault[12] conceptualisait comme une « matrice de transformation » est d'ailleurs fortement mise à profit par Saïd. Dans l'*Orientalisme*, celui-ci soutient également l'idée que l'histoire ne s'est pas formée de façon empirique, mais plutôt comme une construction tributaire de la subjectivité de celui qui la produit, et de l'épistémologie qu'il emprunte. La culture serait donc une construction linguistique, discursive, qui obéit à une stratégie de représentation. Voilà pourquoi cette construction est souvent plus révélatrice des caractéristiques qui sont propres à l'historien, à l'auteur, que de celles de la culture qui fait l'objet de la description.[13]

Parmi les pionniers de cette première école postcoloniale, Homi K. Bhabha avec son oeuvre *The location of culture*[14] s'attardera, au même titre que Saïd, à une épistémologie qui propose l'interrogation des représentations, des discours et des identités individuelles et collectives. Pour Bhabha[6] la postcolonialité est un rappel de la persistance des relations «néo-coloniales» dans le nouveau monde et de la division multinationale du travail. Cette perspective permet la mise en regard de l'authenticité l'authenticité des histoires d'exploitations et l'évolution des stratégies de résistance. Bhabha met de l'avant l'échec du capitalisme en documentant l'intersectionnalité - concept emprunté à la féministe américaine Kimberlé Crenshaw - et le monde social par le biais de facteurs historique, politique, économique et culturel où le racisme et le sexisme ont un impact réel sur la santé des gens du Sud dans de nouvelles formes de colonialisme.[15] Parallèlement, Bhabha sera également reconnu pour son concept « *unhomely* », par lequel il postulera la possibilité d'une fracture de la structure binaire et totalisante du pouvoir. Il associera aussi ce concept à la résistance, celle-ci prenant plus spécifiquement la forme d'une rencontre collective dans la diaspora, l'opposé d'un système qui provoque l'exclusion à travers l'essentialisme et la catégorisation culturelle et identitaire dans un espace normatif inférieur.[4] «*Unhomely*» signifie un état nomade et hydride qui se traduit à la fois par l'impossibilité d'une construction traditionnelle mono-identitaire et la nécessité de penser l'identité comme trans-identitaire.[16] De surcroît, le concept d'hybridité et la notion de troisième espace évoqués par Bhabha signalent l'importance d'une communication interculturelle pour diminuer le *clash* entre le monde occidental et le monde non-occidental. Le troisième espace met en lumière la façon dont la culture occidentale dominante est en position de substituer les représentations culturelles des particularités des cultures non-occidentales.[17] Le troisième espace tel que défini par Bhabha est un endroit d'ouverture à la négociation et à l'accommodation. Il le décrit comme un endroit hybride qui se forme entre deux cultures. L'hybridité étant perçue comme une catégorie culturelle – et comme une stratégie permettant à différents groupes ethniques de cohabiter dans un même espace en laissant place au dialogue dans un lieu où se négocie la différence identitaire ainsi que la pluralité culturelle.[6]

Cet endroit hybride entre deux cultures différentes (autant entre deux (autant entre deux professions distinctes que dans les relations infirmières et patients) peut être favorisé en évitant de perpétuer la production des formes actuelles d'administration et de subjugation coloniale.[17] Il est à noter qu'une ou plusieurs disciplines peuvent elles-mêmes faire office d'empire en renforçant ou en imposant par leurs influences et leurs discours, certaines pratiques de recherche, certaines formes d'éducations, certains modes administratifs.[18] Par ailleurs, l'histoire de la profession montre que les infirmières ne peuvent être isolées du contexte historique et des discours dominants qui ont marqué son évolution notamment ceux qui sont mis de l'avant par la discipline médicale. Sous l'influence de ce contexte et de ces puissants discours, les infirmières peuvent elles aussi s'engager dans des pratiques colonisatrices qui s'apparentent à de l'impérialisme.[19] Ainsi, elles en viennent à adopter des pratiques, notamment à l'endroit des patients, qui peuvent laisser place à un rapport colonisateur/colonisé et réduire le patient à un sujet subalterne. Ce comportement n'est pas sans conséquence sur la qualité des soins offerts et sur l'expérience vécue par les patients. Ce rapport peut être expliqué par un système de contraintes, non étranger aux discours et aux idéologies dominantes, qui pèse sur les infirmières au quotidien dans le cadre de leur travail. Par exemple, comme le souligne Martin, la surcharge de travail à travers laquelle doivent évoluer les infirmières soignantes qui exercent en CH les amène, par manque de temps, à « […] ne plus être en mesure de créer des liens avec les personnes soignées et leur famille pour accéder à l'information sur leurs besoins de santé, pour comprendre ce qu'elles vivent et pour favoriser des solutions adaptées à leurs problèmes ».[20 p398] Ces contraintes expliquent certes qu'en partie la façon dont les infirmières modulent leurs comportements dans le sens de la norme. Toutefois, il apparaît qu'elles ont un effet direct sur la qualité des soins offerts puisque ces contraintes ont pour effet de confisquer aux infirmières la possibilité qu'elles ont de dialoguer avec les patients et créer cet endroit hybride que Bhabha nomme le troisième espace.

La théorie postcoloniale permet de poser un regard critique sur ces pratiques par le biais de la déconstruction des discours hégémoniques qui règnent au sein de notre système de santé. La conjonction de cette théorie avec le féminisme est d'autant plus intéressante puisqu'ensemble, par intersectionnalité, elles mettent en lumière comment le genre, la race et le sexe contribuent à la domination de certains groupes comme les femmes qui sont issues de sociétés non-occidentales.

Arme de déconstruction des discours hégémoniques

La théorie postcoloniale est articulée autour du questionnement, de la résistance aux idéologies et aux structures de pouvoir qui perpétuent notamment l'hégémonie occidentale.[4] Ainsi, la théorie postcoloniale sert notamment à déconstruire l'hégémonie de la science occidentale pour décoloniser les savoirs non occidentaux et permet de reconnaître le savoir subjugué comme une source de savoir légitime. En mobilisant cette théorie en sciences infirmières, nous croyons qu'il est possible de montrer comment les effets de la race, du genre et de la classe ont une influence sur les disparités en santé qui sont issues d'iniquités sociales. Bien qu'il s'agisse d'une explication généralement occultée, les disparités en matière de santé découlent entre autres du contexte historique et des inégalités structurelles.

