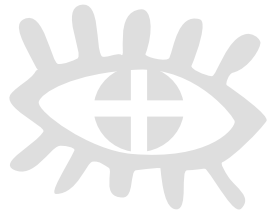


MAKING
CARE
VISIBLE

ANTIRETROVIRAL THERAPY
AND THE HEALTH WORK OF
PEOPLE LIVING WITH HIV/AIDS

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MAKING CARE VISIBLE



**ANTIRETROVIRAL
THERAPY AND THE
HEALTH WORK OF
PEOPLE LIVING
WITH HIV/AIDS**

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This report is dedicated to George W. Smith (1935–1994), person living with HIV/AIDS, mentor, academic and activist. George was a pioneer in community-based HIV/AIDS research in Canada. At countless AIDS ACTION NOW! meetings, he reminded us that the fight against AIDS would be won through a combination of documents and demonstrations.

Making Care Visible:
Antiretroviral Therapy and the Health Work of People Living with HIV/AIDS

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TABLE OF CONTENTS
ACKNOWLEDGEMENTS *ix***INTRODUCTION** • *Eric Mykhalovskiy, Liza McCoy xi*1. Mapping the work PHAs do looking after their health *xii*2. Locating PHA's health work in its institutional context *xiii*How we conducted our research *xiv*How to use this report *xviii*Chapter one: Dealing with doctors *xix*Chapter two: Understanding the social character
of treatment decision making *xx*Chapter three: From compliance to medication practice *xx*Chapter four: The work of information about
HIV/AIDS and its treatments *xx***CHAPTER ONE****DEALING WITH DOCTORS** • *Liza McCoy 1*From patients' satisfaction to patients' work *1*Which doctor? Managing the division of labour *3*The medical visit *7*Getting one's topics covered *8*"Making a scene" *10*Getting information from the doctor *12*Educating the doctor *13*Monitoring symptoms and the diagnostic process *17*Passive mutiny *19*Building a relationship *21*Finding doctors *23*Finding an appropriate doctor *23*Losing doctors *27*Evaluating doctors *28*Respect/trust/caring – being seen as a whole person *30*Acceptance of living practices, treatment choices *31*Taking time to listen, to explain things *34*Conclusion *36*

CHAPTER TWO

UNDERSTANDING THE SOCIAL CHARACTER**OF TREATMENT DECISION MAKING** • *Eric Mykhalovskiy* 37

Introduction	37
Complicating the rational decision-making framework	38
The treatment decision-making discourse and social science research on health	38
Other social sites where the treatment decision-making discourse is expressed	41
The treatment decision-making discourse as articulated by our research participants	42
Problems with the treatment decision-making discourse	43
Taking institutional relations of power into account	44
Compulsion vs. choice	45
The institutional relations of compulsion and choice	46
Exploring the temporal dimensions of coming to be on antiretroviral therapy	49
The ongoing nature of treatment decision making	51
The forms of temporal work involved in coming to be on antiretroviral therapy	53
The work of “making time”	54
The work of “taking time”	55
The work of “informal learning”	58
Creating embodied knowledge	60
Thinking and acting in light of the future	61
Conclusion	63

CHAPTER THREE

FROM COMPLIANCE TO MEDICAL PRACTICE• *Michael Bresalier, Liza McCoy, Eric Mykhalovskiy* 65

Introduction	65
Overview of the chapter	66
Highly active antiretroviral therapy (HAART) and the issue of compliance	67
Moving beyond compliance research – medication practice	72
Medication practice	72
Obtaining medications	72
Realizing the medication day	75
Completing the medication sequence	79
Emotional work: coaching the reluctant self	81
The social character of medication practice	83
Timing, place and the out-of-control body	85
The compliance discourse and medication practice	86

Adjusting the medication schedule – as planned, as lived	87
Summary	89
Missing medication	89
Forgetting	90
Active missing	91
Missing doses and resistance to a regimented life	92
The changing force of compliance discourse	93
Going off medication	95
Compliance, embodied knowledge and pleasure	95
Guilt and going off medications	98
The social circumstances of going off antiretroviral therapy	99
Coping with emotions	99
Family and personal relationships	100
Drug and alcohol use	101
Summary	102

CHAPTER FOUR

SYNTHESIZING INFORMATION ABOUT

HIV/AIDS AND ITS TREATMENT • *Darien Taylor* 105

Introduction	105
Points on the continuum of seeking treatment information	107
How much information is too much information?	109
Assessing the reliability of information sources	111
Creating a community-based language of treatment information	114
“Information overload”	115
Dealing with conflicting or inconclusive information	115
What works for people with HIV/AIDS in treatment information	116
Personal observation as a source of treatment information:	
seeing is believing	117
Personal experience in the delivery of treatment information	118
Conclusion	121

CONCLUSION • *Eric Mykhalovskiy, Darien Taylor* 123

WORKS CITED 127

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INTRODUCTION

ERIC MYKHALOVSKIY
LIZA MCCOY

This report is about the work that people living with HIV/AIDS (PHAs) do to look after their health. Its particular focus is how that work is shaped by and linked with institutional relations involving the health-care system, AIDS service organizations (ASOs) and social service agencies, among others.

The efforts that PHAs undertake to maintain their health have been recognized and supported by AIDS service organizations for a number of years. ASOs have been an important organizational base for challenging traditional medical authority and popularizing models of empowerment that encourage PHAs to take an active role in the processes and decisions that affect their health. In Canada, over the past two decades, ASOs have provided treatment information, health counselling, and other resources that support PHAs' efforts to look after or "manage" their health.

More recently, an emphasis on promoting individual responsibility for health has emerged in health policy and academic circles (Armstrong et al. 2000; Feldberg and Vipond 2000). With heightened cost control efforts in health care and the cutback of hospital and related services, PHAs and others who enter into the health-care system are expected to take greater responsibility for their health and care. They are encouraged to become eager consumers of health information and to take an active role in treatment decisions. In some instances, they or their caregivers are required to pick up the slack where formal services are no longer available or provided.

Our research emerges out of the tensions associated with encouraging PHAs to actively manage their health. On one hand we recognize the practical value and historic importance of community-based efforts to promote

empowerment among PHAs. The knowledge that AIDS activists, PHAs and those who work in ASOs have developed about clinical trials, the organization of health-care services and the clinical care of AIDS has certainly improved the quality of health care PHAs receive. On the other hand, we are wary about what we see as a more general trend within health care to promote individual responsibility for health and care. Particularly troubling is how such calls have emerged as part of efforts to introduce privatization, market relations and consumerism into Canada's publicly-funded health-care system.

We have written this report with a view to contributing to ongoing dialogue in ASOs about how to help PHAs maintain their health. ASOs face numerous organizational challenges. Among them is the way community-based initiatives intersect with and feed into broader institutional transformations in the organization of health services. For example, what is one to make of the way ASOs may be implicated in the transformation and decline of formal health services by contributing to a language and set of practices that encourage PHAs to assume individual responsibility for their health? This report is not set up to provide easy answers to organizational dilemmas of this sort. Rather, we hope it acts as a resource for thinking about how ASOs might continue to support the health work of PHAs in the context of a rapidly changing health-care landscape.

What makes this report unique is how it offers a careful, in-depth look at PHAs' health work that originates in their experiences and ways of talking about that work. People living with HIV/AIDS often say that looking after their health is a full-time effort. Readers who are interested in what that effort involves and how it is shaped socially and institutionally will find the report of interest. Two broad features of our report are crucial for how it can be used in thinking about supporting the health work of PHAs.

1. MAPPING THE WORK PHAS DO LOOKING AFTER THEIR HEALTH

One way we envisage this report being used is as a kind of map or overview of the range of activity that PHAs engage in as part of looking after their health. We want to make visible the often invisible work that PHAs do around their health. Our report does not, in of itself, provide information to PHAs about how to better manage their health; that is the work of ASOs and health-care providers. Nor have we been interested in making judgments about what constitutes good or bad health work on the part of PHAs. Instead, we have gone about creating a picture of the range of practices and activities that PHAs engage in as part of looking after themselves.

This has involved starting our research from the experiences that PHAs have of doing health work, rather than beginning with the forms of activity seen by physicians, health policy makers or others as relevant to maintaining health. It has also meant speaking with PHAs from varied life

circumstances that shape health work including, among others, those who live in prisons, women looking after children, people who live in rural areas, Black Canadians, urban Aboriginal people, gay men, and people on social assistance.

In the end, we did not address the full range of health work that PHAs spoke about in our interviews with them but, instead, focused on the areas that they themselves emphasized. In effect, this meant the array of activities that PHAs undertake as part of entering the formal health-care system, including developing relationships with physicians and dealing with combination antiretroviral therapy. Our report explores this health work under four sections: “Dealing with Doctors,” “Understanding the Social Character of Treatment Decision Making,” “From Compliance to Medication Practice,” and “Synthesizing Information about HIV/AIDS and Its Treatment.”

Rather than simply describing how PHAs look after their health, we have wanted to explore how this work is shaped socially and institutionally. A comprehensive understanding of PHAs’ health work is not reached simply by describing the range of what PHAs do. Nor does it follow from the assumption that the kind of health work PHAs engage in is a consequence of their individual preferences or personalities alone. Instead, thinking about how to support the work that PHAs do looking after their health requires an attentiveness to how that work is shaped within a set of institutional relations.

When PHAs receive treatment information from ASOs, when they make appointments with physicians or deliberate about taking HIV medications, they enter, from the particularities of their daily life circumstances, the work processes and routines of various overlapping institutional sites including the health care system, social service agencies, the pharmaceutical industry, and AIDS service organizations. They also engage with formal systems of thought about the care of the body and the self, realized in notions such as compliance and rational decision making.

In exploring the health work of PHAs, we have endeavoured to locate their efforts in this complex of institutional practices and forms of knowledge, for it shapes and limits the possibilities of their activities. Thus, as part of our discussion we address how the health work of PHAs occurs within particular institutional contexts such as prison or the welfare system. We explore how, in looking after themselves, PHAs enter into the work processes of doctors and other health-care professionals. We examine how their health work is hooked into services provided by ASOs and is organized within particular class, gender, and race relations. An important focus of the report is how a good deal of the work PHAs do to look after

2. LOCATING PHAS’ HEALTH WORK IN ITS INSTITUTIONAL CONTEXT

their health is occasioned by the availability of new forms of antiretroviral therapy. In the end, the “map” of health work that our research presents not only describes the activities that PHAs engage in, but explores how those activities take shape within a web of institutional practices.

HOW WE CONDUCTED OUR RESEARCH

Our research was conducted as a community-based institutional ethnography of the health work done by people living with HIV/AIDS. Institutional ethnography is part of a small but growing body of community-based AIDS research (Lévy, Foley and Forer 1994; Mykhalovskiy and Smith 1994; Trussler and Marchand 1997, 1998; Pawluch et al. 2000) that has been produced in Canada over the past decade. Amidst the enthusiasm for such research, the question of what makes it community-based has not been answered satisfactorily. In this section we clarify our understanding of the community-based character of our research. We also discuss our use of institutional ethnography as a method of investigation and describe some of the key features of our research process.

