Mobile Knowledge: HIV Patients’ Encounter with Endocrinology

Cindy Patton
Simon Fraser University

Abstract: Tracing the movement of new medical information from the laboratory to individual consumers is a challenge to communications theorists and social scientists alike. This article adopts the position of the social study of medicine, which takes into account the impact of people’s perceptions of disease on treatment decisions and outcomes, to locate instances of the movement of information—and its limitations—in a unique setting: a metabolic disorders clinic for HIV-positive patients. Analysis of data from a participatory observation study at the clinic reveals that the clinician, inculcated into endocrinology, must adapt new information to enable communication with patients, who hold a different view of the body heavily informed by virology. This adaptation also occurs in the reverse, as patients adjust their thinking to make room for new information that will directly impact their treatment decisions.

Keywords: Doctor-patient communication; Clinical ethnography; HIV; Endocrinology; Social studies in medicine

Résumé : Retracer le transfert de nouvelles informations médicales du laboratoire au consommateur pose un défi au théoricien en communication tout autant qu’au savant en sciences humaines. Cet article a recours aux études sociales en médecine, où l’on étudie les perceptions des gens à l’égard de la maladie et les effets de celle-ci sur les traitements, afin de situer des exemples de transferts d’information dans un emplacement singulier : une clinique pour les perturbations métaboliques qui traite les patients atteints du VIH. L’analyse de données provenant d’une observation participante menée à la clinique révèle que le clinicien, avec son expertise en endocrinologie, doit reformuler de nouvelles informations afin de mieux communiquer avec ses patients, car ces derniers ont sur le corps un point de vue différent, fortement influencé par la virologie. Cette reformulation a aussi lieu dans le sens inverse, car les patients doivent ajuster leurs perceptions afin de mieux intégrer de nouvelles informations qui auront une portée directe sur leurs décisions à l’égard de leur traitement.

Mots clés: communication médecin-patient; ethnographie clinique; VIH; endocrinologie; études sociales en médecine

Cindy Patton is Canada Research Chair in Community, Culture and Health and an Associate Professor in the Departments of Sociology/Anthropology and Women’s Studies at Simon Fraser University, 515 West Hastings Street, HCC 3150, Vancouver, BC V6B 5K3. Email: healthlab@gmail.com.

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Some biomedical events result in tremendous media coverage that alerts “the public” or specific affected subgroups to relevant issues such as symptoms, modes of contact, and direction and speed of spread. Big Story news coverage often announces and tracks epidemics—SARS, West Nile virus, annual flu, AIDS—and reports on breakthroughs in treatment, mechanisms for disease identification, vaccines for viruses, and even examples of the transformation of ordinary into extraordinary medicine (using aspirin in the control of heart attack risk, for instance). Sociologists of the media and critics in the area of culture studies have expended considerable energy using framing theory and moral panic theory to analyze such mass coverage of biomedical events. Both approaches underscore the relationship between apparently neutral science writing and political opinions and position-taking. Whatever criticism I have of these theoretical tacks (see Patton, 2005), it is the case that sensational media moments seem to affect both public and subcultural understandings of the body and its woes. But against what background, frame of reference, and experiential context? Individuals do not exist in a vacuum between highly publicized biomedical events.

Indeed, science more often proceeds incrementally and non-sensationally. Unlike the big events, which are communicated directly to consumers via the media, the bulk of new information is conveyed person to person, from clinicians and medical paraprofessionals to their patients. The media-consumer relationship is complex and dynamic, affected as much by news outlets’ financial interests and science writers’ professional ethics as it is by the multidimensional possibilities for interpretation. But the ordinary case of moving quotidian updates to knowledge from the research lab to the clinic is even more complex, or at least less theorized; in the drifting and shifting of bio-knowledge there are countless opportunities for professionals and patients to call forth and remake the “facts” that are to be applied in the practical logics of bodily care.

The basic process looks straightforward enough: physicians from many subdisciplines learn about new medicines, diseases, diagnostic strategies, and prognoses from a range of sources, including meetings with drug representatives, academic or professional conferences, medical journals, subspecialty newsletters, and, of course, from their close circle of trusted colleagues. Doctors pass their new knowledge along to other clinicians and to paraprofessionals who, in turn, educate patients. Increasingly, as practitioners and community members collaborate in knowledge translation, paraprofessionals also educate peer educators who themselves go on to educate their constituencies. Of course, laypeople also snatch information straight from medical journals and conferences—knowledge activists and opinion leaders within health and disease constituencies filter science for others, sometimes informally, but also through quasi-official community media such as newsletters, Internet-based interest groups, and individual bloggers, those fractious, self-publicizing, and non-delegated opinionists who recall the pamphleteers of the early French and American Republics.

This general description, however, nowhere near fulfills the ambitions of an older sociology of science, which hoped to be able to predict the flow of information through society—a project that seems near impossible now, with so many way stations between lab and layperson. Rather than chart this complex system
of senders and receivers operating across the multiple layers of scientists’, doctors’, and patients’ investments and strategies, it might be more productive to delaminate the composite object we call “medical information.” Starting in the clinic itself, we can build up a picture of the points of incongruity—resulting variously from professional norms and identities, differential access to background information necessary to “make sense” of new information, subcultural sensibilities, patients’ subterfuge—that operate as constraints on the potentially limitless polysemy and unchecked mobility of “facts.”

The examples I work through in this article point to specific places and players as they confront a new or re-contextualized medical “fact” and then work it into a conceptual framework that initially seems unable to incorporate it. In this analysis of my ethnographic fieldwork in a specialized clinic, I describe the reactions of HIV-positive people—mostly gay men—and their doctor as they work through new medical facts about metabolic issues like cholesterol levels. The majority of these patients arrive at this clinic already steeped in a knowledge set they have acquired in their early confrontation with virology, the specialty that has long dominated treatment for HIV. First, I find the trace evidence of their prior assimilation to the characteristic mode of thinking about the body belonging to virology. I then demonstrate the staying power of patients’ worked and incorporated version of virology by examining moments when they deploy this framework to “understand lipids” by reworking and incorporating facts from a science (endocrinology) with a rather different body-logic as they try to align their HIV diagnosis with their new diagnosis of a metabolic disorder.