En ce sens, la théorie postcoloniale offre des stratégies pour contextualiser ces disparités et provoque l'ouverture d'un espace de dialogue permettant aux populations vulnérables d'exprimer leurs préoccupations et d'être entendu. Elle donne une direction à la recherche et à la théorie infirmière par le biais de la production de savoirs transformationnels qui guident des actions transformatives. Elle offre également un cadre à la discipline infirmière pour mieux comprendre les notions de culture et d'identité comme des concepts fluides et complexes, situés historiquement et construits socialement ; ce qui permet de diminuer la reproduction des injustices et des stéréotypes.[4] Cela dit, les systèmes de santé doivent répondre aux besoins variés des patients puisque chacun d'eux a des besoins uniques qui sont en intersection avec le genre, la race et la classe. Malgré les pratiques discursives qui ont légitimé les injustices et l'oppression dans le passé ainsi que le déséquilibre du pouvoir social et des infrastructures qui en ont résulté,[4] on favorise encore aujourd'hui, certaines populations au détriment d'autres. Pour enrayer ce problème et favoriser l'émancipation des patients à travers leur expérience de soins, il est impératif d'adapter les soins infirmiers en fonction des besoins des individus qui ont été trop longtemps réduits au silence.

La théorie postcoloniale permet l'examen des relations entre le pouvoir et le savoir dans un monde qui transcende ce qu'est le monde occidental. Les auteurs postcoloniaux qui s'inscrivent dans cette perspective se préoccupent des processus dans lesquels le pouvoir prend forme et tiennent compte de la périphérie pour développer un discours capable de corriger le regard colonial hégémonique.[6] Dans un souci d'équité et de justice sociale, la théorie postcoloniale prend en compte les problématiques liées au pouvoir tout en adressant les problèmes de santé en lien avec la race, la classe et le genre dans un contexte sociohistorique et culturel.[5] Un point en commun entre les auteurs est l'engagement à expliquer l'histoire et les effets de cette histoire. Ce faisant, la théorie postcoloniale permet l'examen du quotidien pour déterminer comment les matrices de race, de classe et de genre interviennent dans l'oppression de certains groupes.[4] Le but étant de démasquer les processus coloniaux qui ont construits le genre et racialisé l'identité, tout en permettant de revoir la façon de penser l'identité et la culture.[5] Par ailleurs, selon cette théorie, la culture n'est pas seulement utilisée pour explorer les expériences subjectives des personnes, mais aussi pour examiner le contexte historique, social, et les conditions matérielles dans lesquels les subjectivités sont construites. Ceci dit, la théorie postcoloniale se veut un outil pour diminuer les effets des discours dominants,[3] capable de montrer la complexité de la vie dans ces intersections et ainsi contribuer à bâtir un monde social plus juste.[4] La théorie postcoloniale est d'autant plus intéressante pour la discipline puisqu'elle permet non seulement aux infirmières de remplir leur « mandat » moral et social mais d'adresser un regard critique permettant de dévoiler le discours occidental réductionniste et essentialiste de l'Autre qui est perçu comme étant imbriqué dans une entité culturelle unique, crystalisée et neutre.[15] En sciences infirmières, la théorie postcoloniale est mobilisée de plusieurs façons et elle est souvent liée à d'autres cadres théoriques,[4] tels que le féminisme (théorie féministe postcoloniale) auquel nous avons fait référence plus tôt. Cette tradition de recherche peut également être utilisée pour montrer les problèmes conceptuels qui sont associés au concept de sécurité culturelle. Nous y reviendrons subséquemment.

La théorie féministe postcoloniale

En mettant cette théorie à profit en sciences infirmières, les chercheuses occidentales blanches contribuent à la décolonisation de la recherche en réduisant les perpétuels déséquilibres liés à la répartition du pouvoir, à l'imposition épistémique, et la reproduction des inégalités entre certains groupes. La décolonisation de la recherche consiste notamment à faire de la recherche en en s'intéressant à la vie quotidienne des personnes qui vivent dans des réalités différentes[10] et elle permet de réduire les effets du discours dominant par la déconstruction de la science occidentale qui perpétue la marginalité et la subalternité.[21] En adressant les inégalités en matière de santé liées à la distribution inéquitable du pouvoir, la théorie féministe postcoloniale dévoile les relations taciturnes des groupes culturels différents et permet d'intégrer les savoirs, dits subjugués, dans la théorisation infirmière. De plus, la théorie féministe postcoloniale a pour but de générer des savoirs transformationnels qui peuvent s'appliquer concrètement dans des actions politiques et sociales pour montrer les iniquités en matière de santé qui proviennent de la discrimination du genre et de la race.[10] Pour s'y prendre, les chercheurs effectuent l'analyse macrosociologique d'un phénomène particulier – une analyse globale qui permet de mieux comprendre le contexte socio-économique, historique et politique dans laquelle l'expérience de soins est ancrée.[17] Ce faisant, les infirmières sont à même de constater l'influence de l'intersection entre la race, le genre et la classe. La portée de cette théorie pour le développement du savoir infirmier est importante, car les infirmières sont appelées à travailler avec des clientèles diversifiées et à jouer un rôle d'*advocacy* auprès de celles-ci. Il faut donc accueillir les différences culturelles en décentralisant la production du savoir, pour que les gens qui ont des pratiques culturelles différentes puissent parler, être écoutés et surtout être entendus. De ce fait, nous sommes d'avis qu'il est difficile de produire des connaissances sur une population qui n'est pas à même de participer à la construction de ces savoirs nouveaux. Bien que la recherche infirmière ne puisse pas être neutre, apolitique et ahistorique du fait que nous sommes nous mêmes gouvernées par des discours et des pratiques normatives,[22] il est souhaitable de décoloniser la recherche et de décentraliser les savoirs pour permettre aux subalternes de parler pour eux-mêmes.

Un postulat clé dans la théorie féministe postcoloniale consiste en la reconnaissance de la position et des expériences subjectives vécues par les individus. Par ailleurs, la théorie féministe postcoloniale postule que chaque expérience est unique et doit être localisée dans un contexte historique, social, culturel, politique et économique donné.[19] En incluant les voix de celles qui ont été ignorées dans la production sociale du savoir, cette approche permet d'analyser comment l'histoire et les relations racialisées ont contribués aux iniquités[23] et ont conduit à la discrimination des peuples non-occidentaux.[15] Cette perspective vise donc l'exploration des expériences vécues en intersection avec la race, le genre et la classe, car l'intersectionnalité a une influence sur l'expérience de racialisation des hommes et des femmes dans le monde social ou dans le système de santé. La racialisation fait référence au processus par lequel la stratification sociale crée l'Autre.[19] Cela dit, cette théorie s'inscrit bien dans une visée plus large de la recherche infirmière qui souhaite entre autres, comprendre l'expérience de soins vécue par les patients pour offrir des soins qui répondent aux besoins de chacun. Alors que l'on considère l'unicité de l'expérience vécue, il est important d'examiner les inégalités sociales qui s'inscrivent dans les contextes social, politique et économique puisque leur influence n'est pas sans répercussion sur la santé et les soins de santé. Maintenant que nous avons souligné la pertinence de la théorie féministe postcoloniale pour le développement du savoir infirmier, nous effectuerons une analyse critique du concept de sécurité culturelle en mobilisant ses préceptes théoriques. La sécurité culturelle est un concept fortement utilisé au sein de la discipline dans les dernières années. Il importe donc de mieux saisir sa portée et son sens. Par le biais de cette analyse, nous renforcerons notre position quant à l'utilité de la théorie postcoloniale pour la discipline infirmière puisque nous verrons comment il est possible de l'intégrer sur le plan clinique en contexte de maternité avec les femmes immigrantes, mais également en recherche.