No single activity or convention of research design produced our project as a community-based research initiative. Simply having a community advisory committee or getting feedback from PHAs about our work in progress did not make it happen. In our case, trying to produce community-based research involved organizing activities over the course of our project in ways that might produce a knowledge *for* PHAs. From this perspective, making community-based research is a political question. It is a matter of how the political character of the knowledge one makes – what it speaks, for whom it is intended, where it goes and what it can do there – follows from the overall research process one undertakes, including how research questions come to be defined, the methods of investigation used and the kind of research texts one produces.

Our use of institutional ethnography as a research strategy is crucial to our efforts to produce a knowledge that might go to work for PHAs and those who support them. Institutional ethnography is a way of doing social research developed by feminist sociologist Dorothy Smith (1987). It grew out of the consciousness-raising work of the 1960s and '70s North American feminist movement and has been drawn on in social research on AIDS and other health issues in Canada (Smith, G. 1990; Campbell et al. 1998; Kinsman 1996).

One of the defining features of an institutional ethnographic study is that inquiry begins not from the categories and concerns of academic research, but from the actual day-to-day experiences of people. Rather than simply describing those experiences, as is done in conventional ethnographic research, institutional ethnography seeks to explore how people's experiences are shaped by broad social forces. The goal of institutional

ethnographic research is to make visible how our day-to-day worlds are connected with events and activities that occur outside their immediate purview, but that enter into how our worlds come into being.

In exploring the health work of PHAs, we have found an interesting fit between institutional ethnographic strategies of investigation and the broad goal of producing community-based knowledge. For one thing, institutional ethnography repeatedly returns us to the ground of real people's experiences of the world. Rather than creating a knowledge that begins from and speaks to the world of professional academic discourse, institutional ethnography has invited us to stay focused on what happens among PHAs in their daily lives. And its emphasis on exploring how people's experiences are shaped by social, economic and institutional relations has helped us avoid the objectifying impulse of much social science research.

In practice, our efforts to produce a knowledge that might bear upon what gets done in ASOs to support PHAs' health work has also been made possible by the particularities of who we are as researchers and how we have worked together. Our research does not arise externally to ASOs and communities of PHAs. Our project was not organized as a university-based initiative for which partnership was sought with ASOs or other community agencies. Instead, it began with a group of people variously connected to ASOs and communities of PHAs coming together to collectively do research on HIV/AIDS issues. While some of us are based in universities, our research project did not involve a division of labour where academics do the research and community workers provide advice or access to the field. We worked together as full collaborators and researchers. Our research team of eight people includes a mix of men and women of varied sexual orientation. Some of us are HIV-positive and some of us are HIV-negative. Most have years of experience with ASOs as staff, volunteers, board members, and/or clients. Our collective experience with ASOs has permitted us to operate from an insider's perspective, in the sense of having a practical knowledge of the work of ASOs and of the dilemmas PHAs face in looking after their health.

To supplement this knowledge, and in keeping with the principles of institutional ethnography, we carried out consultations with representatives from ASOs and health clinics in the early stages of our research project.¹ These provided valuable insights into the research and information needs of ASOs that helped structure the writing of our report and the dissemination of our research. Many of the people we spoke with had a dual

1. We held consultations with staff and volunteers from: the AIDS Committee of Toronto, the Toronto PWA Foundation, the HIV Clinic at Sunnybrook Health Sciences Centre, the Wellesley Hospital, Voices of Positive Women, the Community AIDS Treatment Information Exchange, Hassle Free Clinic, the Black Coalition for AIDS Prevention, the Teresa Group, the Prisoners HIV/AIDS Support Action Network and Kingston HIV/AIDS Regional Services.

location as both PHAs and individuals working in ASOs to support PHAs' health. Their comments offered us a first formal glimpse at the interface of PHAs' efforts to look after themselves and the activities of ASOs. They helped set our research off on the "right foot," orienting our subsequent efforts to areas of health work that PHAs undertake. Through our consultations we learned about the importance of antiretroviral therapy for the health work of PHAs. We also began identifying particular social circumstances, such as dealing with depression, that hold consequences for how PHAs' health work is carried out.

Given our interest in producing community-based knowledge about HIV/AIDS, we based our study on research techniques that permit PHAs to speak about what is actually involved for them in looking after their health. Rather than heavily structuring or limiting the possibilities of PHAs' self-expression in the research process through, for example, the use of a questionnaire, we chose techniques that produce dialogue both among participants and between participants and researchers. Our study was conducted between 1997 and 1999, and is based on 16 focus groups and 21 interviews, involving a total of 79 PHAs (57 men and 22 women, with the latter group including two male-to-female transgendered people.)

Our research began with a series of focus groups. Focus groups bring together people to talk about a situation or event that they have in common, but about which they hold different opinions or have had different experiences (Schatzman and Strauss 1973). Focus groups are well suited to research where the purpose is not to investigate individuals themselves, but the situation they share. They also help shift power away from the researcher and toward the participants, who can play a strong role in generating topics and shaping the direction of the discussion to address their concerns. The focus groups we conducted encouraged a diversity of opinion and allowed participants to share and contrast their experiences of looking after their health.

The process we began with focus groups was carried forward with a series of one-on-one, in-depth, open-ended interviews. In conducting interviews, we did not study individual participants, but focused on how their experiences of health work are socially and institutionally shaped. Our interviews added to our focus group discussions by deepening our investigation of the areas of experience identified as relevant by focus group participants. They also provided a more private context in which participants could discuss personal and confidential matters about their health.

In selecting participants for our research we wanted to cover a broad range of experiences and social circumstances that might shape the work of looking after one's health in significant ways. We did not try to produce a representative sample corresponding by age, gender and other characteristics to the total population of PHAs. We were not looking for "types" of peo-

ple in a categorical sense, but for types of experience that our consultations suggested were relevant to the work of looking after one's health with HIV. So, for example, we organized a focus group with people who were living on welfare in assisted housing, since poverty and unstable housing form particular circumstances that shape how health work is carried out. We also spoke with a group of men who were in jail, a group of women who were looking after children and families, several groups of people who live in rural/small city areas outside of Toronto, two groups of Aboriginal people, and a group of Black Canadians, among others. We also carried out focus groups with gay male PHAs.² Given our interest in mapping out the range of work PHAs do looking after their health we made a point of focusing on voices and experiences that differ from those of gay white middle-class male PHAs who are already well connected with ASOs and whose experience, as a result, is already well understood within these organizations.

Our focus groups and one-to-one interviews were also organized around experiences to do with treatment. We recruited people who were on combination antiretroviral therapy, people who had been on such therapy but who had gone off, and people who had never taken it. Even so, we made a point of trying to represent particular experiences we thought we needed to learn about. For example, we sought out people who had recently been diagnosed, people who were coping with depression and people who inject drugs.

Our conversations with PHAs in focus groups and interviews were conceptually organized around the notion of health work. By health work we mean all the mental, emotional and physical activities people undertake in their efforts to look after themselves. Health work is a concept that emphasizes human agency and the active part people play in looking after their health. We orient to it as an empirically "empty" category – one that does not impose a definition on particular lived realities, but waits to be filled as we learn, from the PHAs who do it, what the work of looking after one's health involves, as it is carried out in the classed, gendered and racialized contexts of present day Ontario.

We used the term health work as a conceptual reminder; it was something we drew on to help facilitate conversations with PHAs that focused on what they actually did to look after their health. In practice, we soon learned that using phrases such as "the work of looking after your health" was not always successful in our conversations with research participants. They tended to invoke a moral frame on the discussion that suggested PHAs should work at their health or that certain forms of activity constitute work while others do not. So we avoided using the term. Over time, we

2. Many informants did not, of course, fit into only one of our experience categories. Thus, for example, women and people of colour were dispersed throughout our groups in addition to taking part in groups exclusively focused on their experience *as* women or *as* people of colour.

developed a focus group and interview strategy that centered our conversations on a series of topics to do with looking after one's health. We talked about PHAs' experiences with medical treatments (side effects, pill-taking, etc.), their experiences dealing with doctors (finding a physician, developing a relationship with a physician, etc.), making treatment decisions (whether to take antiretroviral therapy or not, how people started, stopped or switched medications, etc.), learning about HIV medications (finding information, selecting what is useful, information overload, etc.), and securing resources such as housing and financial assistance.

All of our focus groups and interviews were tape-recorded and transcribed. The text was also entered into a software program for managing qualitative research data called HyperResearch. We analyzed the transcripts collectively, meeting over a number of months to discuss and make sense of all of our data. Members of the research team reviewed and summarized transcripts. We also read documents produced through HyperResearch that gathered together all the comments participants made about each of the main topics of our conversations. In exploring the data we tried to carefully identify the range of activity that PHAs engaged in as part of their health work. We tried to make sense of how those activities varied and were shaped by the particular social location and circumstances of PHAs' lives. We also sought to understand how their health work was shaped by the institutional organization of the health-care system.

While our report is based on a collective analysis developed by all research team members, each chapter has different authors. This approach preserves our common analytic direction, while permitting stylistic variation and individual points of emphasis.

HOW TO USE THIS REPORT

Research reports often sit on shelves collecting dust; we want this one to work differently. Our hope is that *Making Care Visible: Antiretroviral Therapy and the Health Work of People Living with HIV/AIDS* contributes to reflective practice among ASOs and beyond that to other community-based organizations currently working to empower people with chronic illnesses. We do not see the report as a source of expertise that provides solutions to specific problems. Instead we view it as a document that opens up discussion and that questions taken-for-granted assumptions about the health work of PHAs and how to support it.

This is not a short and snappy report; in fact it is rather long. It does not offer empirical or numerically-based facts in the manner typical of much research. Nor will readers find in it boxes, statistics, graphs or other devices that summarize or reduce the complexity of our research findings.

By contrast, the report is heavily narrative – it is structured as a display and commentary of PHAs' talk about their health work, around

which we have developed an analysis of how this work is shaped institutionally and socially. We have tried to keep PHAs' stories about their health work intact in our discussion, reasoning that a careful account of what this work involves in its variety and complexity can be a route to rethinking how best to support it. This means using extensive extracts from interviews and focus groups, which sometimes take the form of a conversation involving two or more speakers. In presenting this material, we adhere to the following simple conventions: "I" stands for interviewer and "P" stands for research participant. When multiple participants are speaking, they are distinguished as P1, P2, etc., according to the order in which they speak.

An important note about confidentiality: When people talk about their health work, telling their experience and stories in their own terms, they commonly refer by name to the people (doctors, friends, ASO staff) who are part of that experience. We promised our research participants that we would replace all such names with pseudonyms in our transcripts and also in the final report, and we have done so. We have also deleted the names of hospitals and clinics, and in some quotations we have deleted the names of ASOs, cities and provinces, where we felt that such information might identify the speaker.

While the full potential of the report is realized from reading it in its entirety, we have written chapters that can stand alone in order to meet the needs of readers whose interests are more focused on specific topics. To help orient readers to the contents of the report, we offer a summary here of the key features of each of its main chapters

When people living with HIV/AIDS seek medical care, they necessarily engage with the work processes of doctors and the routine organization of health-care delivery in their province. This chapter examines the work PHAs do around and with their doctors, as recounted by PHAs themselves. It also presents PHAs' assessments of their doctors' communicative and practice styles, with a focus on what our participants considered "best practices." The health work discussed in this chapter includes:

- finding appropriate doctors
- fitting oneself into the institutional organization of medical specialties
- trying to get one's needs met and topics covered during the medical consultation
- educating doctors about HIV
- monitoring the diagnostic process
- coping with insults, confusion, and discrimination
- interpreting the doctor's behaviour and building a relationship.