Although I report doctor-patient conversations in my findings, I do not understand these to be events during which medical facts actually flow between individuals, but rather as moments in a larger, multi-way struggle between scientific subdisciplines and among practitioners and patients, a struggle in which clinicians with different levels and forms of power are forced to adapt to each other indirectly through their negotiation of a more or less shared language and perspective with their patients. What we see is not only the quotidian conveyance of minor changes in medico-scientific knowledge, but also the unstated hybridization of medicine in clinical practice. The implication of this study is that there is likely no single moment in which patients arrive at a “correct” understanding of their diagnosis, nor is there a single moment in which clinicians deem the patient’s understanding to be sufficient to the clinical goals (largely, adherence to medications and physical regimens), but rather, the clinician, patient, and multiple disciplines that they embody are already shifting sands upon which to build “communication”: individual clinicians and patients make do within the larger domain of changing science and changing clinical practice.

Research context and method
From summer 2003 through winter 2004 I conducted a pilot study (The Understanding Lipids Project) in a major North American city at a specialized clinic for HIV-positive people experiencing a range of cholesterol, blood sugar, and morphological changes. There, a doctor and several nutritionists educate and deliver services to HIV-positive persons experiencing metabolic problems related to HIV, HIV treatment, and “lifestyle factors” (diet, exercise, smoking) that do
not differ from those of non-HIV patients. During the time of my study, this set
of metabolic problems was undergoing a renaming—from “HIV lipodystrophy”
to “HIV Metabolic Disorder.” Lipodystrophy is a general diagnosis that refers to
any atypical fat distribution—accumulation, depletion, or both—and is a lively
area of research and clinical practice outside the world of HIV. In people with
HIV, accumulation takes place in the abdomen, breasts, and back of the neck, and
depletion is most prominent in the face, forearms, and lower legs. We know much
more today about the mechanisms of this lipodystrophy, and I was conducting my
clinical ethnography during the period when research results were flowing in and
important theoretical shifts were moving the field of HIV endocrinology into a
more prominent position in the larger field of AIDS medicine. Today, we un-
derstand that fat accumulation on the belly and neck are likely related to specific
medications, while the peripheral body depletion seems related to the long-term
effects of HIV itself. But at the time of my pilot study, these “facts” were still
being produced by clinical observation, patients’ histories, controlled studies, and
via advocacy media and folk terms used by people living with HIV. (“Crix belly,”
named for the drug Crixivan, for example, proved an accurate folk diagnosis of
the cause of dramatic bellies.)

The visible effects of HIV Metabolic Disorder prompted patients to request
referral to the clinic, but there are clinical signs for the “dislipidemias” that
prompt physician referrals. These signs that fat storage molecules are out of nor-
mal range or ratio are usually discovered in the course of standard, simple cho-
lesterol tests. But the normal cholesterol tests are based on bodies not otherwise
damaged by a retrovirus or the medications that combat it; as the science of HIV
metabolics emerged, more refined measures of fat molecule size and ratio were
needed to distinguish between side effect–induced changes of little clinical con-
sequence and true underlying conditions that had been tipped into the cardiovas-
cular danger zone exacerbated by the body’s experience with HIV and HIV
medication.

The patients I saw experienced some combination of these effects as well as
bone density loss, muscle mass loss, generalized fatigue (less clearly related to
HIV treatment but likely a result of linked changes in the mitochondria), and
incremental changes in blood sugar levels. Because knowledge about the effects
of HIV and HIV treatments on the body emerged rapidly during the period of my
pilot study, the professional standing of “the lipids guys” improved and was soon
deemed a subspecialty—HIV endocrinology—that belonged neither completely
to HIV medicine nor to endocrinology. As we will see later, patients and the HIV
endocrinology specialist had to negotiate not only the rapidly changing science of
HIV metabolics, but also the rising professional status of HIV endocrinology.

The research project included clinical ethnography, observation of educa-
tional forums offered by the local HIV treatment information/advocacy group,
interviews with treatment information advocates, and interviews with poor peo-
ple—predominantly women—who did not attend this clinic but were potentially
experiencing HIV treatment–related side effects. Patients were referred to the
clinic through several routes. The majority—gay men who had been living with
HIV for five years or more—were patients of the hospital-based HIV clinic and
were referred by a clinician patients frequently referred to as their “AIDS doctor.”

A sizeable portion of the gay men, however, came from competing medical practices that were founded as the politics and ideologies of HIV treatment evolved and as the medical funding agencies experimented with different forms of reimbursement to group medical practices that managed specific patient populations. In these cases, the referring physician could have been a general practitioner or an HIV specialist associated with an explicitly or implicitly gay- or HIV-focused practice. The last small group, which included the few women and the not insignificant number of heterosexual men from outside the city core, came directly from a general practitioner.4

The clinic was conducted for a half day most weeks, and I attended about half of the sessions offered over the course of a year. During most sessions, I focused entirely on one clinician (doctor or nutritionist). Some days I followed new patients through the set of appointments that comprised their intake process. Intake patients were supposed to see a nutritionist and most did, but few patients were referred back to nutritionists after this initial session. On rare occasions, patients would ask to see the nutritionist again, but it was not clear to me that the doctor had access to information from those sessions. During my study, clinical nutritionists, in conjunction with the main HIV research unit, conducted their own study focused on health outcomes. On several days, I followed patients through their interview for this second study. Several clinical trials of drugs for managing HIV Metabolic Disorder were underway, and, during some of the clinical sessions I observed, patients were recruited to these studies. It is probably important to note here that because of the politics of drug approval early in the epidemic (and still, in relation to new classes of anti-HIV drugs or “salvage” therapies), most people with HIV could only get medications by enrolling in a clinical trial. Thus, since the vast majority of the people I observed were long-term survivors of HIV, they were also veterans of drug trials and research projects. In a process parallel to protocols for gaining consent from patients for other clinicians to observe clinical sessions, the physician or other clinician explained who I was and asked patients for consent for me to observe.