Sécurité culturelle : le concept

Le concept de *sécurité culturelle* est inspiré des principes de protection de l'identité et de partenariat qui découlent du Traité de Waitangi en 1840.[24] Il a été élaboré en Nouvelle-Zélande par deux professeures maories.[25,26] Le concept de sécurité culturelle est, a priori, lié au projet postcolonial. L'intention derrière la création du concept est la déconstruction de la relation de pouvoir que la culture dominante exerçait sur les Maoris. En voulant faire ressortir la distribution inéquitable du pouvoir, ce concept s'inscrit dans la théorie féministe postcoloniale.

Au sein de la discipline, la sécurité culturelle est définie comme une pratique infirmière capable de répondre aux besoins et aux attentes de patients issus d'une culture autre que la culture occidentale en considérant les valeurs et les croyances de ceux-ci. Le concept se définit également à la négative. Une pratique non sécuritaire culturellement comprend toute action qui porte atteinte à l'identité culturelle et au bien-être d'un individu.[24] La sécurité culturelle se situe au-delà de la description des pratiques, des croyances et des valeurs d'un groupe ethnique.[24] Elle se centre davantage sur la connaissance de soi, plutôt que sur l'apprentissage des aspects de la culture des différents groupes ethniques. L'infirmière doit abandonner l'idée qu'elle comprend totalement son patient dans ses pratiques culturelles.[27] La sécurité culturelle s'inscrit plutôt dans une éthique qui favorise le contexte socioculturel dans la discipline infirmière et ne devrait pas être guidée que par des lois et des politiques, mais par la conscience morale de chaque infirmière. En ce sens, la sécurité culturelle est compatible avec une perspective critique, car son attention est dirigée sur la distribution inéquitable du pouvoir et les relations de pouvoir dans le domaine de la santé. La sécurité culturelle permet ainsi de répondre aux problèmes liés au culturalisme et à la racialisation, mais elle favorise également l'engagement moral de l'infirmière pour assurer entre autres la justice sociale.[28]

Interprétation du concept

La sécurité culturelle est un concept qui laisse place à l'interprétation, particulièrement en recherche infirmière. Lorsqu'on ne discute pas des problèmes qui sont en lien avec la sécurité culturelle tels que la racialisation, la discrimination institutionnelle, le culturalisme, la santé et les iniquités en santé, l'accent sur la culture dans le terme sécurité culturelle peut être mal interprété.[28] La culture peut alors être perçue comme un comportement humain fondé sur des valeurs, des normes, des pratiques d'un groupe particulier et les professionnels peuvent avoir tendance à considérer le sujet colonisé subalterne irrémédiablement homogène.[21] Cependant, est-ce que tous les Canadiens blancs ont les mêmes croyances, les mêmes valeurs et les mêmes pratiques culturelles ? Bien sur que non. Ramsden[29] souligne également que le concept peut être une source de confusion pour plusieurs personnes. En effet, elle soutient que la compréhension populaire de la culture comme étant l'origine ethnique peut laisser place à une compréhension simpliste du terme. En outre, elle précise que cette compréhension simpliste met à l'écart les relations de pouvoirs complexes desquels l'essence du mot «sécurité» trouve son origine à titre de composante de ce concept.

Une réflexivité souvent occultée

Pour offrir des soins culturellement sécuritaires, l'infirmière doit entreprendre un processus de réflexion sur sa propre identité culturelle et doit reconnaître l'impact de sa propre culture sur sa pratique professionnelle. Il est important de bien comprendre comment l'histoire, la théorie et le pouvoir opèrent tous ensemble pour apprécier les différences culturelles. Ces différences doivent d'ailleurs être comprises comme une construction des relations de pouvoir à travers le temps. De plus, ce processus de réflexion permet d'avoir un regard critique sur le fonctionnement des établissements de santé et sur l'intérêt de ces institutions à servir la culture dominante. Les institutions cliniques et éducatives sont bien ancrées dans les valeurs et les engagements des perspectives occidentales.[30] Cliniquement et économiquement, le système de santé sert le blanc, et ses intérêts.[30] Ainsi, le concept de *sécurité culturelle* permet la rupture de la croyance que les activités infirmières sont neutres,[19] puisqu'elles ne le sont pas. Le savoir est toujours partiel et incomplet, et il l'est davantage lorsque certaines voix ne peuvent s'exprimer.[23] La théorie postcoloniale nous aide à mettre en lumière l'importance pour les professeurs et les chercheurs de prendre une distance par rapport au rôle d'expert qui leur est attribué en reconnaissant la construction anthropologique de la santé, de la maladie, et du soin.[15] Dans un souci de production d'un savoir honnête, il est crucial que les chercheurs s'approprient la notion de réflexivité, car il est essentiel de reconnaître que sa position peut influencer les résultats de la recherche. De ce fait, il est important que la production du savoir soit respectueuse et représentative de sa construction.[4] Les chercheurs qui adoptent une ontologie critique doivent avant tout comprendre comment leur opinion politique, leurs croyances religieuses, leur genre, leur position raciale, et leur orientation sexuelle ont été construit à titre de norme par la culture dominante, car ils promeuvent les points de vue dé-centralisés et multivocaux dans leurs recherches. Ces points de vue ont pour effet de créer un espace où certains groupes, qui, historiquement ont été marginalisés peuvent ré-écrire leur propre histoire, participer à la production du savoir et retrouver leur identité[19] réelle et non celle imaginée par la culture dominante.

