

La négociation du « domicile » et des « soins » chez les personnes vivant avec le VIH et les sans-abri : une étude de cas ethnographique de l'habitus des soins infirmiers à domicile

Cindy Patton et Helen Loshny

Les auteures combinent le travail de terrain que fait le personnel infirmier affecté aux soins à domicile et œuvrant dans un milieu urbain pauvre, et l'analyse des modèles en évolution de la prestation des services. Elles explorent les notions de « domicile » et de « soins » pour les sans-abri ou sans domicile fixe en tant que caractéristiques d'un habitus des soins infirmiers à domicile, dans le contexte d'approches institutionnelles et professionnelles conflictuelles en matière de soins du VIH. Les infirmières et infirmiers ont adopté une pratique des soins infirmiers novatrice, puisque les modèles existants ne répondent pas aux besoins des « patients diagnostiqués comme souffrant de plusieurs troubles ». Cette pratique est aussi influencée par le mouvement axé sur l'accroissement de régimes anti-rétroviraux comme moyens pour ralentir la propagation du VIH dans la population. Les auteures décrivent la pratique négociée par le personnel infirmier et utilisent la notion d'habitus de Pierre Bourdieu pour élaborer une théorie sur leur capacité à répondre à des demandes concurrentielles.

Mots clés : soins infirmiers à domicile, antirétroviraux, sans-abri, pratique des soins infirmiers, habitus

Negotiating “Home” and “Care” among the HIV+ Homeless: An Ethnographic Case Study of Home Care Nursing Habitus

Cindy Patton and Helen Loshny

The authors combine field work among home care nurses working in an impoverished urban neighbourhood with analysis of changing models of service provision. They explore the concepts of “home” and “care” for the homeless and marginally housed as features of a home care nursing “habitus” in the face of conflicting professional and institutional approaches to HIV care. While the nurses’ innovative practice is a result of the failure of existing models to meet the needs of multi-diagnosis patients, it is also influenced by the drive to increase adherence to antiretroviral regimens as a means of slowing the spread of HIV at the population level. The authors describe the nurses’ negotiated practice and use Pierre Bourdieu’s notion of habitus to theorize about their ability to meet competing demands.

Keywords: home care, antiretrovirals, homeless persons, nursing practice, habitus

Introduction

Over the past decade, home care nursing has come to the fore in Canada’s efforts to put a kinder face and a lower price tag on medical care. In the absence of a cohesive national strategy but with increased spending (Sharkey, Larsen, & Mildon, 2003), this has mandated and enabled much local innovation, as home care providers try to keep pace with the demands of an increasingly diverse patient population whose needs often conflict with the goals and practices of health-care settings and systems. Many approaches to home care now co-exist, but their philosophical and practical differences make it difficult to systematically evaluate whether overall care has improved — which models are working for which patients — or whether costs are reduced. Indeed, there is no broad agreement on what home care is or what it has become, much less what outcomes we ought to be studying. From the perspective of both planning and practice, home care is less a coherent category of care than a demarcation of the site of care: “Home” is the “other place” relative to contemporary institutional care.

The thrust of home care is to offer both long-term and transitional care in the home for those individuals who are expected to get well, experience stabilization of a chronic condition, or never recover and die at home (Health Canada, 2003; Romanow, 2002). Currently, home care includes tasks performed by professional, paraprofessional, and lay caregivers, with a general expectation that the nursing component will be of limited duration; the nursing objective is to help the patient and his or her support network assume the tasks temporarily performed by the nurse. However, researchers have pointed to various assumptions in this model: that patients have good knowledge of and a positive pre-illness experience with care systems; that patients have social support networks in place and reside in stable, secure homes; and that the home is a private, apolitical space where nurses attend knowledgeably to patients' needs while meeting the demands of their often conflicting institutional, professional, and personal roles (Angus, Kontos, Dyck, McKeever, & Poland, 2005; Hollander & Chappell, 2002; Patton, 2005; Purkis, 2001).

Various longstanding and emerging nursing practices come into the ambit of home care. Some nursing practices — wound care, injections — have long been adapted to the home setting, while others — management of addiction — are new to home care. At least since the introduction of morphine, mitigation (or what is known in the professional idiom as palliation) of symptoms for those dying at home was the province of nurses working in private homes. With the rise of specialized care in hospitals, palliation — sometimes critiqued as the medicalization of dying — moved to the institutional setting, though under different names (von Gunten, Ferris, Portenoy, & Glajchen, 2001). The hospice movement, partly a reaction to the dehumanizing effects of technologically driven care practices, highlights the value of non-technological interventions that, as a result of the attention paid to the physical, psychological, social, and spiritual aspects of suffering, have enabled a process of dying with dignity both in institutional settings and elsewhere (Lagman, Declan, Heintz, LeGrant, & Davis, 2008). This has led to, among other things, the development of group housing located in community settings. But the availability of hospice care still varies according to the community and the population group (Subcommittee to Update "Of Life and Death," 2000, Introduction). The growing hospice movement, combined with the move towards increased use of home care, has revitalized the idea of palliative care in the home context.