The appointments with the physician occurred in rapid succession and could be as short as five minutes. The consultation room was fairly large. However, multiple specialists used the room, and they had informally divided up the space. The result was that in our sessions we huddled fairly tightly around a desk. The physical exam space was in an alcove on the far side of the L-shaped space from where I was perched, and the doctor pulled a curtain across the area when he conducted the physical exam. I could hear the exam and see the doctor, but I could not see the patients. Except during the initial session, the doctor took very few notes with the patient present and instead dictated all of his notes after the session. I followed this lead, taking no notes with the patient present because I believed it would be intrusive. Even when the doctor did take notes, I thought it would trouble the patients to see two people making different observations and, hence, writing at quite different moments during the session. I therefore made quick notes between patients while the doctor escorted the outgoing patient down the hall and came back with the next. At the end of each day, I elaborated on my
notes, and these are what I use as my record of the sessions. I did not request, nor did I want, access to the patients’ files; if I needed clarifying information about a patient—which was rare, and usually confined to their age or linguistic category—I asked the doctor. My field notes also record information he chose to offer me as well as his way of teaching medical students, medical fellows, and allied health professionals who came to observe his clinic. On two occasions, the doctor was visited by drug representatives, and these encounters are also recorded, as are the doctor’s public lectures that I attended during the time while I was studying his clinic.

Despite the limitations on my note taking, I improved my data collection after the first few sessions by creating a data collection form (see Figure 1) that ensured I used a consistent measure of patient engagement and knowledge, and consistently recorded the nature of their condition. My transcriptions of conversations were entered in the lower, open half of the form.

**Figure 1: Data collection form**

<table>
<thead>
<tr>
<th>Date ____________</th>
<th>Contact ___________</th>
<th>Present ____________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length of Time ________</td>
<td>Intake/ Follow Up __________________</td>
<td></td>
</tr>
<tr>
<td>Age ___</td>
<td>Race/Ethnicity ________________</td>
<td>M/F ________</td>
</tr>
<tr>
<td>High Cholesterol ____</td>
<td>Primary Wasting ____</td>
<td>Redistribution ______</td>
</tr>
<tr>
<td>Diabetes ____</td>
<td>P/S ____</td>
<td>Cervical Humps ____</td>
</tr>
<tr>
<td>exercise ___________________</td>
<td>wt gain ____</td>
<td>wt loss ____________</td>
</tr>
<tr>
<td>PT: (Patient) __________________________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CO: (Chief Complaint) _____________________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DX (Diagnosis): __________________________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RX: (Treatment): _________________________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pt Knowledge/engagement: _________________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>List of meds, use of “lipids” terminology ______________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asks questions (elaborate) __________________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social dimensions, diet, exercise __________________________</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Of the 100+ appointments I observed, about 20% were follow-up appointments with individuals I had seen earlier, thus over the course of my study, I saw about 20% of the patients who attended the clinic that year. I observed about 20 patients twice and about 5 more than twice. I found the sessions highly routinized, but at the same time, personalized, since the doctor had an amazing capacity to remember details like patients’ hobbies and activities. Intakes took between 15 and 25 minutes, while follow-up appointments were generally between 5 and 7 minutes, with occasional appointments of 15 minutes. In general, I found the physician exceptionally good at explaining test scores, the role of drugs, and the current understanding of HIV Metabolic Disorder. Because he was so consistent in conveying information, I was able to pay close attention to the small moments when patients could not enter into the epistemological uni-
verse of the “lipids guy” (so named by one of the patients I observed) and instead attempted to fit the doctor’s “facts” into their existing patient logic.

Theoretical framework
In my work on HIV globally and locally, I adopt the general theoretical position that is now often called the social study of medicine (SSM), a close cousin of the earlier social study of science (SSS), which examined how scientists become scientists and how their professional cultures produce and use knowledge (Becker, 1961, 1993; Crane, 1972; Harding, 1991; Knorr-Cetina, 1981; Latour & Woolgar, 1979; Rosenberg, 1976). A hallmark of SSS that makes it particularly extendable to the social study of medicine is the combined use of ethnographic fieldwork in scientific laboratories, archival research in the history of science, and critical analysis of literature and arts that describe science or scientific worldviews. As distinguished from almost all other positions in the study of science, the key finding of the multidisciplinary field of SSS is that “good research results” in science are less the rational outcome of following a strict scientific method than a contingent—sometimes even transient—creation of “knowledge” that arises from scientists’ ability to innovate conceptually, to manage the unexpected in the actual research setting, and to persuasively argue, within the specific rhetoric of science, for the validity of a scientist’s work.

Applied to biomedicine, this style of research examines how health-related sciences and clinical professions collaborate on disease problems even when their conceptions of diagnosis, origin, and social effects of a disease differ (cf. Epstein, 1996; Fleck, 1935/1979; Gilman, 1985; Latour, 1988; Mol, 2002; Patton, 1990, 1996; Swanson, Patton, McNamara, & Forsythe, 1992). Like SSS, the social study of medicine is intrinsically multi-method and transdisciplinary, requiring researchers to produce and examine a wide range of evidence gathered through multiple research strategies—such as discourse analysis of media and professional literature, historical research, and ethnographic study of clinical practice—in order to understand the information sources and interpretation styles used by policymakers and citizens when they evaluate proposals for managing public health problems (cf. Brandt, 1985; Patton, 2002; Shah, 2001; Starr, 1982). In addition, SSM explores specific ways clinicians, affected groups or individuals, and the public as a whole come to perceive a disease, how public perceptions in turn shape clinicians’ perceptions of affected patients, and how such perceptual complexes inform patients’ ways of seeking help (Goldstein, 2000; King, 2006; Martin, 1994; O’Connor, 1995). This approach takes into account both the clinician/scientist’s and the client’s perspective on the “medicine” and medical practice that unite them.