Pouvoir et savoir

La *sécurité culturelle* est maintenant un concept utilisé par les sociétés pluriculturelles et il est reconnu comme un standard de pratique en sciences infirmières et dans d'autres disciplines en santé. Ce concept a été perçu comme un guide qui permet de remédier aux problèmes de santé des groupes les plus vulnérables ou marginalisés à travers le monde.[27] Depuis quelques années, l'enseignement par rapport aux connaissances culturelles est bien ancré dans les programmes de soins infirmiers partout au Canada, aux États-Unis et en Australie. L'accumulation du savoir sur les autres cultures est vu comme la réponse professionnelle adéquate pour répondre aux besoins des personnes qui ne sont pas des occidentaux.[19] Toutefois, en accord avec Saïd,[9] nous croyons que « connaître » un tel objet c'est le dominer - c'est avoir autorité sur lui, et autorité ici signifie que «nous» «lui» refusons l'autonomie (au patient), puisque nous le connaissons et qu'il existe, en un sens, tel que nous le connaissons. De cette façon, les groupes ethniques minoritaires sont perçus comme une race sujette, dominée par une race qui les connaît, et qui sait ce qui est bon pour elle, mieux qu'elle ne pourrait le savoir elle-même.

Infirmières «usinées»

Être «blanc» est une position sociale dans laquelle tous les «non-blancs» se battent pour définir leur identité,[30] puisque pour ces personnes, il existe une seule porte de sortie et elle donne sur le monde blanc.[31] Cette lutte est omniprésente, surtout quand l'éducation est vue comme une façon de «produire» des infirmières.[30] Ce phénomène fait référence au registre sémantique de l'économie de marché qui prône l'efficacité, la performance et l'optimisation. La plupart des modèles infirmiers ou des programmes d'enseignement voient les étudiantes comme du matériel brut prêt à être modulé comme des objets dans lesquels on instille des compétences,[30] des modèles et des concepts pour ainsi faire d'elles des produits fonctionnels (visée fonctionnaliste). La fin et les buts de ces produits étant déterminés à l'avance, les étudiantes sont formées dans le but d'être efficaces et efficientes, sans qu'elles comprennent trop l'influence de leurs comportements de «blanche» sur les soins qu'elles offrent. On s'assure qu'elles puissent répondre aux besoins des individus qui correspondent à la norme, sans qu'elles prennent toutefois le temps de s'engager dans un processus de réflexion identitaire. Il faut que le processus devienne collectif pour transformer la pratique infirmière en matière de soins interculturels. Ainsi, tous ensemble, nous devons faire un examen des facteurs sociaux et politiques qui produisent le savoir et certaines pratiques normalisées[16] ou encore des lignes directrices, qui certes, ne correspondent pas aux besoins de toute la population. En ce sens, nous croyons que la qualité des soins serait améliorée si les professionnels de la santé effectuaient une introspection en lien avec les valeurs et les croyances associées à notre culture occidentale,[28] car la sécurité culturelle n'est pas un examen physique, ni l'établissement d'un diagnostic infirmier et requiert différentes habilités[19] qui doivent être préalablement développées chez les étudiantes afin de prodiguer des soins sensibles à la population.

Troisième espace et hybridité culturelle

Une pratique culturelle sécuritaire tend à ne plus catégoriser l'Autre comme étant subalterne,[15] mais bien comme une personne qui est capable de parler pour elle-même. De cette façon, il est possible de créer un espace culturel de compréhension et de dialogue entre le soignant et le soigné. C'est ce que l'on appelle le troisième espace. La création d'un troisième espace permet une hybridité, une compréhension de la culture du soigné. L'hybridité culturelle montre l'importance de l'altérité culturelle lorsqu'on entre dans le troisième espace - terrain de négociation et de compréhension de l'autre.[19] Ainsi, la création de ce troisième espace serait sécuritaire culturellement parce qu'il permettrait d'aller au-delà de la diversité culturelle en ayant une compréhension plus approfondie des différences culturelles entre le soignant et le soigné.[19] Néanmoins, pour créer ce troisième espace, les conditions environnementales et de travail doivent être favorables. La façon dont s'articule les programmes de baccalauréat en sciences infirmières et le système de santé laisse peu de temps pour la réflexion et le dialogue. La sécurité culturelle peut être trouvée dans cet espace hybride où les expériences relationnelles entre les infirmières et les patients, ou entre les professeures et les étudiantes[18] peuvent être exprimées de façon à approfondir la réflexion critique. Au niveau de l'enseignement professionnel, on tend à voir l'éducation comme la transmission du savoir des «experts» aux étudiants.[17] Pour initier cette réflexion chez les étudiantes, il faudrait préférablement créer un partenariat où les étudiantes se sentiront en confiance pour exprimer leurs expériences plutôt que d'appréhender des répercussions que leur réflexion pourrait engendrer sur le plan académique. Par ailleurs, dans les programmes de baccalauréat, on insiste plutôt sur le développement de la compétence culturelle, qui fait abstraction des barrières liées au pouvoir institutionnel et à la réduction des inégalités en matière de santé.[27] Les approches culturalistes comme le modèle de Leininger[33] ou de Campina-Bacote[34] omettent l'importance du passé historique et des conditions matérielles dans lesquels la culture opère, ce qui reflète les attributs essentialistes du soins transculturel. Ces modèles tendent à enraciner les différences culturelles dans des discours statiques de représentation et à essentialiser les personnes non-occidentales sur la base de traits raciaux ou culturels - tout en laissant pour compte les problèmes liées à la racialisation.[19] Par ailleurs, dans les institutions de santé québécoises, les compressions budgétaires, le ratio infirmière-patient trop élevé, le temps supplémentaire obligatoire, etc. ne permettent pas aux infirmières d'avoir une réflexion personnelle identitaire, ni de réfléchir à la création d'un environnement propice au dialogue entre les infirmières et les patients.