The field work analyzed in this article describes a style of home care nursing that has evolved in an environment — an impoverished urban neighbourhood — and among a group of clients — multiple-diagnosis patients, including many HIV+ and Hepatitis C+ individuals residing in

marginal housing — that shatter all of these assumptions and raise new questions about “home” and “care.” For example, a person with a heroin addiction and late-stage HIV disease will have injection-site infections or wounds because of a decimated immune system. Is this person a palliative care patient, an addictions patient, or an HIV patient? This determination becomes harder yet when we consider multi-label or multi-diagnosis patients and the growing public health concern of these and other outpatients spreading communicable diseases (HIV, hepatitis C virus [HCV]) and highly infectious diseases (tuberculosis). The latter concern incrementally affects the practice of home care nurses, who, traditionally distinct from public health nurses, must increasingly monitor medications not only for their patients’ benefit (“maximally assisted therapy”) but also to meet public health goals (“directly observed therapy”). With the rapid, largely unplanned increase in home care nursing, nurses not only have more tasks added to their practice in settings like Vancouver’s Downtown Eastside but also have to negotiate fundamentally different rationales for providing care.

Our research shows that the hybrid model of care described by the nurse/research participants in this study as “action-based care” (Giles & Brennan, 2006) often conflicts with the very institutional pressures and philosophies that militated for expanded home care in the first place. Nurses are aware of these tensions. However, they tend to dwell instead on their reliance on one another: “We knew that regardless of the response of the larger structure, we agreed on what we were experiencing, what was working and what wasn’t” (Giles & Brennan, 2006). The nurses’ agreement, however, does not mean that action-based care encompasses a set of fixed, explicit rules. Rather, in their writing, the nurses describe general principles, including working in pairs and building trust with patients by accepting values specific to the Downtown Eastside, such as the importance of getting something in order to give something: “Regardless of what we think of this attitude [in which everything in this neighbourhood has a value and is negotiable], we can make it work for us.... Simple, small incentives can go a long way... They work with you more, don’t resist with the same obvious hostility. In short they start to trust you. And you start to trust yourself.” (Giles & Brennan, 2006)

In this article we explore the gap between government mandates, professional ideas, and nursing practices in the Downtown Eastside. This area has a population of 16,000 (City of Vancouver, 2001), of whom 5,000 are estimated to be injection-drug users (Buxton, 2003). Many of these people have several medical diagnoses, including HCV, mental illness, addictions, cancer, and diabetes, not to mention the prevalence of

HIV. The associated mortality rates are among the highest in the developed world (CHASE Project Team, 2005; Patrick et al., 1997; Wood et al., 2003). Ethnography, in the context of allied research projects analyzing demography, disease prevalence, and social networks, enables us to raise questions both about the limitations of current home care initiatives and about the development and implementation of HIV/AIDS programs and services in neighbourhoods with high numbers of marginalized people living in substandard housing.

Background: The Shift towards Home Care in the Face of Rising Homelessness and HIV

There has been limited research into the effects of shifting models of care on the home care nurses who have long practised in impoverished neighbourhoods — particularly in the context of increased homelessness in Canada. A recent review of studies on the transfer of acute medical and nursing treatment to the home setting reveals that most studies of home care nursing involve uncritical reporting of how such “hospital in the home” programs benefit the system and increase opportunities for specialization and autonomy in the nursing profession (Duke & Street, 2003). Because of the link between poverty and HIV and between HIV and palliative care, one of the most fruitful areas for assessing the hospital-to-home movement is home care for marginally housed people with HIV. Several studies have analyzed aspects of the most commonly used palliative care model and highlight the perseverance and resourcefulness that home care nurses must possess in order to interact with a variety of health professionals, AIDS services, and social welfare and volunteer organizations, as well as their own health authorities and managers (Bryant, Wancho, & Daigle, 1999; Robinson et al., 2006). These studies are extremely useful for understanding the issues faced by middle-class gay men who are stigmatized by their sexuality and suffer financial loss as a result of their HIV. But while these men often experience downward mobility, they are spared the cycle of homelessness, interrelated with poverty, experienced by the residents of the Downtown Eastside. While middle-class gay men are — or can become — part of a social network supportive of their sexuality and integrated with services, the residents of the physically decaying neighbourhood in question are economically marginalized and enmeshed in the social world of sex trade, drug use and sales, and petty crime. Data from our allied quantitative study and from our interviews with residents reveal that, in spite of rich social networks, these individuals have a tenuous connection with formal services because of stigma associated with drug use, participation in the sex trade, alco-

holism, racism, sexism, misunderstanding of mental illness, and other factors.