Applied in the case I explore here, the approach asks us to consider both the re-emergence of endocrinology in the context of HIV and the way its particular conceptual framework is taken up by people with HIV and the various people who serve them. From the perspective of SSM, the HIV metabolic disorders clinic is not simply the place where patients learn new information, but the scene of a subtle disciplinary shift within the medico-science concerned with AIDS. In this situation, and many other cases of mobile knowledge, clinicians’ and advocates’ professional values, personal motivations for working in the field of HIV,
and beliefs about their clients’/community’s capacity to comprehend scientific information underpin their strategy for working over the facts that are in play in each momentary encounter. Similarly, HIV-positive persons come from varying social and cultural milieus, which affects how they make treatment decisions utilizing multiple different (and often contradictory) understandings of health.

As a clinical ethnographer, I located my “field site” between two cultures: that of virology, exhibited in trace form in the mode of understanding presented by the patients, and that of endocrinology, represented in the information and presentational style of the doctor whom I studied. In my analysis of this space, I do not assume that medical knowledge is incremental, but rather suppose that different subdisciplines may represent rather different logics or, as Ludwig Fleck (1935/1979), from whom I have developed this framework (Patton, 1990, 2002), called them, “thoughtstyles,” enabling a rhetorical analysis of the moves in each subdiscipline as a marker of its underlying thoughtstyle. In the past, I have focused on reporters’ attempts to reconcile or move between competing logics. Here, I examine patients and doctors grappling with contrasting ways of understanding the body. For brevity, I schematize the differences between virology and endocrinology in Figure 2.

**Figure 2: Thoughtstyles of competing disciplines in HIV care**

<table>
<thead>
<tr>
<th>Virology</th>
<th>Endocrinology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linear narrative from infection to cure</td>
<td>Progress and regress in different organ systems</td>
</tr>
<tr>
<td>“Evil” from outside</td>
<td>Malfunctions from multiple sources—family, lifestyle, medications, disease</td>
</tr>
<tr>
<td>“Bullets” against the virus</td>
<td>Balance among elements</td>
</tr>
<tr>
<td>Additive logic—if one bullet fails, replace with another</td>
<td>Add less and more to find middle ground</td>
</tr>
<tr>
<td>Hit multiple targets</td>
<td>Try multiple equivalent solutions (diet, exercise, food supplements, medications)</td>
</tr>
<tr>
<td>Use strongest tolerated drug</td>
<td>Modify lifestyle before prescribing medications</td>
</tr>
<tr>
<td>Objective: maintain patient at “undetectable virus”</td>
<td>Objective: help patient stay within a range of balanced clinical measures and maintain a mainstream “healthy lifestyle” (exercise, no smoking, balanced diet, reduced stress)</td>
</tr>
</tbody>
</table>

The doctor I studied is well regarded among patients and described by colleagues as a good communicator. He is also a popular—almost charismatic—speaker at
educational sessions organized by the clinic and by local AIDS organizations. This clinician is from a working-class background and went to a major Canadian medical school. It was difficult to sort out whether it was this class difference, the lesser standing of his specialty, or both\(^6\) that made him appear deferential toward the scientific knowledge of the HIV doctors and researchers with whom he interacted in the clinic and in public presentations. He has practised in a number of major North American cities and has been in his present position for more than a decade. An outdoorsy sort of person, he is very fit and close in age to the majority of his patients. With his own evidence of middle-age spread, he is highly sympathetic toward his patients’ struggle with diet, exercise, and aging. Interestingly, while he often empathizes with their difficulty in maintaining a good diet, he is adamant about exercise, often telling clients that “exercise is better than any pill I can give you” (Field notes, 0062, 12/11/03). Thus, although he promotes some diet changes and refers patients to the nutritionists, he does not seem to believe this will make much difference for the majority of his patients. In one case, when a nutrition- and fitness-conscious patient asked if he could further improve his cholesterol values through diet, the doctor replied: “No, your numbers are caused by your medications.” On the other hand, I observed that he also trod lightly in relation to patients’ smoking habits. When I asked him why, without hesitation he offered a rationale that hints at his understanding of the specific fragilities of building trust with his patients:

MD: He needs to quit smoking. I tell them to quit but not very forcefully—if they don’t, they feel they’ve disappointed me. (Field notes, 0031, 06/27/03)

As I suggested in the introduction, when I look for the traces of virological thinking in the patients, I do not imagine that they had a complete or transparent understanding of what they had been told by doctors, read in magazines or online, or discussed with their friends. Rather, I hope to show a general consistency to the background logic brought by patients to their encounter with the HIV endocrinologist. But I first want to make two more notes here about other knowledge sources, with other potentially compounding investments and rhetorical forms, that are inflected in my field setting.

First, despite bans on direct-to-consumer pharmaceutical advertising in Canada, Canadians still see much of this type of advertising through American media beamed into the country by satellite. Thus, the individuals in my study may well have learned about their cholesterol and cholesterol medication options through popular media sources. It is far less common, however, for Canadian than for American medical consumers to actually get cholesterol tests: coming from the U.S., I was initially surprised that very few of the patients referred to the lipids clinic had ever had a cholesterol test before the one that resulted in their referral. Thus, as compared to the U.S., I found Canada to have fewer non-clinical and clinical moments in which to “understand lipids.”

Second, although AIDS organizations have diversified their client base since the early days of the epidemic, when they served primarily gay men, it is still uncommon to see anyone other than gay men actively participating in treatment information activities (attending talks and workshops, reading magazines
directed at HIV-positive persons, becoming volunteer information activists). As I discuss in my notes, there are complex issues related to how service for women evolved, and the implications of this history for recognition of HIV Metabolic Disorder are reported elsewhere (see Patton, in press).

Results

Traces of virology

The vast majority of the patients were very conversant with the terms related to HIV and with their HIV medications. More than a third carried a list of their medications, and several brought diaries that recorded their past medications, including when each drug was started and stopped. Some used the colour or function of the pill to identify it rather than its name, but the vast majority knew the trade names for their half-dozen or more medications. Acknowledging the expertise of his patients as a group, and expecting that a concordant discourse had emerged with seasoned follow-up patients, the doctor generally initiated discussion with the term “medication” and the individual trade names, and only switched to vernacular terms like “pills” or “your HIV medications” or “the one you take for asthma” in the face of communicative uncertainty. During follow-up visits, the doctor frequently read the list of the medications agreed upon in the previous visit from the patient’s chart and then asked if these had changed. Rarely were patients unsure about their HIV medications, but frequently they had not incorporated the names of their metabolic disorder–related medications, and the doctor would use trade names for HIV medications, but resort to terms like “the orange pill” or “the one you take for your diabetes” for the drugs he prescribed.