Nouvelle avenue pour le concept

Au Canada, le concept de sécurité culturelle est surtout utilisé pour expliquer certains phénomènes en lien avec les populations autochtones, et ce, d'un angle féministe postcolonial. En effet, le concept de sécurité culturelle est fortement mobilisé par les Associations autochtones canadiennes, plus particulièrement dans le Canada anglais. Par contre, peu d'auteurs ont exploré la possibilité d'une application diversifiée du concept. C'est dans ce contexte que nous proposons un usage différent - une nouvelle avenue qui permet son application en pratique et en théorie dans un contexte de maternité avec les femmes immigrantes. La théorie féministe postcoloniale permet d'analyser de façon plus concrète le contexte culturel de la maternité et les relations de pouvoir qui existent entre les infirmières et les femmes enceintes. L'analyse macrosociologique inhérente à cette perspective met en évidence la continuité du discours et des relations coloniales.[35] Au Canada, la santé maternelle et infantile s'inscrit dans une approche néolibérale qui prône l'autonomie des mères. En ce sens, les mères blanches sont plus susceptibles de recevoir des soins qui correspondent à leurs attentes à cause de leurs préférences et leur socialisation, c'est-à-dire leur façon de percevoir le monde qui rejoint plus les compétences et les ressources des soignantes.[35] C'est donc dire que les mères immigrantes sont victimes de leur propre culture, car les soins sont donnés selon le stéréotype que toutes les femmes d'une même origine ont les mêmes attentes. Elles sont de ce fait réifiées à une même construction identitaire. Les communautés de couleurs n'ont pas seulement été exclues, elles ont été désavantagées par les privilèges et le contrôle des institutions éducatives et des systèmes de santé.[30] Si dans le contexte de la production coloniale, les subalternes n'ont pas d'histoire et ne peuvent pas parler, les subalternes en tant que femmes sont encore plus profondément dans l'ombre.[21] La normalisation de la maternité et des soins maternels engendre une stigmatisation des mères qui ont des pratiques culturelles différentes. Les dynamiques sociales et les discours infirmiers et médicaux produisent de la détresse et influencent la qualité des soins de santé offerts à certains groupes ethniques.[36] Il faut que les soignantes cessent de parler «pour» les femmes enceintes et commencent à écouter réellement ce qu'elles ont à dire. Trop souvent, ces femmes sont subordonnées à l'institution dans lequel elles sont soignées à cause du discours normatif qui y règne. On offre des soins considérés «sécuritaires» pour des patientes mais l'infirmière ne valide pas leur pertinence en lien avec les valeurs et leurs croyances de ces dernières. En ce sens, la sécurité culturelle est un concept intéressant, puisque l'approche réflexive qu'elle préconise met en valeur la reconnaissance de notre propre culture à titre d'infirmière et de personne. Son usage approprié en recherche et en pratique permet de développer des habiletés relationnelles et de promouvoir l'éthique dans les soins tout en acceptant les différences.

Une utopie ?

Au terme du baccalauréat, demander aux étudiantes de prodiguer des soins culturellement sécuritaires est une utopie. En effet, nous croyons qu'il s'agit d'un processus continu qui s'échelonne sur une grande période de temps et qu'il n'est pas réaliste dans les conditions académiques et de stages intensifs actuels, d'avoir ces attentes. Il n'y a pas de changement rapide possible en ce sens et toutes les solutions «techniques» comme l'ajout de cours sur le développement de la compétence culturelle ou ayant trait aux soins transculturels ne font que contribuer au problème plutôt que de faire office de solution solution.[17] Il serait toutefois approprié d'encourager de façon constante le questionnement chez les étudiantes. Il nous apparaît également pertinent de les inviter à prendre position à travers une éducation conscientisante et libératrice et de leur allouer du temps afin qu'elles puissent dialoguer ensemble. Par ailleurs, il serait justifié de les mettre en contact, et ce, dès le baccalauréat, avec ce que constitue la théorie critique et les diverses perspectives qui y sont associées comme le postcolonialisme.

La sécurité culturelle est un concept orienté vers une praxis, car il s'inscrit dans un processus de réflexion pour mener à des actions transformationnelles[37] et ainsi montrer les défis en lien avec la culture, l'ethnicité, le culturalisme et la racialisation dans des champs qui sont spécifiques à la discipline.[28] Une application appropriée en recherche et éventuellement en pratique serait susceptible de promouvoir un réel partenariat égalitaire entre les patients et les infirmières.

Théorie postcoloniale et praxis

Le postcolonialisme demeure une perspective orientée vers une praxis, et ce, en lien avec son mandat social. En effet, l'analyse des contextes d'inégalités sociales, l'exacerbation de la conscience critique et les changements sociaux ayant pour but d'améliorer la santé et de modifier les pratiques de santé actuelles[4] montrent l'importance de critiquer l'hégémonie biomédicale au sein de notre société occidentale contemporaine. Il faut reconnaitre que la recherche et l'éducation sont éminemment politiques et qu'elles consistent en des véhicules de résistance sociale et d'activisme pour générer des changements sociaux.[10] Malgré certaines limites, la théorie postcoloniale reste une théorie intéressante à mobiliser dans le cadre de la recherche en sciences infirmières pour développer une pratique infirmière culturellement sécuritaire. En ce sens, la discipline infirmière ne devrait pas se positionner dans un seul paradigme – ni encourager exclusivement le recours à des théories dites « infirmières ». La recherche en sciences infirmières devrait pouvoir s'ériger à partir de différents types de savoirs et il apparaît important de reconnaitre comment ces multiples formes de savoirs peuvent apporter une valeur ajoutée pour la recherche et la pratique infirmière.[4]

Conclusion

En conclusion, l'utilité de la théorie postcoloniale réside dans sa capacité à mettre en perspective les différents problèmes liés aux représentations culturelles, aux politiques en recherche et entre autres à l'hégémonie biomédicale. Il importe également de se rappeler que la médecine occidentale est en elle-même une source culturelle de production du savoir. De ce fait, il peut être difficile de la voir comme tel, puisque le produit scientifique provient de cette même culture (la médecine occidentale).[4] L'engagement social des infirmières à prodiguer des soins de qualité à la clientèle montre la nécessité d'avoir des réflexions individuelles et collectives quant à nos valeurs, nos croyances et notre façon de voir le monde à travers nos «lunettes» occidentales contemporaines. Nous croyons qu'à travers le dialogue et la réflexion proposée par la théorie postcoloniale, les infirmières seront plus sensibilisées à la différence culturelle et plus disposées à adopter des comportements favorables à l'établissement d'une collaboration interculturelle avec les patients dont elles prennent soin.

References

1.Racine L. Examining the conflation of multiculturalism, sexism, and religious fundamentalism through Taylor and Bakhtin: expanding post-colonial feminist epistemology. Nursing Philosophy 2009; 1:14-25.

2.Clavaron Y. Études francophones, postcolonial studies : Entre mésentente cordiale et stratégies partagées. Neohelicon 2007; 2:39-53.

3.Hawley JC. Encyclopedia of postcolonial studies. Greenwood Press : London, 2001.

4.Mohammed, SA. Moving beyond the ''Exotic'' Applying Postcolonial Theory in Health Research. Advances in Nursing 2006; 29: 98-109.

5.Anderson JM. Toward a post-colonial feminist methodology in nursing research : Exploring the convergence of post-colonial and black feminist scholarship. Post-colonial research 2001; 9: 7-27.

6.De Toro A. Au-delà de la francophonie : représentations de la pensée hybride au Maghreb. Neohelicon 2008; 2: 63-86.

7.Quayson A. Postcolonialism: Theory, practice or process? Cambridge: Polity Press, 2000.

8.Said, EW. Orientalism. Vintage Books : New York, 1978.

9. Young, RJC. Colonial desire: Hybridity in theory, culture and race: New York, 1995.

10.Racine L. Applying the Antonio Gramsci's philosophy to postcolonial feminist social and political activism in nursing, Journal of Nursing Philosophy 2009; 10: 320-90.

11.Racine L. The impact of Race, Gender, and Class in Postcolonial Feminist Fieldwork : A Retrospective Critique of Methodological Dilemmas. Aporia 2011; 3:15-27.