As a municipal service, home care for marginally housed people with HIV might offer a mechanism for providing the continuous and comprehensive care that is necessary for adequate HIV management. Our study asked how palliative care modalities have adapted to the conditions of substandard housing, and how this might enable those who have lost the battle against HIV to die with dignity.

Method

In this article, we analyze data from the ethnographic component of a large, multiyear study of care provision in the Downtown Eastside, called the Homecare for Homeless People with HIV (HCHP) study. The main goal of the study was to evaluate the modalities of home health care provided to homeless and marginally housed persons with HIV/AIDS, with a focus on social relations among homeless persons, in order to make policy recommendations to health planners about improving the quality and continuity of care. The study entailed historical analysis of the various services offered in the neighbourhood, with attention to changes in housing regulations, demographic shifts, and ideological shifts with regard to social welfare, as these factors influence the creation of services by government, church, and advocacy groups. In addition, the team conducted semi-structured, open-ended interviews with residents of the Downtown Eastside, exploring the issues of housing stability, access to food, perceptions of health and illness, health and social service use, relationships, and emotional attachment to the neighbourhood. In addition, one of the co-investigators took part in the cross-sectional Community Health and Safety Evaluation (CHASE) project, a community-based survey of the neighbourhood conducted by residents, and we use data from that survey ($N = 3,530$) in our analysis.

The HCHP principal investigator (Patton) was the team ethnographer, and this article reports on her work following various home care nurses on their rounds during a 15-month period totalling 150 hours over 18 days — all weekdays from 8:00 a.m. to 4:30 p.m. On about one third of those days the supervising physician also made rounds. Field notes were composed between client visits, which could last anywhere from 5 minutes to several hours, depending on what tasks were entailed in the visit. The tasks ranged from wound care to assistance with administration of medication, to reminders of appointments, to assistance with moving the patient to a hospice. The nurses' rounds included visiting two shelters, each of which had both long-term and short-stay clients. All notes were transcribed and elaborated soon after being recorded.

They were analyzed for common and improvisational practices, evidence of policy or practice mandates, and patient acceptance or rejection of the care on offer.

Setting

In 1997 the Vancouver/Richmond Health Board declared a health emergency due to the prevalence of HIV/AIDS among drug users living in the Downtown Eastside. This declaration underlay the introduction of a range of new services alongside the wide variety of support services that had been developed for the neighbourhood over many decades (Patrick et al., 1997; Wood et al., 2003). The latest exceptional services, aimed at HIV, HVC, and addiction, included North America's first legal safe-injection site, a heroin maintenance trial, four new health facilities to increase awareness of health issues, and two new health clinics. In addition, several programs and augmented home care nursing services enable a range of modalities, including the aforementioned directly observed treatment (DOT) and maximally assisted treatment (MAT) for indigent HIV+ persons on simplified antiretroviral (ARV) programs. These semi-linked strategies include two programs that hold patients' medications in a fixed location and the addition of ARV home delivery to HIV+ patients (Wood et al., 2003) by home care nurses already working in the neighbourhood.

Navigating Trust, Domesticating the Clinic

The situation of the nurses observed in this study is different from that conventionally envisaged for home care. Many of the spaces occupied by patients in this setting would, to an outsider, barely register as home. Nurses employ a variety of strategies to acknowledge and respect the boundaries of the private spaces constructed by the marginally housed. Such private spaces can range from a room in a hotel to a bag of belongings next to a daybed in a shelter. By using simple gestures of civility, such as knocking and waiting to be admitted, kneeling on the floor instead of sitting on furniture (unless invited to do so), and being attentive to the daily differences in whether one is welcome at all, the nurses "co-construct" a sense of home with patients. Nurses typically see 10 to 14 patients during an 8-hour shift, and their patients are highly sensitive to the smallest gesture that might indicate a negative value judgement or lack of interest. Given these time constraints and social conditions, and in the absence of an explicit code of practice to govern their trust-building activities, the nurses have developed a "feel for the game" that permits them to build and sustain fragile relationships. When our lead ethnographer first observed the nurses, all of their gestures, postures, and ways of

asking some questions (“How are you tolerating your HIV medications?”) while avoiding others (“Who are these people living in your room?”) indicated a deliberate, orchestrated approach to care delivery. But over time — and especially when the ethnographer observed nurses who were new to this clientele making mistakes, emulating more experienced nurses, and attempting to develop strategies of their own — it became clear that the range of gestures, vocal tones, and phrasings were part of a non-verbal care vocabulary from which the experienced nurses drew improvisationally; they were able to instantaneously size up a situation and find a viable means of providing care. The embodied nature of their knowledge, and their enactment and expression of a unique home care nursing practice, extended their education to include not only what they had learned in school but also what they had learned by experience.