My use of the data collection form and ranking of patient knowledge, developed in relation to simple displays of patient knowledge and the subtle interactions over the register (vernacular versus technical terms) reflect my own expectation, parallel to the doctor’s, of what patients might know and how easily they might switch to, or incorporate, the new logic of endocrinology offered by the doctor. But while he and I converged in our expectations for patient performance, I was also able to see that his stock opening for intake exams, while apparently neutral, actually initiated the patients’ reorientation from virology to endocrinology.

The doctor always began the intake with the question “What is your understanding of why you are here?” This explicitly invited the patient to put their knowledge on the table and gave the doctor an opportunity to identify the appropriate register in which to move through the process of getting and giving (what was likely to be new) information. More generally, the question also invited a spatio-temporal narrative—“Why are you here?”—and many patients used this opening to provide an account of the chain of events within previous clinical spaces that had led to their presence at the clinic. There was subtle but consistent evidence of virology’s temporal narrative in these replies, since many patients tagged their cholesterol changes to the temporal framing of their viral progression and their changing medications, themselves implicitly constituted in a temporal sequence. To clinicians and laypeople highly familiar with the decade-long history of anti-HIV combination therapies, the names of combinations provide both
historical markers (X combination came into use at X time) and a gauge of personal progression (X combo is used early in the HIV progression, Y later, and Z—the most powerful and toxic—when there are no options left). One patient succinctly exhibited his assumption that he and the HIV endocrinologist share the same “time of AIDS” and that this knowledge of the spatio-temporal terms of viral progression and anti-retroviral development is all “common knowledge”: “Every time they get to the edge and have nothing left for me something new comes out” (Field notes, 0041, 07/31/03). I want to look more closely now at several sessions in which patients offered their logic and in which the doctor tried to introduce his.

Coming into the country: Meeting endocrinology head on

On intake, few patients had much understanding of the role of cholesterol or the significance of their test values. The following exchange, from a 25-minute intake with a 40-year-old White male referred from a general practice, is a sort of median case of first encounters with HIV endocrinology. The patient is a good historian of his medical life and presented these facts in a straight narrative sequence whose underlying logic was “time with HIV.” For example, he pinpointed his herpes zoster as the opportunistic infection that enabled his doctor to reveal his underlying HIV infection. Thus, while he appeared to have a solid basis for transacting new medical facts, his acquisition of medical concepts seemed largely to have taken place within the logical framework of virology. However, in general, I classified this patient as less fully acculturated to virology. Referred by a general practitioner, he has less facility with his HIV information than the patients who came via the city’s main HIV practices.

MD: What is your understanding of why you are here?

Pt: I guess it’s because of the high cholesterol.

MD: What pills are you taking?

Pt: The orange one. . . [thinks]. I usually have a list.

MD: [discussing the laboratory test values that resulted in the referral] It was because your triglycerides are too high.

Pt: What are those? I just know that whatever it was my doctor was looking at was 8.

MD: It’s down to 6 now. That’s very good.

[MD conducts family history and patient history and learns that the patient discovered he was HIV-positive in 1989, when he had “zoster,” which MD corrects to “herpes zoster.”]

Pt: I’m on high blood pressure medication.

MD: [Pt does not know medication name, but MD figures this out from the chart.] That is a beta blocker. I want to change you from that to something called an ACE inhibitor. I don’t think a young guy like you needs to be on beta blockers.
MD takes blood pressure: That’s really good, 110/65.
Pt: So maybe I can go off that altogether?
MD: I’d like to keep you on something since it has a protective value.
Pt [clearly not really understanding what protective value means]: Well, okay. (Field notes, 0048, 12/04/03)

In general, follow-up patients acclimatized to the concepts of endocrinology related to their lipids profiles. However, few used the terms “HDL,” “LDL,” and “triglycerides.” Rather, they called these “the good cholesterol” (HDL), “the bad cholesterol” (LDL), and “trics” or “that other one” (triglycerides). These patients had a good sense of what their target values were, but rarely accurately evaluated the magnitude of change in their numbers. The following 40ish-year-old White male follow-up patient is quite a card, but otherwise had a typical level of knowledge on follow-up. In the following exchange, aside from the banter with his doctor, we can see both parties negotiating what are to be the objective measures of successful treatment. Although the patient seemed not to initially understand magnitude changes represented through the mathematics underlying the lab values (and was fond of bargaining with his doctor!), he incorporated lab measures by the end of the 15-minute session.

MD [looking at the lab sheet]: I want to get your trics down.
Pt: What’s the range?
MD: They can go up to 100.
Pt: Well, if I’m 5, I’d say I’m doing pretty good!
MD: I like to see them around 3.

[After some discussion about treatment plan:]

MD: Exercise is better than any pill I can give you. What exercise do you do?
Pt [clicks his thumbs, meaning channel surfing]: What, do you want me to switch hands? Seriously, I pay $45 per month for the gym and I don’t go. Want to hit me? Someone should!

MD: If you walk every day you’ll see your belt go down one notch.
Pt: That’s good!

MD: I want to get you back in here in 8 months, not 6 like I said before. I’m going to give you the extra two months to bring your weight down. And your belt. This gives us something objective to shoot for. See you in July, one notch tighter on your belt.

Pt: And 3 [meaning on his triglycerides]! (Field notes, 0062, 12/11/03)

Based on their experience in the viral-logic world of HIV care, the patients have become accustomed to the idea that the antiviral medication goal is to render their HIV “undetectable,” which many refer to as “zero load.” (Indeed, the
HIV endocrinologist acceded to one patient’s use of this term, only to be corrected by the man’s wife, who said, “Not zero, ‘undetectable.’”) Of the many reframings of their bodies that their acculturation to endocrinology would entail, patients had a particularly difficult time accepting the idea that good and bad cholesterol vary inversely; that their treatment plan was not aimed at “zero” but at some other number; and that in many cases the relative relationship between “good,” “bad,” and “the other one” is an important measure of treatment progress. Indeed, the doctor was greeted with extreme skepticism when, after he had asserted particular values as the goal but the patient’s medication had not achieved these, the doctor was nevertheless satisfied that lowering the bad cholesterol was more important than raising the good cholesterol.