12.Foucault M. Histoire de la sexualité 1 : La volonté de savoir. Paris : Gallimard, 1976.

13.De Toro A. Post-colonialisme, postcolonialité, hybridité, concepts et stratégies dans la francophonie et le maghreb-francophone. (Université de Leipzig). 2005. Disponible sur http://www.limag.refer.org.

14.Bhabha HK. The Location of Culture. London and New York : Routledge, 1994.

15.Racine L. Implementing a postcolonial feminist perspective in nursing research related to non-Western populations. Nursing Inquiry 2003; 10:91-102.

16.Boehmer E. Écriture postcoloniale et terreur. Littérature 2007; 154:82-90.

17.Anderson JM. Current directions in nursing research: toward a poststructuralist and feminist epistemology. Canadian Journal of Nursing Research 1991; 23:1–3.

18.Holmes D, Roy B, Perron, A. The use of postcolonialism in the Nursing domaine, Colonial Patronage, Conversion and Resistance. Journal Of Advances In Nursing Science 2008; 31:42-51.

19.Racine L Perron A. Unmasking the predicament of cultural voyeurism : a postcolonial analysis of international nursing placements, Nursing Inquiry 2012; 19:190-201.

20.Martin P. Contraintes vécues, idéal normatif et actions déployées en vue de tranformer l'exercice de la profession infirmière en centre hospitalier : une étude exploratoire auprès des infirmières québécoises politiquement engagées [Thèse]. Montréal : Université de Montréal; 2015.

21.Spivak GC. Can the subaltern speak ? Cary Nelson and Lary Grossberg : Chicago, 1988.

22.Holmes D, Gastaldo D. Nursing as means of governmentality. Journal of Advanced Nursing 2002; 38: 557-65.

23.Reimer-Kirkham S, Anderson JM. The Advocate-Analyst Dialectic in Critical and Postcolonial Feminist Research : Reconciling Tensions Around Scientific Integrity. Advances in Nursing Sciences 2010; 3:196-205.

24.Nursing Council of New Zealand. Guidelines for Cultural Safety, the Treaty of Waitangi and Maori Health in Nursing Education and Practice. 2011. Disponible sur http://pro.healthmentoronline.com/assets/Uploads/refract/pdf/Nursing_Council_cultural-safety11.pdf

25.Ramsden I. Kawa Whakaruruhau. Cultural safety in nursing education in Aotearoa (New Zealand). Nursing Praxis in New Zealand 1993; 8:4-10.

26.Papps E, Ramsden I. Cultural Safety in nursing: The New Zealand experience. International Journal for Quality in

Health Care 1996; 8: 491-7.

27.Aboriginal Nurses Association of Canada. Cultural competence and cultural safety in nursing education. 2001. Disponible sur : http://casn.ca/wp-content/uploads/2014/12/FINALFRAMEWORK.pdf

28.Browne AJ, Varcoe C, Smye V, Reimer-Kirkham S Lynam MJ Wong S. Cultural safety and the challenges of translating critically oriented knowledge in practice. Nursing Philosophy 2009; 20:167-79.

29.Ramsden I. Cultural safety/KawaWhakaruruhau ten years on: a personal overview. Nursing Praxis in New Zealand 2000; 15:4–12.

30.Allen AG. Whiteness and difference in nursing. Nursing Philosophy 2006; 7:65-78.

31.Fanon F. Les damnés de la terre. Paris : Masparo, 1961.

32.Basu Khan K, McDonald H, Baumbusch JL, Reimer-Kirkham S, Tan E, Anderson JM. Taking up postcolonial feminism in the field : Working through a method. Woman's Studies International Forum 2007; 30:2-24.

33.Leininger MM. The theory of Culture Care Diversity and Universality. NLN Publication 1991; 15:5-68.

34.Campinha-Bacote J. The Process of Cultural Competence in the Delivery of Healthcare Services : a model of care. Journal of Transcultural Nursing 2002; 13:181-4

35.De Souza R. Regulating migrant maternity : Nursing and midwifery's emancipatory aims and assimilatory practices. Nursing Inquiry 2012; 20:293-304.

36.De Souza R. One Woman's Empowerment Is Another's Opression : Korean Migrant Mothers on Giving Birth in Aotearoa. Journal of Transcultural Nursing 2014; 25:348-56.

37.Chinn PL, Kramer MK. Knowledge Development in Nursing: Theory and process (9th edition). Elsevier: Missouri, 2015.

Pour contacter les auteurs:
Marie-Pier Labelle, inf. B.Sc.
Étudiante au doctorat
Université Laval
Faculté des sciences infirmières
Pavillon Ferdinand-Vandry
1050, avenue de la Médecine, local 3572
Québec G1V 0A6
Canada
Courriel : Marie-Pier.Labelle.1@ulaval.ca

Patrick Martin, inf., Ph.D
Professeur adjoint
Université Laval
Faculté des sciences infirmières

Commentaire/Commentary

Theoretical Nursing Knowledge in the 21st Century

LOUISE RACINE

Introduction

In an editorial published in Advances in Nursing Science, Chinn reports that nursing's theoretical and philosophical traditions have been "deleted from nursing curricula in favor of content deemed more essential to practice."[1 p1] Chinn coined the term "nursesogyny" to describe the rejection of nursing theoretical and philosophical heritage developed by early nurse theorists. Chinn's "nursesogyny" may deserve further exploration. Such as what could be the risks of erasing nursing philosophical and theoretical traditions (disciplinary knowledge) from education and practice? How the suppression of disciplinary knowledge might affect the future of nursing as a discipline? How the erasure of disciplinary knowledge might affect nurses' roles in interprofessional health care teams?