CHAPTER ONE: DEALING WITH DOCTORS

**CHAPTER TWO:
UNDERSTANDING THE
SOCIAL CHARACTER
OF TREATMENT
DECISION MAKING**

This chapter raises questions about the use of a rational decision-making framework for understanding how PHAs come to take antiretroviral therapy. It offers an alternative that explores how PHAs come to be on antiretroviral therapy as a social process. The chapter emphasizes:

- the institutional relations of power that shape how PHAs come to take antiretroviral therapy
- the forms of compulsion that PHAs experience as part of starting medical treatment
- the temporal character of coming to be on antiretroviral therapy including the work of “making” and “taking time”
- the informal learning and embodied knowledge that PHAs draw on and participate in as part of going on antiretroviral therapy.

**CHAPTER THREE:
FROM COMPLIANCE TO
MEDICATION PRACTICE**

Most PHAs in Canada follow some kind of medication regimen that can involve taking large numbers of pills daily, often according to a strict schedule. This chapter examines the work of actually carrying out such a regimen, as described by our research participants. The approach we take substitutes the neutral and comprehensive term “medication practice” for the morally-laden and descriptively-limited term “compliance,” in order to focus on the range of work people do around their medication.

The chapter examines:

- how the discourse of compliance functions as a normative framework that some PHAs draw on in their medication practice
- the invisible work that goes into “following instructions”
- the emotional and social character of being on antiretroviral therapy
- PHAs’ processes of adjusting or simplifying medication schedules
- missing doses and stopping antiretroviral therapy as purposeful activity
- the clash between embodied and biomedical ways of knowing health
- social circumstances of daily life that make it difficult to carry out a drug regimen.

**CHAPTER FOUR:
THE WORK OF
INFORMATION ABOUT
HIV/AIDS AND ITS
TREATMENT**

The dissemination of information about HIV/AIDS and its treatment undertaken by or for communities has operated under a number of assumptions about literacy, the role of information in decision making and the relationship of information to a comprehensive sense of well-being. This chapter details the work done by PHAs in relation to

HIV/AIDS treatment information and subjects these ruling assumptions to scrutiny. Research participants describe the work that they do in order to understand complex medical information, assess conflicting information about HIV/AIDS, and use general information about HIV/AIDS to come to an understanding of their particular situation. In the course of outlining the assumptions and the work of treatment information, this chapter examines:

- the various points occupied by PHAs on the continuum of seeking and using treatment information, from those who “do not want to know” to those who actively seek and use treatment information for decision making
- how PHAs work to assess the reliability of HIV/AIDS information
- the language of treatment information
- “information overload”
- the crucial role of personal experience in gathering and assessing treatment information.



CHAPTER ONE

DEALING WITH DOCTORS

LIZA MCCOY

Finally I asked my friends who I knew that were HIV-positive, “Who should I go see, who is your doctor, what is he like?” And finally I found this doctor who would like sit with you all afternoon and just talk to you and see how you were feeling.

Doctors, clinics and hospitals are for PHAs a resource and condition of their health work. When people living with HIV/AIDS seek treatment and medical advice, they engage with the work processes of doctors and other medical professionals. They enter into these processes as active participants. Rather than viewing PHAs as consumers receiving a service or objects of professional work routines, our focus here is on the work PHAs do around and with their doctors, as recounted by PHAs themselves. This line of analysis takes the standpoint of PHA patients, and places the individual PHA and her or his experience within an institutional organization of medical practice and health care delivery. (For a similar approach examining the experience of people living with disabilities who are clients of home care services, see Campbell, Copeland and Tate 1998).

Much of the research concerned with the experiences and views of patients is organized around the concept of patient “expectations” (Kravitz 1996) as these affect levels of patient “satisfaction” with health services (Sitzia and Wood 1997). This kind of health services research typically uses survey methodology to measure rates of satisfaction with particular forms of

.....
**FROM PATIENTS’
 SATISFACTION TO
 PATIENTS’ WORK**

health service, such as managed care (Kerr, Hayes, Lee and Siu 1998), hospital stays (Lasker and Toedter 1994), or treatment modalities (Cleary et al. 1992). In recent years the shift toward the use of performance or outcome measures in the funding and accountability of health services has increased managerial interest in patient (consumer) satisfaction research (Huby 1997).

This research is, of course, not without its critics. The concept of patient satisfaction has been criticized (Williams 1994) as primarily a managerial object lodged within a consumerist model which doesn't get close to the way people actually experience and think about their health care. Calnan (1988) points out that the concept of "expectations," on which satisfaction research is based, is similarly misleading, in that many people who visit the doctor or hospital don't have clearly formulated expectations of the service they hope to receive, although they do have definite reasons for seeking treatment at that time, along with their own criteria for evaluating medical care – and neither reasons nor evaluative criteria are discovered by satisfaction surveys. Williams, Coyle and Healy (1998) interviewed people about their responses to a standard satisfaction survey and found that many positive responses hid more negative experiences, a finding which calls into question the high satisfaction rates that patient surveys typically record (see also Dougall et al. 2000 and Williams and Calnan 1991).

An alternative to fixed-choice surveys uses open-ended interviews or questionnaires to elicit fuller accounts and evaluations of health care (see for example Annandale and Hunt 1998; Arntson, Makoul, Pendleton, and Schofield 1989; Calnan and Williams 1996; Duhamel 1997; King 1989; Lupton, Donaldson and Lloyd 1991; Petchey, Farnsworth and Williams 2000; and Wiles and Higgins 1996). This research strategy invites participants to describe their health care experience in their own words, using their own evaluative criteria. As such, it tells us considerably more about how people use and view the health services they are offered and, at its best, examines how these views and experiences arise within the organization of local health care delivery.

Our research also involved an open-ended approach. During our focus groups and interviews, we would ask participants about their relationships with their doctors. This was a topic about which people had a great deal to say. They spoke, often vehemently, about what they liked or didn't like about their doctors' professional practice and style of communication. We followed up on these comments when necessary to draw out more detailed accounts, because we saw our research as a potential vehicle for bringing PHAs' views to the attention of doctors and other medical personnel. But our overall focus on health work meant that we had another interest in hearing about people's experience of medical services. We didn't just want to know what people liked or disliked about their doctors, nor were we pri-

marily interested in understanding how people evaluate medical services: we wanted to know about the kind of work PHAs had to do in order to have access to – and take part in – formal health care services in Ontario. Thus, when we examine our participants' accounts of going to the doctor, we aren't reading them for what they tell us about individual PHAs or their beliefs; rather, we are reading them for what they tell us about the organization of outpatient health care delivery, viewed from the perspective of those who are the patients. (See Strauss et al. [1984] for an excellent account of the work chronically ill people do when hospitalized.)

In this chapter we begin with a look at distinctive features of the health care system and routine forms of service delivery that evoke characteristic forms of work among PHA patients. We conclude with a look at participants' comments about doctors' practices that they found helpful and unhelpful.

All the people we spoke to had entered into a formal relationship with the health care system as a PHA. They had doctors who knew about their diagnosis and monitored their health as seropositive individuals. Most were on antiretroviral therapy as their main treatment, which necessitates an ongoing relationship with a doctor or clinic. Some had extensive health problems and so were involved in continuous rounds of appointments and treatments. But all had been to doctors for their HIV, including one person, asymptomatic, who was a member of HEAL, a group which disputes the link between HIV and AIDS.

The contemporary organization of medical care is structured by diversification, with medical knowledge and practice divided up into specialties focused on specific areas of the body, specific bodily systems or types of malady. Primary care physicians or general practitioners underlie this diversification, directing individual patients to different specialists, as well as handling routine medical care that is not seen as requiring specialist services.

PHAs must fit themselves and their health care needs into this institutionalized division of labour. Very few people reported seeing only one doctor. A common arrangement was to have a primary care physician, preferably one with HIV expertise, as well as an infectious diseases specialist. In addition, many PHAs consulted other specialists as various health problems arose. Some of the people who spoke with us had chronic health problems running parallel to their HIV, such as sickle cell anaemia and diabetes, for which they maintained ongoing relationships with specialist doctors in those areas. Some PHAs included psychiatrists and mental health professionals among their group of health care providers. People who could afford to, saw a dentist. A small number reported seeing

**WHICH DOCTOR?
MANAGING THE
DIVISION OF LABOUR**

naturopaths and chiropractors in addition to their doctors.¹ Thus, for people living with HIV, a health condition that affects many aspects of a person's physical and emotional life, seeking professional advice and treatment is rarely a matter of one-stop shopping.

Furthermore, PHAs don't consult doctors only for routine health monitoring or for the treatment of specific conditions. Doctors also serve as points of access to financial and material resources, such as long-term disability or income assistance programs, which are bureaucratically allocated through text-based processes requiring a doctor's report or signature. Going to the doctor is for some people also a means to ensuring or enhancing economic survival.

Some of the PHAs we spoke with hadn't had regular doctors before their diagnosis. Instead, they had gone to drop-in clinics, emergency rooms or a company nurse on the few occasions they needed medical care. Becoming a PHA meant learning how to establish a relationship with particular doctors; it meant learning about types of doctors, what they do, and when to see them.

The hematologist [who diagnosed HIV] sent me to an HIV specialist at the [hospital] and he said that he would see me every three months or something unless something specific went wrong that I needed to see him. And I would need a G.P. as well as him.

Once hooked into this system, PHAs seeking medical treatment learn how to map their needs and health troubles on to the organization of specialties within health care delivery. It was an easy matter for most of the people we spoke with to produce a list of their various health care providers, such as the following:

Dr. A. is my primary care doctor. Um, I see a Dr. C. at [hospital] for my diabetes. And I forget her name but I see a skin doctor for this rash I developed recently. God knows what from yet. She had no idea. And I see a dentist regularly. Dental care is very important. And uh, I see D. who's essentially, well, I forgot her title but she's a therapist I met at [addictions clinic] originally. I referred myself there. And uh, I see her almost weekly, every Wednesday morning at ten o'clock. Very rarely I'm not there. I don't miss appointments. And I see E. at the HIV clinic at [hospital] and through her I see Dr. F. who's the psychiatrist.

1. Because the provision of medical services is organized into a *de facto* two-tiered system, so-called "alternative" health practitioners are only available to people with comprehensive medical insurance or sufficient personal income.

For PHAs with a set of two or more health care providers, one area of health work involves matching up, as best possible, whatever is troubling them or whatever they need with the appropriate doctor/therapeutic resource. This can involve some initial self-diagnosis: what sort of problem is this? Many of the people we spoke with described how they used their different doctors, in terms of what problems they took to which doctors. Here's one person's strategy:

I: What do you see [G.P.] for?

P: If I get a cold and cannot shake it off. But I really do not need to see her for anything. Like I had a stone and that was while I was taking the Crixivan and I went to see her about that.

I: So do you see her for anything that has to do with HIV?

P: No. I go to the clinic every month and I usually wait until I get there if I have some sort of problem. Like these rashes. I do not know if it is some illness or not but I think it is something more than a G.P. can handle, I think it is either drug related or nerve related.