**Soft logic and uncertain solutions**

Coming into the country of endocrinology required more than simply learning new math. It also required patients to change their expectations about the doctor’s role in interpreting lab results and choosing medications. Early HIV drug regimens were very standardized—drugs were titrated to patients based on their body weight and CD-4 counts. As early treatments stopped working and new combination therapies emerged, there was also a sequence in which the various drugs were given. With the twin advances in HIV therapy and HIV substrain diagnosis—that is, with the rise of drugs that target different aspects of viral reproduction and phenotyping of viral strains—it has become possible to offer “boutique” treatment combinations. Clinicians now know which drug combination is most likely to be effective with which viral strains. Especially when an individual patient’s own virus has mutated, we now know what drugs are likely to work best next.

Ten or fifteen years ago, before this ability to tailor treatment to virus (notice: the treatment is matched to the *virus*, not to the person who hosts it), patients developed an expectation: everyone receives more or less the same drugs for the same lab values. Despite advanced knowledge of viral strains, this expectation has stuck: genotyping is just another test to determine which drug and in what dose: lab value(s) X = treatment Y. Although the possibility of metabolic side effects has entered into the equation, side effects—good and bad—are largely only allowed to influence HIV treatment decisions when two drug combinations are roughly equivalent in terms of viral suppression, but one has fewer side effects. Indeed, patients who stated that their AIDS docs had switched their drug combination to one that was more effective for them, but had metabolic side effects, had the expectation that the HIV endocrinologist had a list of standardized treatments to “fix” problems caused by the high-tech HIV medications.

In the following exchange, a 43-year-old White male highly familiar with HIV medications expresses ongoing confusion about the lipids-related lab values. In his session, he did not ask for a change in his current HIV medication (which would likely have resolved the lipids problem), but instead looked to the HIV endocrinologist to “add” another drug to the arsenal. When the MD seemed less than decisive about the efficacy of solving the HIV medication–driven change in triglycerides with the relatively wimpy tried-and-true standard treatment (a statin), the patient expressed perplexity at the lab values rather than at the reality that HIV endocrinology does not work via the hit-hard logic of HIV combination therapies.
The session got back on track when the MD offered the patient a place in a clinical trial, re-establishing himself as a scientist and the patient’s body as the scene of a potential scientific breakthrough. But at the end of the session, the patient seemed unconvinced about the new subdiscipline he had encountered and about the gradualist approach of its practitioner. The patient seemed to want to gain control over his treatment decisions by equalizing their knowledge: if only he understood the “numbers” he would be able to plug these into a standard formula and decide for himself what cholesterol drug to add to his combination therapy:

MD: What is your understanding of why you are here?

Pt [reports viral load and CD-4 counts. He says he started protease inhibitors in January]: I’m a poster boy for PI! [However, he has experienced a very great increase in triglycerides, which he and his doctor believe is driven by Retonavir.]

[MD reviews lab values.]

Pt: These are new numbers for me.

[MD places him on an entry-level statin and discusses the patient’s eligibility for the trial of a new medication.]

Pt [interested in the trial but says again]: I’m not used to these numbers.

(Quantitative notes, 0025, 06/27/03)

In a context in which the dominant narrative had the AIDS virus (or, “something bad from outside”) being reduced to near nothing (“killed”) with drugs (“something good from the outside”—even if toxic and rife with adverse effects), the HIV medication–prescribing doctor developed as more or less a technician, fitting drug combinations to lab values through a formula that admitted no art or judgment. This sense of the doctor as technician has been reinforced in highly publicized mass distribution programs (such as the World Health Organization’s “3X5”—three million people on anti-retrovirals by 2005) that rest on an assumption that HIV prescription, at least in “low resource” countries, is largely formulaic and no longer requires the level of doctoring perceived to exist in the postindustrial world.

By contrast, the lipids problem is “inside”—whatever its multiple and interacting causes—and can be “fixed” through a range of adjustments to dynamic health practices, including exercise, diet supplements, and pharmaceuticals. As opposed to virology, which has exhaustive means of identifying minute differences in viral strains and offers multiple drug combinations to kill it, endocrinology (or at least the aspects of the discipline seen by patients at the time of my research) appears to provide only rough guidelines to doctors. HIV endocrinology dramatically foregrounds clinical judgment about what treatments to offer, while state-of-the-art virological HIV treatment makes judgment appear to be an enactment of technical standards. Activist HIV patients conduct their own research and present their doctors with their options, asserting themselves as equally capable of “reading the literature.” Stepping into the world of endocrinology thus disrupts these patients’ expectation of how they will be able to participate in their own care.
On one hand, since so much of what they will be asked to do involves self-monitoring of lifestyle, they could see themselves as far more in control of their care than in situations where they must rely on tests and high-tech drugs. On the other hand, because HIV endocrinology rests so heavily on the old-fashioned art of clinical judgment, patients seem to experience themselves as lacking in the essential elements (first, information; second understanding) they need to even the playing field between the doctor’s knowledge and lay knowledge.

In the absence of a vocabulary sufficient to bridge the knowledge/power gap between patients’ work in the understanding of virology and the new demands of endocrinology, the doctor at the lipids clinic asserts his clinical judgment as a "strategy." In the following long-ish follow-up appointment with a roughly 45-year-old White male patient, the doctor emphasized clinical judgment by assigning the patient to the status of a highly particular “case” rather than a mere member of a class whose needs might be known in advance. However, the doctor’s approach failed, and he resorted to a logic like that of virology. Given this opening to his preferred logic, the patient dragged the doctor across the epistemological divide and tried to initiate a discussion of the lab values related to virology. The doctor rejected this conversation by juxtaposing the clinical judgment he had just displayed with what he implicitly evaluated as the simplistic, technocratic knowledge of HIV doctors:

[Pt has very low “good cholesterol” and is very disappointed that this has not improved more.]