Instead of comprising a rational interaction, in which patients and nurses directly modify each other’s behaviour, this approach reflects what the French philosopher and sociologist Pierre Bourdieu calls “habitus” — a “generative principle of regulated improvisations” (Bourdieu, 1977, p. 78). Habitus can help us to analyze how the nurses’ practice retains its nursing roots while evolving in the Downtown Eastside context to become embodied knowledge enacted daily.

From this perspective, the motions, signals, and postures with which the nurses engage patients to establish a sense of home are a form of embodied knowledge acquired through the processes of professional and institutional acculturation and years of adapting their practice, or having it adapted, to the changing worlds of their patients. Such a conception of knowledge, activated and expressed in the language of the body in real time and space, accounts for the context-driven, situation-specific nature of the nurses’ practice, while at the same time recognizing their expertise as practitioners. This explains the nurses’ refusal to reduce their action-based model of care to a list of rules and their decision to share their general impression of what it takes to inhabit the space they do (Giles & Brennan, 2006). For Bourdieu (1977), it is not so much the set of gestures that endures, is added to, or subtracted from over time, but the internalization of a practical logic or generative schemes for putting them together in the right place at the right time (pp. 78–83).

The emphasis on the embodied, temporal, and spatial dimensions suggested by the notion of habitus highlights the continuities as well as the contradictions inherent in practices that are manifested in the nurses’ minute-by-minute judgement calls, which can serve to both operationalize and put them at odds with the central ethos of their own action-based care approach of being consistent, reliable, non-judgemental, respectful, collaborative, and supportive (Giles & Brennan, 2006). These contradictions (a source of tension between the experienced nurses and

nurses working with other patient groups) are evident in, for example, the nurses' practice of using cigarettes and bus tickets to initiate and sustain their relationships with patients. It is impossible to know whether the nurses had extended an existing practice of offering enticements or had been prompted by patients to modify their practice. In any case, our lead ethnographer observed multiple daily encounters in which residents signalled their role of patient by asking the nurses for a cigarette or for bus fare. At first this seemed to be a form of anonymous and guilt-inducing panhandling, but over time the ethnographer realized that most people in the neighbourhood knew the nurses' approximate schedules and actually came looking for these small tokens. Occasionally the nurses turned down these requests, but more often than not they took the opportunity to engage the individual by giving the small token high symbolic value. The exchange served as a reminder that even if the person was not currently on the nurses' roster he or she was still their patient. This is comparable to a middle-class person's sense that *even if I haven't been to my doctor this year, she is still my doctor, and even though I remain well, I am her patient*. In some cases — especially with highly independent patients — it was the nurse who initiated the exchange, as if to remind poor persons that even if they were no longer technically under care, or possibly even refusing care, as “patients” they still belonged to the nurses.

The following field notes illustrate the symbolic value of a free cigarette and demonstrate the nurses' improvisational use of a transaction to slip almost imperceptibly into the formal role of nurse:

Jane (pseudonym) is living in a temporary shelter, but the nurses have known her for many years through the variety of her settings. When she first re-emerged at the shelter, she was primarily getting meals and sometimes did not return to her bed at night. The unit managers, concerned about her well-being as winter approached, but also about her “taking up a bed someone else could use,” asked the nurses to see her. When they called Jane in, she gave a cursory account of her current situation, and as she left, one of the nurses asked if she wanted a cigarette. For a period of several weeks, she returned to the drop-in clinic with various complaints (since attending the clinic implies a complaint), but mainly to talk about her relationship with her current partner and to receive her token cigarette. Jane was not around for a period of time until one day she was rushing out as the nurses came in. She stopped and got into the queue to see the nurses, and finally said in a whispered tone, “Can I get a cigarette?” I thought the nurses, who were especially busy that day, would give her the cigarette and let her go on her way. But instead, one nurse, renowned for her toenail and fingernail trimming abilities, started a conversation about Jane's new haircut and clothes. As they chatted, Jane picked at one nail, infested with a fungus, and the

nurse asked if she could take a look at the finger. Jane said, "That one's so ugly — there's a fungus." The nurse asked if Jane would like her to trim the nail, and in the course of the "manicure" Jane revealed many more details about her situation and declining health. In this instance, the nurse transformed the cramped first-aid room that serves as the shelter's clinic into a home-like domestic space of female bonding and caring.