The division of medical labour is maintained, in part, through the work of patients who do their form of triage and take their health problems to different people. But it is also maintained by doctors themselves as they respond to the questions and troubles that patients bring to them. And that response teaches patients whether their triage work is acceptable and whether the topics they wish to raise are appropriate. The doctor's control of admissible topics is clearly visible in the research on doctor-patient communication that relies on transcripts of actual medical visits (see for example Ainsworth-Vaughn 1998; Fisher and Todd 1983; Waitzkin 1991; West 1984). But we get glimpses of it in comments such as the following:

I: When you went to see your doctor for something that was troubling you about how you're feeling or . . .

P: It would have to be physical . . . cause he actually is not comfortable with me when I talk about depression, he always says "Aren't you seeing a psychiatrist or whatever?"

As he describes it, this speaker's triage work has been informed by his doctor's practice of deflecting talk about depression. We heard from other participants about this very issue. It is an area where the institutionalized division of labour fits the least well with people's experience of their health and health needs. Some people who spoke with us did not view their emotional life or relationships or family and financial circumstances as firmly

separate matters from the physical health issues they brought to their doctors. Doctors who were willing to make time to talk, and who saw emotional or life issues as appropriate topics, were greatly appreciated.

And if I have any problems I can talk to him about them. I like that in a doctor . . . If I was having a rough time with a relationship I could talk to him about that. He would help me out with that. He's helped me get therapy with the [hospital], to see a psychiatrist. My other doctors, I couldn't talk to them about my problems.

As the foregoing example shows, the division of labour is far from absolute. There is overlap in the topic areas doctors will entertain and the spheres in which they give advice and offer treatment. This can occasion some difficulty and compromise, as for the following speaker:

I go to the [HIV] clinic in the hospital. I have a primary care physician and to tell you the truth I would rather go to him. I trust his judgment now, I have a better rapport with him. The reason I don't [go to him] is because I am hardly treatment naive and I just feel more secure about getting experimental drugs and study drugs at the hospital than with him. To tell you the truth, I would rather go to him and I would probably go to see him more often if it were not for the fact that I hate it when my primary care physician gives me advice that contradicts what they tell me at the hospital and personally I have more faith in my primary care physician than I do in the hospital.

The patient's "triage" work (Is this a trouble I need to take to a doctor? Which doctor?) involves not just an assessment of the trouble that matches it with available expertise; it can also centre on the personalities and practice styles of the health care providers available. Sometimes it surfaced in people's accounts that they approached their different doctors as different relationships. Which troubles they took to which doctor had as much to do with the nature of the relationship, and the doctor's manner, as it did with expected areas of expertise. This seems to be particularly the case when the issue to be brought to the doctor is one that might call for special understanding on the doctor's part. For example, one man who was hoping to obtain legal approval to buy marijuana for medical reasons had been putting off approaching a doctor about signing the required form. As was common, he had two doctors, a G.P. and an infectious disease specialist, and was in the process of deciding which doctor to ask. He was leaning toward asking the one he thought would "understand better as to how I feel and what I'm thinking and stuff like that."

We found that quite a few people described their doctors in terms of relationships and personal qualities. For example:

Certainly the G.P., I have a really easygoing relationship with her. She would probably, you know, be considered the more friendly of the two but as I've often said, I don't need my infectious diseases specialist to be my friend I need her to be a brilliant medical doctor. [With] my G.P., friendship is a little more important (laugh) – their bedside manner. I mean it's not that I want a rude or brusque immune deficiency specialist, but it's really the brains that count there and I think I got that.

Here we get a glimpse of some of the thinking work people do around their doctors, in which they assess and interpret and make allowances for the type of people their doctors are. For some PHAs, this is thinking work they do on their own. Those who have opportunities to meet and talk with other PHAs, and who share experience of the same doctors, can do some of this interpretive work collaboratively, as in this exchange from one of our focus groups:

P1: She's the specialist. She's the one that decides the big things, if I need to be hospitalized or if I'm in a hospital or things like that, the change in my medications. She's like always busy and she gives you an exam in a minute, not like where my doctor takes a few more minutes.

P2: Cause she knows you're seeing your doctor.

P3: Yeah

P2: Another thing too is that she is probably so knowledged that she just has to look at you and know if there's something wrong.

Here Participants 2 and 3 are proposing to Participant 1 a more positive way to view his specialist's practice of conducting rapid medical assessments. This kind of interpretive work is an important aspect of people's health work around doctors, since taking part in medical encounters not infrequently involves patients in experiences that are confusing or upsetting. As we will see throughout the rest of this chapter, engaging with the health care system involves a constant process of making sense of what is going on.

THE MEDICAL VISIT

The medical visit is the standard vehicle for obtaining medical advice and treatment. It takes place in the doctor's office or hospital or clinic, according to a schedule managed by the doctor's staff – or in the case of emergency rooms and drop-in clinics, through a procedure of on-the-spot triage

and resource allocation also managed by the staff. People present themselves as patients by making appointments or showing up. Then they wait, usually in a waiting room, and are eventually shown into a room where they wait for the doctor to come in. Sometimes blood samples are drawn by nursing staff or an interview with a medical student or resident occurs before the patient sees the doctor. The actual consultation with the doctor is just one part of the visit, although from the patient's perspective it is usually the main part. It begins, typically, when the doctor enters the consultation or procedure room, and ends when the doctor leaves or shows the patient out. The doctor typically initiates the interaction and controls the duration of the visit and the use of time within it, including which topics get taken up as appropriate matter for the consultation. As we have seen with the examples above, patients can introduce topics that are in some way discouraged or dropped by the doctor as irrelevant. The interaction initiated and maintained by the doctor is frequently organized to produce the elements of the standard medical interview, a sequential ordering of topic areas and activity slots in which the doctor asks questions, examines the patient, orders further tests if necessary, or develops a treatment plan. Questions asked by the doctor are designed to elicit information from the patient that is relevant to medico-scientific diagnostic strategies and that can be noted down in the patient's chart as evidence and warrant for any treatments prescribed (Aldrich 1999; Waitzkin 1991). What patients want to talk about may not appear diagnostically relevant within this schema.

When people talk about their doctors, this organization of health care delivery and its routine operations lie behind and provide the sense for the stories they tell. Through their stories we can see how this organization occasions particular kinds of work among PHAs, work that attempts to shape or intervene in the allocation of resources and use of time as managed by doctors and medical office staff. Some examples follow.

GETTING ONE'S TOPICS COVERED

It isn't only the doctor who comes to the medical encounter with a sequence of topics that must be gone through in order to achieve a satisfactory completion of the business at hand. Some patients prepare for the medical visit by drawing up a list of health troubles and questions.

Every time I go to any doctor or whatever, I got my book out here, or I've written, I always know what I'm going for. So I have a piece of paper, one to ten or twenty and I make sure every single thing is covered as possible.

Because the doctor controls the duration of the medical visit and determines which topics are admissible, getting one's topics covered is not always a simple matter for the patient.

A sense of urgency pervades the following account. The speaker has found a way of approaching his medical consultation like a business meeting. He describes a balance between steering the conversation in the area of his chosen topics, while monitoring and limiting his use of the doctor.

Well, he is a physician with many, many, many, many, many to the nth degree patients. I have to . . . he speaks very fast and has everything ready to talk to me, so I have to steer the conversation so that I can make sure the points that I wish to cover are covered. I managed . . . to devise a means by which I set something of an agenda so that we understand, he and I, what it is we are going to accomplish and in how much time we are going to have to do it. As he has a great many patients I must limit my amount of time. So I don't see him too often, unless it's called for.

The following speaker describes a situation where he feels he has to choose between ordinary, relationship-building pleasantries and getting his medical topics addressed. Here, somewhat unusually, it is the patient who exhorts the doctor to get down to business.

My doctor is fairly good if you sort of tell him what to do, but I go in for a fifteen minute appointment and he's usually three or four minutes late for that and there's ten people in the waiting room, so I feel very, very rushed . . . Now what I do is I'll try to remember a day before or whatever to write down the stuff and I'll say to him, okay this is what we need to cover. Because also he's a nice guy and he likes to tell a joke or two or whatever and of course that eats into time as well. It's nice to develop that relationship with your doctor but, you know, when I'm pressed for time it's like okay, you know what, we don't have time for that today, today we need to deal with this stuff, so I'm quite forceful with him.

Notice that although this speaker describes himself as forceful in shaping the use of time and discouraging topics that waste that time (which is more commonly done by the doctor), he does so within an overall organization of time he doesn't control. In fact, it seems he would like to have both the pleasantries and the coverage of his concerns – it is because he doesn't control the scheduling that he has to choose and exert control within his allocated portion of time with the doctor. Note also that the doctor apparently goes along with this, probably because the hierarchy of topics reinforced by the patient is consistent with standard medical practice. A patient who wanted more pleasantries and social talk in the consultation – and many do – would probably have less success making that happen. Many of the people who talked with us described doctor visits in which they had

little control and input into the duration and organization of the consultation. Some felt rushed and had not found a way to get their topics covered. Others were happy with the time they got for the consultation and the doctor's willingness to do some social talk or talk about personal problems they might want to raise, but the sense was very much that this was up to the doctor. You were lucky or you weren't.

“MAKING A SCENE”

When people don't control important aspects of the medical visit, sometimes the only way they can intervene in the work process of the doctor's office or emergency room is by going beyond what is for them a normal and preferred style of interaction. They find they have to “make a scene.” Notice, in the following stories, the terms the speakers use to describe their actions: “cranky,” “aggressive,” “nasty,” “grouchy.” In their stories, they observe and comment on their own behaviour, often with regret but also with an element of pride.

One area in which people described “making a scene” concerned their participation in the teaching process that goes on in many hospitals and some doctor's offices. Medical sites often fulfill a teaching function as well as treating patients. These activities have separate ends, yet happen simultaneously. In the health care delivery process the patient is the beneficiary; in the teaching process the patient is a resource. While a few people said they didn't mind the student doctors, because they felt they were getting a lot of attention, which they considered a good thing, others found the experience of being teaching objects mildly irritating on up to infuriating. At times they felt the need to intervene actively in this aspect of the medical visit.

Here the speaker is successful in cutting short the time spent with the resident before seeing the specialist.

There's always a new one, or the same one. You don't get used to them because you see one now, the next time you come in, it's another one. It hasn't been bothering me because, if I'm really cranky then I'll give her trouble and she'll call the doctor sooner than she wants to.

Another speaker describes how he redefined himself from teaching object to subject:

I yelled at one guy once, he was a student there and . . . they were doing that abdominal sort of thing that they do and he was talking to the other one that was teaching . . . and they were talking about their careers and everything else and I might as well not have been in the room . . . and after he was done he said to her thank you, he

thanked her because she was training him and then left the room and did not say anything to me. I said “Aren’t you going to thank the guinea pig?” I was really mad and made a big scene. I asked her to leave. “I do not want you treating me.” So there is a person who is pissed off at me because I am being grouchy.

The work process of medical sites follows a standard routine but in a way that requires constant decisions within set parameters, especially around the allocation of resources (appointments, time, treatment) to particular individuals on a particular day. It’s into that aspect of the work process that people often try to intervene. For example, for some people, the long waits common in emergency rooms called for an active attempt to influence the organization of time and allocation of resources:

If I’m ringing the bell and doing everything and . . . I’m going by the hospital rules, and I know that I’m in pain and I keep hushing it down . . . and I’m not getting any better, I’m sorry the nasty part of me is going to come out. I’m starting to get more aggressive, like, “Hello? I’m here, I’m in pain, I need something here to calm me down.” . . . And even when the doctor comes, it still takes ten years to come with the medication, so you still have to constantly go on in the same way until you get the medication.