Pt: Is there anything I can do with diet?

MD: My tactic is to drive the cholesterol as low as possible. That means the good gets very low, but that isn’t that big of an issue.

[Pt then asks if his T-cell counts are on the lab sheet. MD shows him the lab report and the parts related to metabolics.]

Pt: But do you have the T-cell or whatever numbers?

MD: I’ll let the T-cell counters deal with that! (Field notes, 0061, 12/11/03)

Patients brought a range of knowledge to their encounter with endocrinology in the clinical setting, and, especially at intake, the doctor had to be quick on his feet to guess what background knowledge was being put into play and whether a patient could remain in the higher register of communication (including technical terms and names) or would move to the vernacular. In the following 30-minute intake with a 45-year-old White male who is still working as a stone mason, we see the doctor engage in complex manoeuvres as he recovers from the mild insult by the patient that his knowledge was somehow less clear than that of the AIDS doctors with whom the patient is familiar. The doctor answered a range of questions not completely related to the patient’s metabolic problem, while trying to keep the session on track in the process of developing a treatment plan for severe dislipidemia. The first follow-up question raised by the patient fell squarely within the doctor’s specialty. But it was not clear that the patient understood that
cholesterol and wasting are parts of an underlying syndrome, or whether, bereft of a clear expectation of what the “lipids guy” could and could not do, he was simply going down his list of complaints:

MD: What is your understanding of why you are here?

Pt: I have high cholesterol and you are the lipids guy.

[MD collects patient history: Pt had gone off HIV meds four months, his lipids are okay, but his viral load increased. He resumed a combination therapy six months prior to this appointment, and his lipids declined, but not much. As the appointment unfolds, the patient reveals that he has seen an article in the newspaper about a new drug—Evandia.] (Field notes, 0026, 06/27/03)

As the intake unfolds, we discover that although the patient knew he was referred for his “high cholesterol,” he wanted to discuss another problem. But it was unclear how he related these bodily symptoms to his clinical signs: “Is there anything new in the wasting department?” As the doctor discussed current reconstructive surgery options to address facial wasting, it became clear that this frank and physical expression of his long-term HIV infection was of far more concern to the patient than the lab values that had brought him to the clinic. While the doctor was also concerned about wasting—especially the full-body wasting that drops people below a life-sustaining BMI (Body Mass Index)—he was more concerned with this patient’s cholesterol. The doctor tried to move the conversation back to the issue of the new drug.

MD: I’d be willing to put you on that. . .

[MD addresses the patient’s concern about fatigue he has experienced on statins—drugs like Lipitor. The patient has lots of questions about how the new drug works, and he is especially concerned about liver toxicity.] (Field notes, 0026, 06/27/03)

Initially, I took this concern about liver toxicity to indicate that this was a highly and widely educated patient. However, as I observed more patients asking about liver problems, and as I saw the doctor reply to these concerns compassionately but with a subtle cue that this was not really a reasonable question, I realized that the concern with one’s liver was another sign of the depth of patients’ acculturation to the concerns of HIV treatment. Having spent many years on highly toxic drugs, they had learned to exercise great concern over their livers. Many HIV patients undergo routine liver function tests as part of the HIV medication treatment regimes, so they know they should always query their doctors about liver complications with their medications. Nevertheless, I don’t believe many had any concrete idea of what their liver actually does. In the closing moments of this transaction, the patient pushed the doctor to distinguish between a lipid-control medication that metabolized in the liver and “the other” drugs. Guessing that the patient had some understanding of the liver as a cleansing organ, the doctor resorted to this explanation of the action of the new class of drugs:

MD: It works in the gut—the liver never sees it.
Pt: Where does it [the cholesterol] go?

MD [now trying to move the appointment along]: You just poop it out.
(Field notes, 0026, 06/27/03)

Recovering alternative frameworks: Offering patients new science for old logics
In these few examples I have tried to demonstrate the limitations that one thoughtstyle—virology—puts on another—endocrinology—as medical facts are relayed in one clinical setting. Much of the doctor-patient communication literature presumes that doctors have more power than their patients to impose meaning on the facts they present. But I have suggested that the HIV endocrinologist’s power to assert his expertise either through imparting critical information or through the exhibition of his clinical judgment is importantly limited by the patients’ own prior incorporation into another medical discipline’s understanding of causal relations, treatment strategies, and the role of the doctor. But there are other limits on the polysemy of medical information, some of which I have mentioned (media, subcultural knowledge), and one I want to raise here.

It has been important to me to emphasize the fundamental difference between virology and endocrinology as the difference between the magic bullet orientation of the former and the holism of the latter (Patton, 2007). In a solid minority of cases, patients highly acculturated to virology seemed to fairly quickly take up the more holistic concepts of endocrinology. Consistent with my social studies in medicine approach, I have not evaluated these as cases of smarter patients or better explanations by the doctor. Instead, I see this as evidence of the complexity of knowledge of patients who, however well trained as HIV patients, also already hold mobile beliefs and engage in more complex practices of care than their HIV medicine–prescribing doctors may realize. In the following interview with an unusually articulate patient, we see quick movement among different approaches to medicine, which he has incorporated into his own—apparently uncontradictory—system of care. This patient is a public figure who had just entered a clinical trial to repair the damage that lipodystrophy had caused to his face.