Nurse scholars report that interprofessional practice improves teamwork, increases collaborations between health professionals, and focuses on patient-centered care.[2,3] In addition to benefits, interprofessionality brings some challenges to nursing. For instance, Sommerfeldt[4] underlines the needs for nurses to define and articulate their roles in interprofessional clinical settings. The corollary is also true. Nurses researchers need to articulate their roles in interprofessional research teams. A clear articulation of nurses' roles depends on a clear understanding of what nursing disciplinary knowledge is. Moreover, a clear articulation of nurses' roles requires an understanding of how nursing knowledge applies to practice and improves health outcomes. Providing answers to these questions prompts revisiting the nature of nursing knowledge. Affirming nursing as a science is the main reason earlier nurse theorists developed grand theories and conceptual models. The aim was to establish nursing as a scientific and academic discipline.[5] Meanwhile, the usefulness and relevance of theories and conceptual models of nursing to practice may have been consciously or unconsciously obfuscated. In other words, the scientific mission of nursing took precedence over its applied and social mission. In addition, competing worldviews about the philosophy of science also explains the theory-practice relevance gap.[5] For some nurses, nursing practice must guide research to solve problems encountered in clinical practice.[5] For others, nursing research must drive theory generation and guide practice. A philosophical orthodoxy resulting from the influence of natural sciences on nursing knowledge contributes to this binary divide between theory and practice.[6,7] The theory-practice gap originates from the dissociation between intellectual content and problems encountered in nursing practice. This disarticulation from nursing practice would prompt the rejection of the whole enterprise of theorizing in nursing. The upshot is to see previous theories and conceptual models as “irrelevant, inadequate, and naïve”,[1 p1] and, therefore, not useful at the bedside.[8] Does rejection of the whole theorization enterprise represent the solution to the theory-practice gap? Similarly, how long nurse scholars shall engage in developing and testing theories that merely work in addressing problems relating to nursing practice? These are valid points to consider as organizational and academic pressures towards the implementation of interprofessional models of health education and healthcare delivery increase. Sommerfeldt [4] urges nurses to discover and articulate what nursing brings to health care that other health professions do not. This issue is critical as nurses must define the contributions of nursing and delineate their roles among interprofessional healthcare or research teams. A lack of understanding of nursing knowledge may illustrate the risks of ‘nursesogyny’ aptly described by Chinn[1] as the process of expunging nursing theoretical and philosophical traditions from education and research.

What Constitutes Nursing Disciplinary Knowledge?

The Canadian Association of Schools of Nursing (as cited in Thorne) defines disciplinary knowledge as relating to the “history, practice context, and theoretical underpinnings of nursing.”[9 p1] Chinn suggests that nursing theories and conceptual models represent the “building blocks of nursing heritage. ”[1 p1]

The goal of nursing remains the understanding of human experiences of health and illness. Nurses need to focus on the particularities of the illness affecting each patient they encounter while using general or teleological knowledge that applies to human health and illness processes. [10] For instance, persons living with diabetes type 2 present similar signs and symptoms of the disease, yet the ways individuals adapt to their illness represent the particular knowledge that makes each person unique. The experience of living with type 2 diabetes mellitus occurs within a psychological, social, and cultural context that shapes the individual experience of illness.

As nurses focus on phenomena intersecting with humans’ health and illness experiences, Carper[11] suggests using four patterns of knowing. She emphasizes the use of the empirical, ethical, aesthetic, and personal ways of knowing to apprehend human experiences of health and illness.[11] These patterns of knowing are useful to understand the metaphysical and moral issues encountered in nursing practice. White[12] adds the sociopolitical way of knowing to incorporate the broader environment of health in the appraisal of clients’ health issues. Kagan et al.[13] suggest the emancipatory way of knowing as a means to raise nurses’ consciousness on the gendered, cultural, economic, and social inequities affecting health and nursing practice. Simply put the acquisition of specific ways of knowing guides clinical judgment and nursing actions. The use of nursing philosophical and theoretical bases inform about the goals of nursing and how to implement these goals in practice. However, this assumption comes with a caution. The position that all nursing theories must derive from nursing theories and conceptual models is ontologically and epistemologically untenable. It is an unsustainable standpoint because of the underlying theoretical reductionism and the fact that contemporary nursing practice involves dealing with health problems embedded in sociocultural contexts marked by relations of power. Despite a call to acknowledge paradigmatic and theoretical pluralism in nursing, realism and biomedicine prevail in shaping nursing knowledge. This dominance of positivism, postpositivism, and biomedicine constitutes a colonization of nursing knowledge.[14,15] Although issues of “colonial patronage” have been discussed by some nurse scholars, the idea of colonization of knowledge remains to be further debated.[15] Similarly, a debatable disciplinary consensus exists to recognize health, the environment, nursing care, and individuals or groups as representing nursing’s phenomena of interests. Nurse theorists see these concepts as amenable to changes as the discipline confronts emerging professional issues.[16,17] At this time of nursing history, these concepts represent the main elements of theorization in the discipline. These concepts are examined from both nursing and non-nursing theoretical approaches. [18] For example, the use of a population health theory does not preclude the nurse from drawing on theories of self-care to enhance individuals' autonomy. A nurse may also rely on an intersectionality theoretical approach to further comprehend how race, gender, and social class intersect to impact experiences of illness. The use of a nursing lens locates nursing practice within the philosophical foundations of nursing and differentiates "what nurses are and what they do."[17 p.E28]

The Risks of Erasing Disciplinary Knowledge

Turkel, Ray, and Kornblatt[19] argue that the teaching of nursing philosophical and theoretical knowledge represents a priority in contemporary nursing education. "Nursing theories incorporate what is meaningful in nursing by not only illuminating the essence of nursing but in determining what ideas are critical to and shape nursing."[19 p194] A lack of exposure to nursing theories may undermine the future development of disciplinary knowledge and the advancement of the profession.[20] Theories useful to practicing nurses should be derived, generated or tested from a broad nursing perspective. A nursing perspective encompasses the relations between humans, health/illness, care, and the broader gendered, social, political, cultural and financial contexts of care and health care delivery.

The complete expulsion of philosophical and theoretical heritage from nursing education may lead to the impoverishment of nursing thought, jeopardize the advancement of the profession, and weaken nurses' professional identity. A specialized and distinct body of knowledge distinguishes nurses from other health practitioners. This specialized knowledge is rooted in nursing philosophy. McCrae contends that nursing knowledge represents "human values that transcend time and technology".[8 p226] Without the knowledge of the philosophical and theoretical anchors of nursing, nurses may be in danger of losing or disconnecting the humanist value of care from nursing's ethical and social mandate.[21]

Conclusion

In conclusion, nursing conceptual models and theories represent fundamental pieces of the archeology of nursing knowledge. These archeological pieces can be refined, revised, and advanced.[1] Conceptual models and theories suggest guiding practice through a diversity of philosophical perspectives instead of using them from prescriptive approaches and uncritical applications. It is the work of nurses to make nursing theories relevant to practice, yet this does not mean that the philosophical bases of nursing are de facto irrelevant. On the contrary, overlooking nursing philosophical and theoretical knowledge may undermine the contributions that make nursing a distinct discipline and profession. Ultimately, "nursesogyny" or the erasure of nursing philosophical bases and theories may jeopardize the future of the science and the art of nursing.

References

1.Chinn PL. Nursing theories for the 21st century. Advances in Nursing Science 2014; 37(1):1.

2.Bilodeau K., Dubois S, Pepin, J. Contributions des sciences infirmières au développement des savoirs interprofessionels. Recherche en Soins Infirmiers 2013; 113(2):43-50.

3.Lapkin S, Levett-Jones T, Gilligan C. A systematic review of the effectiveness of interprofessional education in health professional programs. Nursing Education Today 2013; 33(2): 90-102.