I find that when I go to visit somebody, like HIV-positive people in the hospital, I always have to be the one who has to say “Excuse me, she’s been here eight hours and hasn’t seen a doctor. What’s happening?” And basically you have to be really loud and get your point across, and it’s just like you talk to them quietly and they just ignore you and then when you go and you try to be assertive, then they look at you like, and it’s sickening that you have to go to that point to get your point across.

There is a clear sense of what this kind of health work costs the PHA in emotional effort, in lost dignity. People seem to feel proud of themselves for having succeeded in obtaining resources and shaping the medical work process toward their needs or the needs of the person they are advocating for, but they don’t seem to feel proud of the interactional forms that are necessary to bring that about. People worry that if they don’t do this kind of work and act in these ways that they’ll be overlooked or suffer needlessly, in a context of understaffing and high workloads. Thus the routine for the patient or the patient’s advocate is to effect a rupture in the routine of the institutional work process. And it becomes, for some, a duty to attempt this.

People who are visible minorities may be particularly oriented to this aspect of health work. Their work of intervening to improve access to medical services becomes part of their everyday work of dealing with racism (see also Ragins 1995).

I know so many people who have been discriminated against through the medical system and I'm not one of them because I know what I want, I know you're supposed to give it to me, I'm not begging you, and I want it. And that's basically how I come across. So, but I've heard people cry and say "I'm never going back to that doctor, I'm never going back to that organization, I'm never going back to that hospital" because the way they were treated, but I can't say that's ever happened to me. Well, I mean, because of my race. I can say it's happened because of HIV, but I can't say it's happened to me because of my race. Because I'll say to them, "That's racist, and I hope you know that's racist and I hope you know I'll report you." You know what I mean?

The work of challenging or coping with racism in medical sites also involves the interpretive work of trying to figure out if what is happening is racism or some other form of discrimination – or perhaps just routine practice in an under-funded hospital.

I took someone to the hospital and they didn't have a bed because this person was living with HIV. The nurse said "We don't have a bed here," and I said "Are you the person who is in charge of the hospital to give me that information?" And she said "Sir, we just don't have any beds." So there was a trolley and I took a pillow and I said "Lay here." And he said "Why are you doing that?" and I said "We are camping here tonight." And like five minutes later she came up and said "There's a bed on, like, the tenth floor" and I said "Good for you nurse." And just thinking about it, I wasn't sure what to think about it . . . I couldn't figure out if it was around his HIV status or it was around his colour.

GETTING INFORMATION FROM THE DOCTOR

Many of the people who spoke with us viewed medical visits as potential opportunities to get information about treatment options, side effects, the activity of the HIV virus, etc. Some saw themselves as fortunate that their doctors were generous and competent information providers:

I have got to know him and rather trust him and he does not steer me wrong, he does not wait for me to ask questions, he explains

everything and I like that and then I do not have to be thinking for a week before I get there everything I need to ask him because he is going to explain it all anyway.

The generous doctor doesn't require a lot of preparation work on the part of the PHA, such as making lists of questions to ask. His or her generosity with information also means the PHA doesn't perhaps have to put so much work into learning about potential new treatments, knowing that the doctor will pass things on: "Every time we go in, if there is anything new, he's got his little white board and he shows you things."

But others found that they had to work to get their doctors to share the information they assumed their doctors had. This was sometimes difficult and frustrating, because people didn't always know how or what to ask that would be successful in stimulating the doctor to give information. Often, they didn't have a specific area to ask about, just a general sense of being underinformed and a worry that the doctor was withholding what could be important information.

They [doctors at HIV clinic] . . . will just give a medication but not enough explanation on side effects. Maybe it is me that does not ask enough questions. I think it should be told even though you do not want to hear it or you cannot come up with the question. Like am I supposed to come up with all the questions for these medications? They just give me something and tell me what it is.

If you don't ask your doctor they won't tell you . . . I had to figure out how to ask my doctor to describe things.

In this context we might note the health work people do talking and listening with other PHAs, as it becomes a resource in their work with the doctor, providing them with topics to raise and questions to ask, as an aid in eliciting information.

If I think what [friends] are telling me is really interesting or something that I should be thinking about then I will take that to the doctor and say, I've heard this, what have you heard?

Most of the people we spoke with lived in Toronto, but we also spoke with eleven PHAs who lived in areas to the east and to the west of Toronto in Southern Ontario. Some lived in small cities, others in rural areas. In their communities there were few, if any, doctors who specialized in the treatment of HIV. (In some rural communities, there were few, if any, doctors at

EDUCATING THE DOCTOR

all.) So some PHAs travelled regularly to Ottawa or Toronto to consult an HIV specialist, especially if they wanted to pursue experimental treatment. Others made do with the local doctors who were willing to take them on as patients. Even those with HIV specialists in the big cities had to find local doctors for routine medical treatment and refilling prescriptions. In one area we visited there was an HIV clinic; unlike in Toronto, however, it was the only such clinic around, and PHAs dissatisfied with the clinic or its doctors had few options to go elsewhere. And they too had to find primary care physicians among the local doctors.

The PHAs who lived outside the big cities, therefore, looked after their health in collaboration with doctors and medical personnel who often had limited experience of HIV. For some, this involved them in the work of educating their doctors.

We had no doctors where I lived and then we got a G.P. so the first question was, do you have any experience? And he said "I have no experience, I have never had an HIV patient, I know nothing about it." But he said, "I am willing to learn if you are willing to teach."

One form this teaching takes involves bringing printed material in to the doctor.

He [G.P. in small city] has about four to five patients HIV-positive and some with full-blown AIDS. He is a great guy, a wonderful doctor. I have taken him in all kinds of textbooks from here [local ASO] and from different places and he has developed a small library on HIV and AIDS and he has really learned a lot about it.

The following speaker has analyzed the gaps in his doctor's knowledge, and seeks systematically to fill them.

P: I bring lots of information in to my doctor . . . and read it with her.

I: What are the areas of knowledge that seem to be weaker that you feel that you need to be supplementing with her?

P: Um, the information that she has about clinical trials and drugs, and what their side effects are, especially the hypercholesterolemia that goes on with protease inhibitor use. She really doesn't have information about that or really any ideas about what we might try to either prevent it or correct it or whatever, so I can like bring her lots of information about that . . . That kind of stuff – she doesn't have very much new information that hasn't been published as a med-

ical standard. I can say she's fairly unaware of it unless I provide it to her.

His education project is carefully timed not to overburden or offend the doctor.

I do a lot of thought about how much information I give to my doctor and when I do it, and sometimes when I go in just for a routine picking up of my lab results, if I haven't given her any information recently I might throw something at her that I've been holding on to for a while because I don't want to overload her with stuff. Sometimes it's when something new comes out, that I bring that in because it relates directly to my case and other times it's just like new research that I'm bringing in I think that she should know this information, because it's a strategy that I might consider in the future or, pretty much anything like that.

Teaching the doctor during times of sickness and stress, on the other hand, can be especially effortful, as another speaker told us:

One time during the ice storm I ran out of medications I needed and I had to get this doctor and I had to go find the spelling of the medication and I was fucking furious . . . He did not know anything, he didn't know the doses and I am thinking, I am not feeling well but I have to take that responsibility. I went home, found the pill bottle and he wrote the prescription. Okay, this man wants to learn, I want to live here, I have to be willing, too. Then I go home and vent to my partner or here [HIV support group]. It is like occasionally it gets to the point where I just want to be the patient.

Another type of educating around HIV in areas outside Toronto involves diagnosis and identification of appropriate treatment. This kind of educating work is not always accepted or appreciated by local health care providers.

A few weeks ago I had my friend in [to the ER]. He was having a dramatic reaction to Septra, which is a drug used as a prophylactic for PCP, and I knew he was having a reaction to it because I had it and I took him in and told them what was happening and it took four hours until they decided to give him Benadryl and it gets frustrating.

The following speaker is highly conscious of his HIV as an experience involving extra work for the local doctors, and he manages his use of their

services in a way that is attentive to that experience. For their discomfort becomes his discomfort.

I'm very selective about when I access medical care because I find it very frustrating, and, um, also (sigh) I find medical care and unless I have something serious that I shouldn't be accessing medical care, that's the sense I get when I go into the emergency room here or to my family doctor here . . . It's a difficult interaction for them as well. Because of HIV . . . They're unfamiliar, they don't have the standard procedures at their finger tips, so it either means a lot of consultation and negotiation for them or they have to go do some research, or make references, or make phone calls and that kind of thing and that's extra work for them and really they'd rather not be doing that.

So he does some of that work for them.

I usually kind of make the diagnosis myself before I go, and I find out what possible treatments are, what possible procedures are, or what the next diagnostic procedure is, that I want, before I go.

This is emotionally difficult work, on a number of levels.

And I also have a lot of I'd say anxiety and indecision about when it's appropriate for me to ask for these things because I'm not a medical expert myself. So, even though I have a fairly good idea, I think, of what's going on, or what I want, how I want to proceed, that isn't always like, immediately accepted by who I'm suggesting it to, whether it's in an emergency room here or to a doctor, whereas in Toronto, they're usually right on the ball and say yeah I agree with you or no I don't, I think we should try this instead, or whatever. They just have a lot more experience.

The limited HIV experience of their doctors meant that some PHAs became extra-vigilant in monitoring the diagnostic process.

Rural doctors go by the book. Last year I ended up with an infection and because my numbers did not match what is in the book he did not look at it. I went through losing weight, being really ill and because my numbers did not match, they did not check for MAC . . . All the symptoms I had matched something but because my numbers did not match: we are not going to check for that . . . Finally I

said you need to look at MAC. Because they do not have enough experience, even my specialist did not think of that right away, that was frustrating.

Yet, it is not only PHAs with doctors who lack HIV experience who do active work around the diagnosis of their ailments. PHAs we talked with in Toronto as well as those in outlying regions described how they monitored their symptoms and tried in various ways to shape the diagnostic process.

Some PHAs described acting conscientiously as a source of information for their doctors: bringing forward symptoms, warning the doctor when they feel something isn't right, suggesting possible diagnoses or problems to test for. Knowing their own bodies, and in some cases, having more experience of HIV than their doctors, many of the PHAs who spoke with us took the task of monitoring symptoms and diagnostic work seriously. Even PHAs who trusted their doctors' expertise expressed the conviction that they needed to do active work around monitoring their symptoms in order to bring to the doctor's attention what might be important information.

MONITORING SYMPTOMS AND THE DIAGNOSTIC PROCESS

He expects me to tell him if there is something wrong. I do not know about the other people, but I guess he trusts me to tell him if I find something wrong.

Some PHAs reported keeping health diaries.

I would go from the journal and make the notes . . . so that I could say 9:30 a.m. on Tuesday I had tingling in my fingers, is this neuropathy or what?

This speaker stopped keeping such a detailed journal, however, after he began to learn that "what was coming up was to be expected." He was reassured by this exercise, in which what he reported was not taken up by the doctor as symptoms demanding further exploration or treatment.

But other participants recounted stories where they were convinced that what they were reporting was something serious that needed attention, even when the doctor could see nothing wrong.