In this interaction the nurse builds from the simple act of offering a cigarette and asking nothing in return to enacting other forms of caring that incrementally bring the patient from a state of apparent disregard for her personal welfare to caring about her appearance. Some weeks later this patient sought more permanent housing and resolved (from her perspective) her relationship with her partner, and eventually she returned to treatment for her multiple medical problems, including HIV.

Negotiating Privacy

Let us examine another situation in which the nurses must negotiate trust and privacy — the cramped confines of a social housing unit. Unlike the suburban home, which presumes a degree of privacy and security from policing forces, the spaces of marginally housed people, where the nurses carry out their practice, are under surveillance. In fact it is not uncommon for patients to go outside their room to receive treatment or medication drop-offs, or simply to meet the nurse. This practice is likely related to their experience of being harassed by police, having to cope with the variable rules concerning visitors, and having their rooms scrutinized by housing personnel, who demand that tenants maintain varying levels of cleanliness and orderliness. Patients may have drugs and drug paraphernalia lying about or may even be actively dealing drugs from their room. Patients who are in the sex trade may have a customer in their room or may simply have evidence of their trade there. Patients living in social housing may be violating regulations by keeping a live-in partner, and patients in single-room-occupancy dwellings may be violating rules that require a nightly fee for "guests." It is not unusual for residents of these relatively luxurious social housing units to make informal rental arrangements with relatives or acquaintances. The nurses have to carefully negotiate their arrival with these people, since from the point of view of the "couch renters" their quasi-contractual relationship with the tenant entitles them to at least partially control the space. The nurses must make quick judgement calls in the face of a changing cast of characters if they are to maintain the trust of patients who have little reason to put their faith in the "system" or its representatives. One of the ways in which nurses maintain this trust is by cultivating a reputation for not disclosing patients' activities to police, building managers, or others regarded by patients as monitoring them.

The field notes record a number of visits to an older white woman living in one of the nicer social housing complexes:

Each time we visited, there was a different young, white woman sitting politely at the kitchen table, whom I initially assumed to be daughters or relatives. On a later occasion, there was a young Native woman at the same table, sitting equally quietly and politely. This time, our earlier automatic assumptions — based on age and race — were challenged, and I looked more closely at the neatly ordered table. I realized that the table was a tidy display of various tools for consuming drugs — pipes and cooking devices, but no visible syringes. I still couldn't quite understand what I was seeing and asked the nurses who the young woman was. They looked at each other and one said, "We really don't know. I guess we assume she is a customer."

The nurses more or less unconsciously took on this kind of nonchalance in the face of the complicated and questionable activities they witnessed. In fact, we suggest that because of their enmeshment in the particular home care habitus of the Downtown Eastside they no longer saw things the way others might. In the case above, it was not that the nurses consciously ignored the drug-dealing activities of their patient, or that the patient intentionally left the evidence in plain view (no doubt she had put the actual drugs away); rather, these tools of criminal activity were accepted as everyday items that did not merit attention. In order to preserve the patient-nurse relationship, a line had been established regarding what had to be left unsaid. This "unnoticed noticing" was very difficult for new nurses and for outsiders such as ethnographic researchers. We would often stare at drug paraphernalia and, when caught by the patient, quickly look away.

Palliative Care and HIV Miracle Drugs

Palliative care was one of the important care philosophies underlying the nurses' practice. In the early days of our field work, one of the nurses spoke of her experience in the field of palliative care and her interpretation of her current practice as a form of palliative care. Indeed, we learned that one of the official criteria for adding an HIV patient to her caseload was the declaration of the case as palliative. The historical changes in the survival rates post-HIV diagnosis confound the official understanding of which patients are classified as palliative, and when. In the late 1980s middle-class persons with AIDS (or PWAs) began to reap the benefits of anti-HIV drugs with the introduction of protease inhibitors and other innovations in anti-HIV drugs. In the 1990s this particular group of PWAs began a dramatic decline in morbidity and mortality. The picture has been quite different for disadvantaged persons, whether they live in developing countries or in decaying neighbour-

hoods in the developed world. Because of their disconnection from primary health services, and because they are often diagnosed with advanced disease, when the home care nurses began caring for the emerging group of Downtown Eastside residents with AIDS there was still a strong perception that PWAs in the neighbourhood would not survive and therefore that virtually any PWA there would sooner or later be “palliative.” Based on the horrific experience in that decade of having many patients “die with their boots on,” as they put it in their educational presentations, the nurses devoted tremendous energy to making it possible for PWAs to die with some degree of dignity, including access to structured pain management (as opposed to self-medicating with illicit drugs).