4.Sommerfeldt SC. Articulating nursing in an interprofessional world. Nurse Education in Practice 2013; 13(6):519-23.

5.Risjord M. Nursing Knowledge. Science, Practice, and Philosophy. Oxford: Wiley-Blackwell 2010.

6.Herdman EA. The illusion of progress in nursing. Nursing Philosophy 2001; 2(1):4-13.

7.Thorne S, Reimer Kirkham S, Henderson A. Ideological implications of paradigm discourse. Nursing Inquiry 1999; 6(2):123-31.

8.McCrae N. Whither nursing models? The value of nursing theory in the context of evidence-based practice and multidisciplinary health care. Journal of Advanced Nursing 2011; 68(1):222-9.

9.Thorne S. What constitutes core disciplinary knowledge? Nursing Inquiry 2014; 21(1):1-2.

10.Thorne S, Sawatzky R. Particularizing the general. Sustaining theoretical integrity in the context of an evidence-based practice agenda. Advances in Nursing Science 2014; 37(1):5-18.

11.Carper, BA. Fundamental patterns of knowing in nursing. Advances in Nursing Science 1978; 1(1):13-23.

12.White J. Patterns of knowing: review, critique, and update. Advances in Nursing Science 1995; 17(4):73-86.

13.Kagan PN., Smith MC, Cowling WR, Chinn PL. A nursing manifesto: An emancipatory call for knowledge development, conscience, and praxis. Nursing Philosophy 2009; 11(1):67-84.

14.Georges JM. Evidence of the unspeakable. Biopower, compassion, and nursing. Advances in Nursing Science 2011; 34(2):130-5.

15.Holmes D, Roy B, Perron A. The use of postcolonialism in the nursing domain: colonial patronage, conversion, and resistance. Advances in Nursing Science 2008; 31(1):42-51.

16.Newman MA, Smith MC, Dexheimer-Pharris M, Jones DA. The focus of nursing revisited. In: Reed PG, Crawford-Shearer NB (eds). Perspectives on Nursing Theory. Philadelphia: Wolters Kluwer, 2012; 362-71.

17.Willis DG, Grace PJ, Roy C. A central unifying focus for the discipline: facilitating humanization, meaning, choice, quality of life, and healing in living and dying. Advances in Nursing Science 2008; 31(1): E28-40.

18.Meleis AI. Theory: Metaphors, symbols, definitions. In: Meleis AI (eds). Theoretical Nursing. Development & Progress. Philadelphia: Wolters Kluwer, Lippincott, Williams, Wilkins, 2012; 23-38.

19.Turkel MC, Ray MA, Kornblatt L. Instead of reconceptualizing the nursing process let's rename it. Nursing Science Quarterly 2012; 25(2);194-8.

20.Karnick PM. Nursing theory: the neglected essential. Nursing Science Quarterly 2013; 26(2):130-1.

21.Pearson A. Dead poets, nursing theorists, contemporary nursing practice (2). International Journal of Nursing Practice 2007; 13(6):321-3.

To contact the author:
Louise Racine RN Ph.D.
Associate Professor
University of Saskatchewan
College of Nursing
Health Sciences Building, E-Wing room 4344
104, Clinic Place
Saskatoon, Saskatchewan, S7N 2Z4
Canada
Email: louise.racine@usask.ca

APORIA
LA REVUE EN SCIENCES INFIRMIÈRES • THE NURSING JOURNAL

ABOUT APORIA

Aporia is a peer-reviewed, bilingual, and open access journal dedicated to scholarly debates in nursing and the health sciences. The journal is committed to a pluralistic view of science and to the blurring of boundaries between disciplines. Therefore the editorial team welcomes critical manuscripts in the fields of nursing and the health sciences that include critique of dominant discourses related to the evidence-based movement, best practice guidelines, knowledge translation, managerialism, nursing and health care practices, ethics, politics of health care and policies, technology, bioethics, biopedagogies, biopolitics etc. Research results in nursing and health-related disciplines are also welcome. *Aporia* encourages the use of various epistemologies, philosophies, theoretical perspectives and research methodologies. In the critical analyses of health-related matters, *Aporia* embraces a wide range of epistemologies, philosophies and theories including cultural studies, feminism(s), neo-marxism, post-structuralism, postcolonialism and queer studies.

While the public already pays to fund health research, it is inconceivable that the public should be required to pay yet again, to gain access to research results. Subscription to scientific journals can sometimes reach up to thousands of dollars that are paid directly from public funds. Aporia inscribes itself along the margins of this practice by allowing for a definite fracture to take place within the current trends in the field of scientific publication, which constitute the dominant model for the diffusion of knowledge. *Aporia* is, therefore, a free online journal. Following the footsteps of Deleuze and Guattari, the *Aporia* team firmly believes that freedom is only made possible in the margin; an autonomous space that is controversial, sometimes polemical and without censorship that does not sacrifice scientific and academic rigor. As such, the objective is to encourage access to scientific knowledge and to give the reader an opportunity to actively position himself/herself regarding the written words in order to give a plurality of meanings to the text.

Therefore, *Aporia* adheres to the following principles:

-Freedom of speech
-Critical pedagogy
-Recognition of local knowledge(s)
-Critique of dominant discourses.

SUBMISSION

Research manuscripts, theoretical and philosophical pieces must not exceed 7,000 words. Commentaries and responses related to published articles must not exceed 3,000 words. Manuscripts and the cover letter should be submitted to aporia@uottawa.ca.

Cover Letter

Papers are accepted for publication in the Journal on the understanding that the content has not been published or submitted for publication elsewhere. This must be stated in the cover letter, which should be sent with the manuscript. The cover letter must contain an acknowledgement that all authors have contributed significantly, and that all authors are in agreement with the content of the manuscript. When applicable, it should be stated that the protocol for the research project has been approved by a suitable and relevant Research Ethics Board. All investigations involving human subjects must include a statement that subjects provided informed consent and anonymity should be preserved. Authors should declare any financial support or relationships that may cause conflicts of interest.

Authorship Credit

Each author should have participated sufficiently in the work. Authorship creditsshould be based on substantial contributions to:

-conception and design, or analysis and interpretation of data;
-drafting the article or revising it critically for important
-intellectual content; and
-final approval of the version to be published.

Preparation of the Manuscript

Research manuscripts, theoretical and philosophical pieces must not exceed 7,000 words. Commentaries and responses related to published articles must not exceed 3,000 words. Submissions should be prepared in word-processing software using Arial 11. The text file should be double-spaced and set with top, bottom and side margins of 2.5cm or 1 inch.

For more information, please visit Aporia online at http://www.oa.uottawa.ca/journals/aporia/index.jsp?lang=.