One time I had TB and my neck was huge and she kept telling me there is nothing wrong and I said "There is something wrong, this is not my neck, you cannot tell me there is nothing wrong here, there is something wrong." And I went 3 or 4 times and she said "There is nothing wrong." And I said "You better check because this

is getting worse not better.” And she did like three or four tests and sent me to a cancer specialist and I went there and the doctor says there is nothing wrong. And I said “You are going to keep telling me there is nothing wrong but I know there is something wrong.” Then she said “Okay I am going to check a sample here and see what is wrong with you.” And the results came back as TB and I was like “You see!” And she said “I would like you to keep pushing me and when you tell me something is wrong, you just keep telling me every time.” She says I am very good at that so keep doing it.

In this story, not only is the speaker monitoring her body and bringing forward information about her symptoms; she pushes to keep the diagnostic process continuing until the cause of the problem is discovered. This can be difficult work – to insist something is wrong when doctors, on the basis of diagnostic procedures so far undertaken, say that nothing is wrong. In this case, the outcome was a happy one, not just because the TB was discovered at last and treated, but because the doctor acknowledged the speaker’s work and the importance of it in a way that seems to have been gratifying to her. Interestingly, the doctor does this by regularizing the work, suggesting that she expects the same sort of situation to arise again and again.

Another participant referred to “this whole arguing thing and trusting my body” and gave the following example:

I listen to my body and I had a lump that my doctor had said not to worry about and I said “Look it, this is not just a swollen lymph node, there’s more to it.” And like the KS had gone into a hundred percent remission with the cocktail and this is eight months later and when the surgeon removed it, it was virtually replaced by KS, that lymph node. It’s the only thing that’s come up with KS since I went on the cocktail and it went into remission, but I knew that was it and I knew.

Another story about the work of insisting that symptoms be looked into, this time with graver consequences:

My late lover was misdiagnosed. He had a great big lump under his arm and he went to Dr. X. And he complained how much this lump hurt and meanwhile the thing is the size of a baseball, and they were like “We are going to look after that in two months, look at it and take a biopsy.” Meanwhile the cancer was growing at a rapid speed and he started getting lumps here and there and now he is dead and his doctors, at the time they felt terrible and they said

“We did not know that he had non-Hodgkin’s lymphoma, we did not think because he had such a high CD4 count that he would develop that at that stage.” I was like “Now you know. I think you should learn to be more thorough and listen to your patients.” For weeks and weeks and weeks he complained of pain and they just did not seem to do anything and he is dead now.

These are stories where the PHA’s knowledge or suspicion is proven right, for these are the kind of stories that are most commonly told. We can safely assume, however, that there are many times when the patient doesn’t turn out to be right, when her or his fears turn out to be groundless. Our focus is on the work itself. Many PHAs do this symptom monitoring and informing, and sometimes pushing and insisting, on a regular basis; as one person put it, “It is your health and you have to look after it.”

So far the focus has been on fairly active forms of work around doctors. A lot of this work is similar to the kinds of good health-consumer practices recommended in advice books like *Managing Your Health* (Patterson and Robichaud 1996) although the lived reality can be a lot more complex than what is presented there. But when we talk about health work, we aren’t only talking about active patient assertiveness. Doctors and medical sites occasion a range of work from people, and people deal with what they encounter there in various ways.

PASSIVE MUTINY

PHAs can encounter situations at the doctor’s office that are frightening, infuriating, troubling, confusing. It is not easy to be assertive around each and every upsetting moment. For some it’s a matter of picking their battles, for others it just feels impossible to speak up or insist on change, particularly when feeling at a disadvantage – for example, if the trouble is that one doesn’t understand what is being said, or if the doctor seems to be pushing medication. It can be hard to refuse medication and still be sure of the doctor’s support and continuing care.

It is important to recognize passive mutiny or suppressing one’s reaction as a kind of health work. Holding back, not asking questions, appearing to go along, accepting prescriptions one has no intention of filling, suppressing rage and confusion are all strategies for managing the relationship with the doctor – and often the resort of those who feel disempowered. For example, the following speakers describe situations where they kept concerns or disagreements to themselves:

For me there are days I am timid and there are other days I can be a bit more assertive. If I have a problem I will try to solve it in my head because he is not going to listen anyway.

I was threatened by the doctor as I understand it if it [viral load] reaches the 10,000 mark that we will talk about medications and I thought within myself well you can talk but I do not have to take. I think it is false hope.

Some people reported that they found themselves putting off medical visits, without having made a deliberate decision to do so. The following speaker attempts to analyze why he has stopped going to see the podiatrist, even though his toe problem has not yet cleared up.

I should have gone back. I've been totally avoiding going back cause I just, I don't want to go (laughs) you know, and it's not, I can rationalize it, it's not life threatening, it's an inconvenience . . . Part of it was I felt, when I said to the podiatrist "Well you know this is a side effect of the medication, this happens." And the podiatrist I felt very dismissively said "Medication doesn't cause ingrown toenails" and you know, and I just thought well, you know, fuck you.

Furthermore, the doctor's practice around used needles seemed clearly wrong and dangerous, yet in the context of being "freaked" about the medical procedure, the speaker found himself silent.

When I was in like the procedure room, when he was doing the stuff, it just, it kind of freaked me out, because he, like they, you know, they freeze your toe with the needle and stuff and then he recapped the needle, which is not part of universal precautions, you don't recap needles, and there were no sharps containers in the room, and . . . like I thought all of these things but I didn't say anything, you know, and so I found myself in this passive patient role, cause I was freaked out about him like slicing my toenail.

Below is another account of retreat, of stopping going to the doctor. In this case, as the speaker tries to articulate reasons, what comes up is discomfort with the changes in practice and billing that took place after changes in OHIP coverage.

I push on with my life, kind of push away my family doctor, because he's not really . . . First of all, I've had him for, um, 11 years . . . He's from my mom's days and everything . . . And then, I guess they get fucking saturated lately, and I lose trust for him, and I don't feel I can talk to him, and stuff like that. Because we were at a point where I can just walk in and get an appointment

and stuff like that, and now if I want something, like, I have to make this appointment, which I understand that, but, um. He never used to charge me for anything I need and stuff like that, like if I need a letter for certain places, he never used to charge me and now I have to start paying for letters . . . And um, since I live down here in the west end, there's kind of that distance too, so if I need something I'll go to my pharmacist and my pharmacist will call him and say what I need. He used to give it over the phone and now I have to come in and see him, and he's just giving me the run around. You know, so now I'm really not seeing a family doctor, I haven't seen a family doctor for a while, but I'm still in touch with my, um, sickle cell specialist and my HIV specialist.

While some people find themselves dropping away from doctors they don't feel comfortable with, others describe sticking around and fighting to build a better relationship.

As previously discussed, many PHAs talked about their doctors in ways that emphasized the kind of relationship they had with them. Related to this, of course, is the work some PHAs do to establish a good working relationship with their doctors. Not surprisingly, the people who described this work in interviews and focus groups had gone through particularly tough times with their doctors.

BUILDING A RELATIONSHIP

I find that her treatment, I don't know if she was scared of me or whatever, but it was really strange. And I know that she was knowledgeable with HIV, so it wasn't about that, but I remember we had so much fights in the first few years because I knew somebody who was her doctor and she treated her totally different from the way she treated me. Then I didn't just take what she had said. I had information, I was very involved with AIDS so I knew a lot of stuff and I'll tell her, and I'll say I don't want this, and I don't do this, and she'll tell me this and I'll say no or whatever, but we used to have lots of fights. I find that when I came in there, it was like "You are black, what do you think you are telling me, I'm the doctor?". . . I went in there and I knew what I wanted and all that and I was fed up and for the first few years it was so hard to build up this relationship, but I also knew that I wanted this relationship because I didn't have the time or the energy to go through that again. So we worked at it, and now I'm at a comfortable level with her, but it wasn't always like that. For the first few years I hated her, but now we're at a point where she's okay. I'm not in

love with her yet, but yeah, it's a struggle, because you always have to put up this front and be this person because they treat you like, it's hard.

Visible minorities do some of the most emotionally difficult work around their doctors in order to have access to medical advice, treatment and support. When they choose doctors on the basis of HIV expertise they may be choosing doctors who are white and who have little experience with non-white patients. As another participant put it, "I've never seen a black man in my doctor's office . . . I only go to my doctor for HIV and he only specializes in HIV, so that's why I really go." Like the previous speaker, his relationship with his doctor started off badly and continued uncomfortably for about six years until they had a fight around medication. He gave a detailed account of the process through which he and the doctor developed a better understanding of each other.

We had a fight because he said it was time I started medication and I said "Well, I had to think about that." And he was talking, and I could see his frustration and he could see my frustration, so I sat back and asked "Are you frustrated?" and he said "Yes" and I said "Fuck you." I said "You are frustrated? Sorry, you expect me to take the medication for the rest of my life, and you're frustrated about the decision that I have to make?" And, and, he said "You don't come to see me," and I said "What do you think I'm hiding from?" I said "Tell me why I don't come to see you. I have this decision to make and you're not making it any easier for me." So he said "Well, don't stay away then. Come and see me more often then if you're going to take the medication, but don't stay away."

The speaker eventually went through his own process of getting to a point where he felt ready to begin medication.

We're in a good relationship right now because I went back to him and I said "I want to talk to you," and he said "Ok, sure," and I said "I really want to thank you for being so persistent, for being there, and for not, I was scared that you were going to send me to another doctor." And he said "Well, I was scared that you were going to go away and not come back . . ." So we both had fears . . . At first I didn't know where he was at when we had this struggle . . . not that he wasn't clear, but I just had this perception that doctors have this mandate to push medication. So that's what he wanted, but when I analyzed everything that's when I realized there's this passion about caring about me too, personally.

FINDING DOCTORS

Receiving an HIV diagnosis triggered, for many people, the search for an appropriate doctor. People who already had doctors had to decide whether to change to a doctor with HIV experience:

I just remember after my first appointment with her after, well she told me over the phone that I tested positive, and then wanted to see me the next day, and . . . I just remember (laughs) her saying “Well you know I haven’t had a patient with HIV before so we’ll be learning in this together,” which was very honest and very nice of her, but I remember leaving her office and thinking, well, no we won’t be learning about this together.

Sometimes, the new PHA’s current doctor was unwilling to continue treating them.

When I was diagnosed in 1990 I was living [outside Toronto] and the doctor that diagnosed me said at that point that he did not want me to remain as a patient of his. I don’t think he was afraid of the disease, I think he was afraid he could not help me as much as he thought I would need. So then I had to start looking for someone who would specialize in it or was at least knowledgeable about it and knew how to treat it and prescribe or counsel or whatever on the disease. I could not find anyone in [that region], I even went to [hospital] and they did not want to deal with me.

Thus for whatever reason, many of the people who spoke with us mentioned doing some work around finding a doctor at the time of their diagnosis, which in some cases was ten to fifteen years earlier. However, we learned that finding appropriate doctors is not a one-time task for PHAs, and difficulties still remain. People move, and have to find a new doctor. People become dissatisfied with their doctor, and decide to look for a new one. And individual doctors themselves are not stable resources – doctors quit their practice, they burn out, get sick, retire, leave to work in the U.S., lose their licenses. All of these occasions the work of checking out available doctors and deciding which one to stick with, at least for the time being. Quite a few of the people we spoke with had recently changed doctors or were in the process of contemplating or anticipating a change. We discuss aspects of this kind of health work below.