But the easy equation between later-stage PWAs and palliative care changed in the late 1990s as the new, lifesaving ARVs became available to this group. In British Columbia ARVs are fully covered under the provincial health plan, so the barrier to access is not financial. Also, Vancouver’s health authorities and practitioners have grounded their decisions about who is placed on ARVs explicitly on a human rights approach (BC Ministry of Health, 2006). In addition, Vancouver places no restrictions on access to ARVs (Wood et al., 2003), while other jurisdictions in the developed world require abstinence from illegal drugs (Oppenheimer, Hernandez Aceijas, & Stimson, 2003; Wolfe & Malinowska-Sempruch, 2004), evidence of stable housing, or even enrolment in group therapy or programs aimed at transforming chaotic lives into “normal” ones. Today, therefore, extremely sick individuals are sometimes restored to quite normal health, and in many cases it is hard to know if HIV medication will amount to palliation or cure. On the other hand, a patient who has been doing very well on medications may become involved in street life and stop medicating, taking a rapid downward turn. The nurses had several patients who had gone through this cycle many times, with each downward trend signalling imminent death and each upward trend enabling the patient to resume a fairly normal life.

In their ethical commitment to providing universal access to ARVs, the nurses have been influenced by AIDS doctors at the BC Center for Excellence in HIV and Clinical Trials Network, a group known around the world. Yet the nurses are the caregivers who cope with the practical results of the doctors’ human rights, drugs-for-all approach: Once they feel better, many patients — possibly most — choose to return to the life that placed them in harm’s way in the first place. The challenges presented by this situation are quite different from those encountered in mainstream palliative care. In the face of considerable political controversy, the nurses have had to develop a form of practice that saves the lives of people whom many citizens would just as soon forget. Within the

Bourdieusian framework, such adaptations and innovations are not rules of practice but, rather, logics for generating practice. Thus the nurses have developed a rationale that, even if never formally codified, implicitly provides a basis for maintaining continuity across an individual's course of treatment and a consistent approach across the population group. This logic emerges from practice, is oriented to the situations encountered in daily life, and is often antithetical to the principles of rational logic that the treatment algorithms, much loved in clinical practice, attempt to codify. "The logic of practice is logical up to the point where to be logical would cease being practical" (Bourdieu & Wacquant, 1992, pp. 22–23).

These concepts, when applied to nurses' search for practical, logical solutions to competing care mandates, show how such solutions transform both palliative care and addiction treatment. The concept of harm reduction is hotly debated among care providers in this community. In harm reduction, the objective of care is shifted away from abstinence towards mitigation of the social and physical harms of substance use. Those providing HIV care employ this framework while at the same time treating the infectious disease that has resulted from harmful practices associated with drug use (the harm is threefold: the needle-sharing that results in infection, the challenge to the suppressed immune system posed by the drugs, and the drug-induced behaviours that affect self-care — including adherence to treatment). Because harm reduction is not accepted by all service providers in the Downtown Eastside, the nurses' practices continually meet with conflict. For example, there have been several cases of methadone-maintained patients doing well on HIV drugs but becoming too feeble to leave their room to fetch their medications and methadone. When the nurses attempt to deliver these drugs to recovering addicts managed by a 12-step group (whose goal is abstinence), they can be prevented for days from entering the building, the managers arguing that home delivery "enables" the patients' "addiction" to methadone.

Medical personnel who are unfamiliar with the complexities of life in places like the Downtown Eastside have difficulty comprehending the cycles of good health, when people often resume their street lives trading in drugs and sex with a vengeance, and poor health, when they are extremely and seemingly irreversibly ill. To conventional practitioners and many lay people, palliative care is inappropriate for these patients when they are well, even though they are diagnosed with debilitating and fatal illnesses. A comment by a nurse taking extra shifts in the unit expresses this perspective very well: "If she's out at night turning tricks for the \$400 to buy drugs, then she's not palliative." Most providers find it hard to accept the harm reduction strategy invoked to justify this use of pallia-

tive care, which allows patients to consume their street drugs. This stems from the moral assumption that activities like smoking crack or trading sex for money are of a totally different character from smoking cigarettes, drinking alcohol, or eating badly — behaviour that would be overlooked in conventional palliative care patients.

While the changing care demands related to improved life expectancy for impoverished people with HIV — an outcome of new treatment modalities — are not unique to AIDS, the stigma attached to people with HIV and the activities they likely engaged in while contracting it shift the moral calculus of improving quality of life. It is not entirely clear that Canadian society wants to save the lives of marginalized people, especially if those saved are unable or unwilling to pursue a middle-class lifestyle. In the Downtown Eastside, success means medical success; people who are doing well on their ARVs and who have undetectable viral loads require ongoing, frequent interaction with nurses if they are to maintain their new level of health. It appears that the universal-access philosophy based on human rights will continue to hold sway despite counterbalancing attempts at cost containment that might limit care to those who show promise for leading a “productive life” according to middle-class standards (e.g., by making liver transplantation inaccessible to people with HIV). But the costing and evaluation systems for home care that determine when a patient has had a sufficient number of visits to make it on his or her own do not take into account the special goals imposed on home care nursing practice by the philosophical commitment of universal access to HIV medications.