Pt [seemingly embarrassed about getting facial enhancement]: I’ve felt so good and had so few problems; if I can make myself feel better and keep going, why not? (Field notes, 0039, 07/24/03)

After a long discussion about green teas and their potential value for cholesterol control, he said: “The ancients incorporated Western medicine; Westerners should incorporate these traditions. Along with salmon oil and the other stuff.” After some discussion about lab values, he offered the following assessment, which calibrates the differences between virology and endocrinology and between “medicine” and “well-being” by constructing the patient himself as a clinical “case” in which the most important element seems to be his own subjective state, an assertion of his self-knowledge over that of both of his doctors:

Pt [makes transition from chat]: But about my case, Crestor is fabulous, my viral load is undetectable, and I feel great. (Field notes, 0039, 07/24/03)

Through their encounters with various forms of biomedicine and their “complements,” each with their own interrelationship between forms of clinical judg-
ment and prescription, and in the context of their other, prior knowledge of their bodies, patients adopt their own form of judgment, which gives shape to the medical facts they receive. Sometimes they see themselves as a “case,” other times as a “class”; sometimes their bodies are a battleground on which harsh drugs attack an offending invader, sometimes they are delicate dancers in a quest to find balance among integrated organ systems. But however multiple, mobile, and complex are patients’ understandings of their body and systems of care, they are not unlimited, nor are they idiosyncratic results of infinitely complex lives. By asking not “Where does information come from?” but rather “What logics do facts require and implement?” I hope to have sketched out an approach to understanding how information moves within and across multiple power gradients and, especially, how it is that science, produced at considerable remove from where it is deployed, maintains the status of its original producers, even when the “facts” make their final appearance in the hands of lay users.

Notes
1. This study was funded through a grant from the SSHRC Small Institutional Grants Programme, and through the William and Ada Isabelle Steel Fund, and was reviewed and approved by the Simon Fraser University Research Ethics Review Board as well as the ethics review board of Providence Healthcare.

2. This drift from diagnosing symptoms that first appear patently on the patient’s body to the use of clinical and laboratory signs that later enable the clinician to demonstrate the interrelated signs and symptoms common to a “disorder” repeats the history of “AIDS” and almost all other twentieth-century diagnoses. In my original research plan I admit that it was no stretch to imagine I would find virology and endocrinology jostling for position. But it was sheer luck to have been there exactly at the moment when the list of “adverse effects” of HIV medications and the inexorably unfolding tale of long-term wear and tear by the virus itself were deemed to be a single “problem,” later redefined as HIV Metabolic Disorder. But that is a story complex enough to merit treatment elsewhere. Fleshing it out would require more detail about how individual doctors from different medical subspecialties came to recognize various symptoms and signs; how they interpreted them; how the rapid output of research reports and the resituating of scientific and clinical discussion from subspecialty journals and the adverse events conferences to standalone HIV Metabolic Disorder publications and conference sessions came about; and how the very rapid invention of a new market for existing and emerging “cholesterol” and “diabetes” drugs all came together as the medium in which patient and specialist now meet.

3. Because of the complex history of service provision in the city, a substantial portion of women with HIV go to a women’s clinic that has its own endocrinologist and nutritionist. The women interviewed in my study did not routinely get their care at that women’s clinic, however, and relied instead on the local providers in their impoverished neighbourhood. Among those providers are research clinicians whose primary work is in the HIV unit in the hospital that houses the clinic I studied and report on here. I deal with the complex biological, historical, and social factors that have resulted in considerable sex differences in the side effects of HIV in another essay, “Unexpected Side-Effects: Uncovering Local Impacts of Knowledge Proliferation about HIV Metabolic Disorder in Two Distinct Populations,” in Knowledge Production and Translation in a Globalized Era: Issues and Implications for Women’s Health (Patton, in press).

4. I did not have access to referral information beyond what was described by patients in their appointments. However, it was my impression that the level of understanding about HIV among general practitioners in the region was high enough that when faced with abnormal blood sugars or cholesterol counts, they understood that this was not necessarily independent of their patients’ HIV and required at least a preliminary assessment by an HIV endocrinology specialist.

5. Fleck argues that scientists undergo a long process of becoming acculturated to the “style of thought” of their specialty. However, when they actually practise their science, they draw upon logics from outside that specialty. This suggests that while “expert knowledge” has a specific form and culture, it is more hybrid when put into play. I have interpreted Fleck—aligning his history of syphilis and its treatment with Foucault’s Birth of the Clinic (1963/1973) and Archeology
of Knowledge (1972/1982) as well as with Pierre Bourdieu’s work on expertise, especially in
Academic Discourse (1965/1994), State Nobility (1989/1996), and Science of Science and
Reflexivity (2004)—to suggest that it is possible to roughly outline the “thoughtstyle” of a med-
cal discipline through analysis of textbooks, conferences, and clinicians’ practice.

6. In both Academic Discourse (1965/1994) and State Nobility (1989/1996), Pierre Bourdieu con-
vincingly demonstrates that the “aptitude” for various academic disciplines is linked to sociocul-
tural class. He shows that professionals in disciplines such as literature and philosophy “prefer”
creativity and expansive thinking, qualities cultivated in and valued by the upper classes, while
areas such as geography and economics rely on systematic and organized thinking precisely at the
cost of flights of fancy, qualities more nearly associated with the lower middle classes. I see no
reason to imagine why the subdisciplines within medicine—however much Canada tries to level
class within the medical training system—would not also follow along in parallel with class dif-
ferences cultivated in society at large. Certainly, there is a well-documented sex difference among
those who practise clinical subspecialties: women predominate in the fields that require traits cul-
tivated in women (family practice, paediatrics), while men predominate in fields that require mas-
culine qualities (surgery, emergency).

7. Here I am echoing the work of Alvan R. Feinstein (1967), who, more than 25 years ago, gained
renown for his highly regarded work on clinical judgment. Using a systematic approach to ana-
lyzing the “parameters” involved in clinicians’ decision-making processes, Feinstein articulated a
researchable model of clinical judgment that could be linked with clinical outcomes. In a 1994
article (Feinstein, 1994) written to counter the emerging movement that would soon be called
“evidence-based decision making,” he contested what emerged as the quantitative methods used
to, in his view and mine, eliminate clinical judgment from clinical practice by using the idealized
model of the clinical trial as the model for clinical practice. There is a much longer history to this
dance between clinical judgment and attempts to define and regulate the administration of phar-
aceuticals. Kane Race (2005) argues convincingly that from the early twentieth century on, the
very idea of scientific trials of pharmaceuticals has rested on the assumption that doctors have
poor judgment about what drugs to give a patient. And of course Michel Foucault (1963/1973)
and Georges Canguilhem (1978/1991) have detailed the longer history that underwrites both of
these authors’ assessments of the role of doctors in the history of care.

References