People found doctors with HIV experience through various routes. Sometimes they were given a referral from a current doctor, sometimes they

FINDING AN APPROPRIATE DOCTOR

obtained listings of doctors from the ASO serving their area. An important part of the doctor search for many people involved talking with other PHAs. Through conversation, people learn about doctors who treat HIV-positive patients, but they also develop an idea of what is possible, what to look for or avoid. Over and over we heard people talk about how they asked their friends or PHA acquaintances to recommend doctors. One participant described how he turned down a doctor's offer of direct referral in favour of asking his PHA friends. The specialist who had recently diagnosed his HIV was prepared to refer him to a G.P. with HIV experience:

But I sort of said "No, I'll do that, I'll look after it." . . . I think I went back to him after friends of mine spoke highly of [a certain G.P.]. So then I went back to him and I said "Do you know this guy?" And he spoke highly of him as well: "Yes I do." So I had a professional recommendation and personal recommendations and I don't know what else I can do. . . . I thought about it, but you're chasing your tail with that too. I don't know these doctors. You know, and you hear some scary stories about doctors sometimes too. Well "They missed something" or you know "They didn't tell you this" or "That guy's an idiot," but how am I supposed to know? I don't know the first thing about any of this.

Consider the work pointed to in this account. The speaker talks to friends, he goes back and talks to the specialist, and he thinks about it – and what he says suggests something about the experience of this thinking: having to make a choice about doctors, which could have life-saving or life-threatening consequences, in a context of inadequate information.

Some PHAs reported visiting several doctors, "auditioning" them, as one participant put it, and checking out the functioning of their offices before deciding which doctor they wanted for "their" doctor. This was a process that could take years. Different people emphasized different personal traits or elements of practice in their search for the right doctor.

It took me about eight doctors before I finally found the right one. I was basically interviewing them and seeing if they were willing to treat me as an individual.

I have had positive results in auditioning a doctor. I had to wait, my appointment was at four and I saw all these people going in and it was a good 45 minutes before I actually got in, so I asked the nurse and she said, some patients we have to spend more time with because they need counselling. And the doctor's reply was the same.

When I had to find a new physician I went into the community and asked other people living with AIDS and I interviewed five [doctors] and asked what experience they have with HIV, what percentage of their practice was HIV-positive, what their connection to the [local hospital] was, what support mechanisms were, how they responded.

ASOs and the health consumer literature provide training and tips on interviewing doctors, but as with all advice, for the following speaker, it isn't always easy to put into practice – and the reality it is meant to shape has ways of slipping beyond reach.

I did go to a forum once where they said about it [interviewing doctors] but, even so, I mean you can interview someone and they can give you all the right answers. But when you go to work with them over any length of time . . . and every doctor will tell you something else. I've had that. One doctor will tell you one thing and another doctor will tell you another thing and a third doctor will tell you something else and so then what do you do? I struggled with that one.

Finding a good doctor is a different matter for the following speaker. Note that for this speaker, the doctor's office isn't just a resource for her medical care; it becomes a site where she is inspected and reported on to social service agencies.

The last six months I have been trying out doctors, I tried one and I missed two appointments and they sent me a letter saying they do not want to see me anymore . . . The next doctor I tried out . . . it was a turn off because as soon as I walked in – the baby was about a year old . . . All they said to me when I got there was “Well you know you are high risk we have to call [Children's] Aid.” You know what I mean. They did not even ask me what have you been using for support, what have you been doing, where have you been – because the last time they saw me was before the baby, so I did not like that approach so I just left. [I went to] another doctor close to where I live, and then . . . the nurse goes “We don't give narcotics here, eh?” I said “I haven't said anything yet how do you know I want narcotics?”

PHAs who use or have used street drugs – or who just look to medical professionals like the sort of people who do – seem to have the greatest trouble finding a doctor and doctor's office where they feel comfortable.

I have gone to different offices and stuff. There is one place I went into and this is no word of a lie and he asked, I told him straight up that I was HIV-positive and he said he does not take HIV-positive people and I said “What do you mean.” And he said he does not take drug users and stuff like that. There is prejudice out there. I told him I was not a drug user. I did not get into the whole spiel with him and said to hell with him. There are not a lot of doctors taking patients now because of the cutbacks.

Interviewing or checking out doctors, as a kind of health work, depends on there being a pool of doctors to check out. In the past, the pool was restricted because few doctors had experience with HIV or were willing to take on HIV-positive patients. Now that the virus has been around for almost 20 years, there are more doctors with HIV experience, and the new treatments give doctors something to prescribe and monitor. Yet the pool remains restricted. Reflected here are the organization of the supply of doctors (numbers trained) and the organization of payment for doctors, which as the speaker below describes, work in multiple ways to limit the availability of doctors with HIV experience willing to take on new patients.

If I decide to change doctors now, say something happens to change my relationship with my doctor, now I would have an awful time trying to find one who will take on new patients because they are overloaded. Because of the increase in the amount of people being diagnosed positive as compared to new doctors coming into the market, considering the number of caps and stuff in the government. A lot of people are going elsewhere to practice.

In areas outside Toronto, the pool of doctors experienced in HIV or willing to treat HIV-positive patients remains restricted, as the following speaker discovered:

I did a lot of talking with other PHAs about what their experiences were with their doctors, and even if their doctors were willing to take on additional patients with HIV, and I found that to be the biggest stumbling block – that doctors are just not willing to take patients that have HIV infection, because they think that it’s highly intensive work or stuff that they can’t keep up with.

Some of the people we spoke with reported periods when they travelled frequently to Toronto because they couldn’t find a local doctor to handle their routine medical needs. For some, the solution was to move, either to Toronto or to another city or town in their region. One PHA, who was also

the mother of an HIV-positive child, had to move in order to find a doctor for her daughter: “The family doctors there did not want to take care of her, they were scared.”

A striking feature of participants’ talk about their doctors was the number of people who reported having had a string of different doctors, necessitating their commencing the doctor search over and over again. In some cases, people changed doctors on their own initiative, because they moved or because they were dissatisfied with their previous doctor. But we were surprised at the number of people who talked about having to find a new doctor because their old doctor was for some reason no longer available.

LOSING DOCTORS

My original doctor I had seen for six years was a cool guy but he had lost so many patients to HIV he could not do it anymore. He dropped out of practice and into work for WCB [Workers’ Compensation Board], totally away from HIV, so I was stuck without a doctor.

I lost that doctor, he went to the States a few years ago . . . I looked for another one, I was very open and made an appointment and was very pleased with him but I lost him and now I have to start all over again.

Individual doctors make decisions about their careers and try to balance their medical practice with their own health needs and other priorities. They do this within an institutional organization of career opportunities and OHIP fee schedules. Specialization in HIV is particularly demanding for doctors who are committed to their work; a common issue for doctors who specialize in HIV work is burnout.

The following speaker has lost one doctor after the other.

I went to PWA, I found Doctor A. [but then] he had to have an operation. I went to Doctor B . . . and then he got fed up and then he went to San Francisco . . . Then from there I went to Doctor C. who was very, very right up to date and all of that and just out of university and . . . he had to quit and go to Vancouver, he got burned out . . . Then I went to Doctor D . . . [But then] Doctor D . . . lost his job so he referred me to Doctor E.

Other participants described a series of changes, some of which they initiated and some of which were forced on them. In the following story,

notice how the decision to find a new doctor is based on treatment preferences and financial resources:

I was diagnosed in December of '85. I got my results back and I had a general practitioner who was tilted very heavily towards holistic stuff but I got to the point where I could not afford the kind of stuff he was recommending because none of it was covered, so then I went to a lecture at MCC and there was an AIDS doctor, a young fellow, who came down and gave the lecture and I thought well, maybe I better see someone who is a little more specialized and he was also HIV-positive – and he retired a year after I started seeing him, so I went to the doctor who took his place and he was a very nice man but a pill pusher kind of and believes everything that the medical people say . . . So I eventually quit seeing him and the doctor that I am seeing now was at the clinic at [hospital] [that] my first doctor had recommended . . . He is very easy to talk to which is important to me.

The doctor's preferences around medication were for some people a key factor in deciding whether to change doctors and what to look for in a new doctor. For people who were suspicious of medication the goal was to avoid "pill pushers"; others wanted doctors who would prescribe antiretroviral therapy right after diagnosis ("hit early, hit hard"). One person described changing doctors out of a concern that his previous doctor wasn't staying at the cutting edge of new knowledge about HIV treatment: "I'm coming to the realization that I may be changing doctors every so many years, primary care physicians, just to keep current."

EVALUATING DOCTORS

Our focus up to now has been on the work involved in being a patient: organizational work, thinking work, interactive work, emotional work. We have looked at patients as active participants in the relations through which medical care is delivered.

In an institutional context where the power asymmetry favours the doctor, and doctors shape the consultation visit – its duration, the topics taken up as appropriate – more than patients, the individual characteristics and practice styles of doctors can make a big difference for their patients. As becomes clear through PHAs' accounts of their work of finding doctors and managing their relationships with doctors, there are some really good doctors out there, as well as doctors who, for various reasons, are not much help to particular patients. Here we examine what our participants had to say about their doctors, with an emphasis on those practices they found helpful and those that were problematic for them.

In listening to people talk about doctors, we were struck by common themes that crossed the many accounts we received. At the same time, variations within these themes expressed people's different experiences, especially of class and race/ethnicity. Doctors working in the area of HIV are, for the most part although not exclusively, members of dominant racial groups. For the most part, they live middle class, financially stable lives. They usually enjoy a high social status, in the community at large, but especially within medical settings. They are all highly educated and proficient in medico-scientific discourses.

The PHAs we spoke with were positioned in a range of social locations. Some had a lot in common with their doctors: they were white and highly educated, they held or had held professional employment. Some had put considerable time and effort into gaining a familiarity with medico-scientific discourse in the area of HIV/AIDS. Not surprisingly, people with this experience rarely described problematic relationships with their doctors where they didn't feel respected or listened to, for example. While the personality of the doctor was not irrelevant to them, what they tended to emphasize was the doctor's knowledge of HIV, his or her willingness to stay at the cutting edge of new developments, and access to experimental treatments.

Other PHAs we spoke with had a lot less in common, on the surface, with their doctors. Some had only basic education, some were poor, some were in prison or had been, some were members of visible minorities (Aboriginal, Black), some lived partially on the street, some were or had been drug users or prostitutes. For people with experiences such as these, the doctor-patient relationship was fraught with tensions and characterized by a noticeable power imbalance. They could not show up for a medical appointment and assume that they would feel respected as a person or get the doctor's full attention. Some, having come under various forms of state surveillance and been the object of interventions by social workers and other professionals, could not easily view the doctor as a service professional working for them (this was especially the case for people in prison who were restricted to seeing the prison doctors). In their experience and expectation, doctors were part of the ruling regime that tried to hold authority over them. Others were not very familiar with medico-scientific ways of talking about bodies, illness and medication. Or they found the assumptions and blind spots of this conceptual frame unattractive and were unwilling to adopt it in reference to themselves and their health. While people with these kinds of experience also wanted competent doctors with HIV expertise, the big issues they emphasized concerned the doctor's manner toward them and the doctor's ability to respect and engage with their reality and the particular needs that arose from it.