Discussion: Competing Care Philosophies, Impossible Practice

In conversations with the nurses, we discussed at great length the complexity of their jobs, and they have written in nursing journals about their understanding of their practice (see, e.g., Giles & Brennan, 2001; Griffiths, 1996). From their point of view, it is their patients’ “multi-diagnoses” that make the job difficult. They believe that each patient should be treated more holistically, not as a person with an “addiction” or with HIV, but as a person for whom several social and medical labels function synergistically, calling for different treatment approaches and rendering each individual “problem” more complex.

On the one hand, the ways in which individual patients deviate from the norms of nursing’s various subdisciplines make them difficult to treat. On the other hand, the nurses’ job is guided by structural forces. As frontline workers, nurses have little opportunity to consult on the policies and mandates that will ultimately make their jobs easier or more difficult. The nurses who work with HIV patients in the Downtown Eastside

serve conflicting masters — even more so than their home care colleagues in falls prevention, wound care, or diabetes management. They are upholding a long tradition of out-of-hospital nursing, providing care to people who have no other means of improving their lives. At the same time, they work under the authority of doctors who themselves serve different masters when it comes to making decisions about who is placed on ARVs: Doctors too must negotiate the practical consequences of prescribing treatment for conflicting reasons. The doctors' reasons are both noble and political in the context of obtaining resources for people with HIV; there is no doubt that they care about their patients, but they are also invested in proving that their city can deliver world-class care. While many of Vancouver's doctors "do time" in the downtown clinics, few make house calls. It is primarily nurses who are bringing health care to the most intimate spaces and moments. The complexity of providing continuous care in conditions often described as chaotic is only intensified as individual physicians and the public health system make policy decisions about treatment out of concern about compliance with drug regimens and its consequences for population health. It is the frontline nurses who, in generating a home care habitus, have developed and adapted flexible and innovative solutions for people with a range of diagnoses and a range of treatment options, many of which stem from fundamentally conflicting care mandates and models.

References

- Angus, J., Kontos, P., Dyck, I., McKeever, P., & Poland, B. (2005). The personal significance of home: Habitus and the experience of receiving long-term home care. *Sociology of Health and Illness*, 27(2), 161–187.
- BC Ministry of Health. (2006). *Goals of HIV/AIDS services in British Columbia: A harm reduction approach*. Victoria: Author. Retrieved October 13, 2006, from <http://www.health.gov.bc.ca/hiv/goals.html>.
- Bourdieu, P. (1977). *Outline of a theory of practice* (R. Nice, Trans.). Cambridge: Cambridge University Press. (Original work published 1972.)
- Bourdieu, P., & Wacquant, L. J. D. (1992). *An invitation to reflexive sociology*. Chicago: University of Chicago Press.
- Bryant, S., Wancho, B., & Daigle, B. (1999). Changes in HIV homecare. In B. Daigle, K. E. Lasch, C. McCluskey, & B. Wancho (Eds.), *HIV homecare handbook* (pp. 1–28). Sudbury, MA: Jones & Bartlett.
- Buxton, J. A. (2003). *Vancouver drug use epidemiology*. Vancouver: Canadian Community Epidemiology Network on Drug Use.
- CHASE Project Team. (2005). *Community Health and Safety Evaluation (CHASE) report*. Vancouver: Vancouver Coastal Health Authority.
- City of Vancouver. (2001). *Ensuring the healthiest community future for Vancouver*. Vancouver: Author. Retrieved October 1, 2006, from <http://www.hc-sc>.

- gc.ca/ahc-asc/alt_formats/cmcd-dcmc/pdf/media/releases-communiques/2001/2001_64ebk2.pdf.
- Duke, M., & Street, A. (2003). Hospital in the home: Constructions of the nursing role — A literature review. *Journal of Clinical Nursing*, 12, 852–859.
- Giles, S., & Brennan, E. (2001). “Home” nursing of HIV-positive clients in the urban core. *Canadian Nurse*, 97(1), 33.
- Giles, S., & Brennan, E. (2006). *Action-based care in Vancouver’s DTES*. Retrieved October 12, 2006, from <http://www.multidx.com/abc/abcWeb.html>.
- Griffiths, H. (1996). Nursing in the urban core. *Nursing BC*, November–December, 14–16.
- Health Canada. (2003). *First Ministers’ Accord on Health Care Renewal*. Retrieved October 10, 2006, from http://www.hc-sc.gc.ca/hcs-sss/delivery-prestation/ftcollab/2003accord/index_e.html.
- Hollander, M., & Chappell, N. (2002). *The National Evaluation of the Cost-Effectiveness of Home Care*. Ottawa: Health Transition Fund, Health Canada.
- Lagman, R., Declan, W., Heintz, J., LeGrant, S. B., & Davis, M. P. (2008). A day in the life: A case series of acute care palliative medicine — The Cleveland Model. *American Journal of Hospice and Palliative Medicine*, 25(1), 24–32.
- Oppenheimer, E., Hernandez Aceijas, C., & Stimson, G. (2003). *Treatment and care for drug users living with HIV/AIDS*. London: Imperial College Centre for Research on Drugs and Health Behaviour. Retrieved August 22, 2006, from http://www.ahrn.net/library_upload/uploadfile/Treatment_care_for_DUs.pdf.
- Patrick, D. M., Strathdee, S. A., Archibald, C. P., Ofner, M., Craib, K. J., Cornelisse, P. G., et al. (1997). Determinants of HIV seroconversion in injection drug users during a period of rising prevalence in Vancouver. *International Journal of Sexually Transmitted Diseases and AIDS*, 8(7), 437–445.
- Patton, C. (2005, November 5). *Homecare for homeless people with HIV*. Paper delivered at 2005 Home Care Summit, Banff, Alberta.
- Purkis, M. E. 2001. Managing home nursing care: Visibility, accountability and exclusion. *Nursing Inquiry*, 8(3), 141–150.
- Robinson, L., Dugger, K., Fong, G., Heintzman, T., Hnizdo, S., Libby, J., et al. (2006). Palliative home nursing interventions for people with HIV/AIDS: A pilot study. *Journal of the Association of Nurses in AIDS Care*, 17(3), 37–46.
- Romanow, R. (2002). *Homecare in Canada*. Discussion paper of the Commission on the Future of Health Care in Canada, Roy Romanow, Chair. Retrieved August 21, 2006, from http://www.chsrf.ca/other_documents/romanow/pdf/homecare_e.pdf.
- Sharkey, S., Larsen, L., & Mildon, B. (2003). An overview of home care in Canada: Its past, present, and potential. *Home Health Care Management and Practice*, 15(5), 382–390.
- Subcommittee to Update “Of Life and Death.” (2000). *Quality end-of-life care: The right of every Canadian*. Final Report, Part I. Ottawa: Senate of Canada. Retrieved January 24, 2007, from <http://www.parl.gc.ca/36/2/parlbus/commbus/senate/com-e/upda-e/rep-e/repfinjun00-e.htm#PART%20I>.
- von Gunten, C. F., Ferris, F. D., Portenoy, R. K., & Glajchen, M. (2001). *CAPC manual: How to establish a palliative care program. Evolution in Canada*. New

- York: Center to Advance Palliative Care, 2001. Retrieved January 24, 2007, from <http://64.85.16.230/educate/content/rationale/evolutionincanada.html>.
- Wolfe, D., & Malinowska-Sempruch, K. (2004). *Illicit drug policies and the global HIV epidemic: Effects of UN and national government approaches*. Working paper commissioned by the HIV/AIDS Task Force of the Millennium Project. New York: Open Society Institute. Retrieved October 12, 2006, from http://www.soros.org/initiatives/health/focus/ihrd/articles_publications/publications/cnd_20040316.
- Wood, E., Montaner, J. S., Bangsberg, D., Tyndall, M., Strathdee, S., O'Shaughnessy, M.V., et al. (2003). Expanding access to HIV antiretroviral therapy among marginalized populations in the developed world. *AIDS, 17*, 2419–2427.

Authors' Note

This research was a component of the 4-year Homecare for Homeless People with HIV study supported by the Canadian Foundation for AIDS Research (grant #016009) and the Social Sciences and Humanities Research Council (grant #855-2003-0003).

The authors acknowledge the input, feedback, and investment of time of the home care nurses in Vancouver's Downtown Eastside.

Comments or queries may be directed to Cindy Patton, Health Research and Methods Training Facility, Suite 3150, SFU Harbour Centre, 515 West Hastings Street, Vancouver, British Columbia V6B 5K3 Canada. E-mail: healthlab@sfu.ca or ckpatton@sfu.ca.

Cindy Patton, PhD, is Canada Research Chair, Department of Women's Studies and Department of Sociology and Anthropology, and Head, Health Research and Methods Training Facility, Simon Fraser University Harbour Centre, Vancouver, British Columbia, Canada. At the time of the study, Helen Loshny, MA, was Project Manager, Health Research and Methods Training Facility, Simon Fraser University Harbour Centre.