There were also many people whose experience vis-à-vis doctors fell somewhere in between – their concerns and priorities are not easily generalized beyond the obvious, which is that they too wanted doctors with HIV expertise who treated them with respect and compassion.

But what do respect and compassion look like in actual practice, for actual individuals? What is it about their doctors and their doctors' practice that is particularly appreciated by PHAs? Conversely, what are the practices that are offensive or upsetting to PHAs?

These are important questions to consider, since the medical visit is a central condition in PHAs' ongoing health work. It is also important because one thing we learned is that relationships with doctors affect, for some people, their treatment choices and medication practices. When people don't feel respected and listened to by their doctors, when they feel that medication is being forced in an authoritarian manner, when their doctor doesn't take the time to explain things or can't figure out how to explain things in ways that make sense – when this happens, some people stop going to their appointments, or don't bring up questions relevant to their treatment, or make choices about refusing or stopping medication that they might not make under other circumstances.

**RESPECT/TRUST/CARING –
BEING SEEN AS A
WHOLE PERSON**

People used different terms, but what the following comments all have in common is that the speakers are describing how their doctor's manner makes them feel comfortable, cared for, respected, valued – seen and recognized as the people they are.

It's caring, it's caring about you as a person, just not as a patient . . . you're not number 110 coming in to see her that day, you're a person. I guess she talks to you on a personal basis, not like a doctor patient relationship . . . Some doctors you go into and they'll say "How are you feeling? What can I do for you? What do you need?" Basically, that's it. They give you a prescription and you're out the door in eight minutes. With her it's – you know "What have you been up to? How's things going? And how's your mom? How's your family?"

P1: It is a trust thing. I do not mean I want to get personal with them, I just want to feel that they are not aloof, they are not above me, they are not better than I am.

P2: For me it is comfort level. That is, you know, to have a relationship with the doctor is that I have the comfort level that I feel that I can ask or scream in his or her face if I feel I need to and that is going to be accepted as OK, not that I do. That if

*I really feel strongly about something that I can say it.
A respect.*

He's treated traditional [Aboriginal] people with AIDS in the past, he's very respectful. If I were to say to my doctor "You know what, take your medicines and shove them up your ass, I'm doing our medicines." He'd say "You know that I support you and if you need me for anything, you let me know" and he would support me. My doctor is cool about that.

We heard strong praise for those doctors who provide options and respect their patients' choices, especially the choice not to take antiretroviral therapy.

He is wonderful, just magnificent . . . He gives an informed choice, freedom of choice, he's not judgmental, he listens to me as much as I listen to him. His favourite philosophy is "You know what it is good for you and you also know what is bad for you. I will give you your options and you tell me what you want to do." I like that and respect that. He is not just pharmaceutical or pill based, you know what I mean?

I found her excellent, you know, the interaction and what she had to say and her position and, you know, she talked about doing the drugs when I'm ready and she understood my position of not doing them. So she had a much more rounded view, even though she's the head of this HIV unit. Most of the medical community, a lot of the medical community is going to say "Do drugs" right? So she didn't push it.

I have a great relationship with both my doctors. I can tell them anything, refuse any treatment, or say "I don't like this or that for me" and they will respect it. They never push anything, so I have a good relationship with them.

Linked to a notion of respect is acceptance – of who a person is, of the way they live. This was particularly an issue for people who often encountered disapproval or disdain because they used drugs, had been in prison, were transgendered or poor. People who live on the margins with limited resources lead lives that make it difficult to do health work in ways that are readily recognized and approved by doctors – for example, choosing HIV medication and taking it as prescribed, keeping appointments on time,

ACCEPTANCE OF LIVING PRACTICES, TREATMENT CHOICES

making one's treatment and health maintenance a priority. Therefore, some PHAs particularly appreciated doctors who they felt accepted them and who worked with them, within the constraints and priorities of their lives, rather than expecting them to conform to a set of practices and priorities that didn't fit their reality.

She's pretty good because she knows when I'm having a hard time and she will spend time talking to me about what is going on . . . The student doctor, it was like she couldn't understand why I would go off my medication when my viral load was undetectable: "Are you crazy?" She never said anything, but it was like "Wow, it was undetectable, and now it's two thousand, what - ?" You know you could tell she was frustrated, like "You were doing so well, and why did you come off?" And she didn't understand. And then Dr. X came in, and she just, like "I wouldn't even tell you to go back on the medication. You have too much to deal with." You know what I mean?

I: So you were seeing him already and you started taking the crack and then you went to him and what did you do?

P: Uh, well he, talked to me, he listened to me first of all. So you know, sort of, you know evaluating what's, what's happening and so on. Because by that point he also knew that I was having depression problems and he'd, he'd gotten to know me as a person. And uh, he was empathetic, you know, like understanding the difficulty I was having, the pain I was going through. He was in no way rejecting, you know . . . He was doing his job on a very high level (laughing)

My doctor would be impressed if I start the HIV medication but I won't. I will tell her that I am going on the street to buy these things [drugs] with my money and just do it just to see how much she cares actually. I would say "Okay, you won't give me this [opiates] . . . you know I will probably go buy these drugs." She is, "You do what you want, think about it." My doctor has gone so far as to phone a shelter and take me to it and pay for my bed and give me money on top of that. I have no problem with that. That is more than caring, that is going the extra mile and then some . . . When I go to my visit she always brings in a student nurse. I get a kick out of it because I start grandstanding my lifestyle trying to shock the student because I know there is going to be a reaction about it later. My doctor is used to it now. She sends me cards and everything while I am in there [prison]. I have high support from my

doctor. She is very polite and I know she goes to these seminars about it [HIV]. I know she knows what she is doing and I know she is not pushing on these drugs because the best time to take them is when you are ready to take them.

This last account weaves a number of elements commonly identified as desirable in a doctor. Not only is the doctor caring and respectful and accepting of the speaker's life (while holding a firm line about not giving him opiates), she doesn't push antiretroviral drugs and she makes an effort to keep up to date on HIV treatment. Of particular interest is a theme echoed by other speakers who live on the fringes of the social safety net: the doctor's willingness to extend her care beyond the boundaries of the typical medical encounter, in this case, arranging shelter and giving him money. Here the doctor steps outside the typical institutional division of labour – where doctors diagnose and prescribe, therapists talk about feelings, social workers and social service agencies help with housing and shelter, food banks supply food, etc. It's easy for people to fall between the cracks, and what is available is not enough to meet all the need in any case. Thus some PHAs particularly value doctors who recognize what is needed and try to find a way to provide it.

He was doing house calls and before I had the baby, at the time I was in some not very nice places, he would still come. One time I was somewhere where I had pneumonia and he came to where I was and brought me medication and made sure I ate and stuff like that. That I liked.

My medication, I can't afford to buy it. I mean, I have a very good doctor who supplies me, I'm very grateful because she gives me the medication, she tries to get it. I'm in the office when she's on the phone with a pharmaceutical company to give me the medication because I couldn't afford to buy it when I was pregnant because I was working part time and all that, and I'm very grateful . . . And there were times when she bought the medication with her own money for me, and that's when I really thought, wow . . . Could you expect more from a doctor when she goes that far out for you? So I have great respect for her.

He checked my hearing and he talked to me about so many different things, and then finally I was leaving and he said "I'm going to write you a prescription." I said "Okay," and he said "Do you have medical coverage?" I said, "No." He said "Okay" and he ripped it up and he said "Let me go to the pill storeroom and get one for you."

And I left feeling so touched that he did that . . . I went back twice and he gave me the same.

The doctors described here have clearly found ways of practicing medicine that begin from and reach into the realities of their patients' complex and sometimes chaotic lives, addressing their primary needs and creating an atmosphere of respect and support.

TAKING TIME TO LISTEN, TO EXPLAIN THINGS

Just about everyone disliked feeling rushed during his or her visit.

I had asked [family doctor] who to go see for HIV care and she sent me to some loon, some factory, bring them in, give prescriptions and let them go. And it was very, they hardly even looked at you.

What I noticed happening in the last two years is that there is an increase in patients but a decrease in doctors . . . When you get a doctor who has an overload of patients, you walk into his office and you wait the 15 or 20 minutes to see him and you are in and out in ten minutes and you have not accomplished anything. There is no time to spend with your doctor to sit and actually talk and say this is how I feel, this is what I think I should do, what do you think.

You get a prescription and quick chat, how do you feel, here is your prescription, go get your blood taken and that is it.

Participants valued doctors who took time with them.

Finally I asked my friends who I knew that were HIV-positive who should I go and see, who is your doctor, what is he like? . . . and finally I found this doctor who would like sit down with you all afternoon and just talk to you and see how you were feeling.

I felt that she did give me the time, maybe not all the answers but certainly the time.

If you need to sit and talk to her about what you problems are, how you're feeling et cetera, she'll spend 20 minutes with you, instead of eight minutes like a normal doctor does . . . And, uh, she always asked what's been up with my life, how I've been feeling, how my transgender issues are going.

Great enthusiasm was expressed for doctors who not only make time to listen and talk with their PHA patients, but also explain things in ways that work for them and are empowering.

And he was very good, he obviously explained things well, he showed me charts and how this pill will attack the antibodies. He was a very good doctor.

He's wonderful. Great personality, very caring, very compassionate . . . He sits and he talks to you. Uh, this first time I went to see him he said "This is my assistant, she's training, she has to – can she interview you, do you object, how do you feel," et cetera? He said "Then both of us will come back and talk to you." And then they both came back and he spent about 45 minutes talking to me. Which none of the other ones have really ever done.

I: *What kinds of things did he talk with you about?*

P: *Um, being bad, not taking my medication on time, that sort of thing.*

I: *What did he say? Do you remember?*

P: *He said it was very dangerous not to take the medication on time, because the virus mutates.*

Most of his appointments in the morning are hour sessions, he explains everything and explains how the cocktail works and how it protects in certain styles and certain ways, so you understand what you're taking and why you're taking and stuff.

He educates you. Lord, every time we go in, if there is anything new, he's got his little white board and he shows you things. And we are a very well informed group of patients. I've referred several of my friends. Like one of them . . . he's not over-educated but [our doctor] can explain it to him so he's educated and understands what's going on.

In contrast, here is a very different experience:

I would like to find a different doctor, I mean, I don't – obviously he doesn't do anything for me, I mean I'm not taking my scripts, I don't feel comfortable with him. I feel the information that he gives me is not, I'm sure it's accurate, but I mean the, I too have problems with reading and not understanding things like that and for me to ask him to explain it to me, he's like "Well, I've got another patient

coming in.” You know, you got your 40 minutes, have a nice day, here’s your prescription, you know, if I want to find information, like thank God for PWA, ACT, you know and my friends . . . I’ve been with other friends that, you know, they’re in their doctor’s office for like 45 minutes to an hour and they come out and they’re completely satisfied. They know what they’re getting, what they’re taking, what’s going on and like I said about my doctor, I have no idea what’s going on in my life. You know he gives me a prescription for whatever I’m taking, of course I act like I’m going to go to the drug store and take it and a week later he’ll say do you feel better and I don’t. And I can’t turn around and blame it on the doctor. Because he’ll say “Well, you know I told you.” Well no, you didn’t. “Well then, of course you’ve got short-term memory loss.” Well, no. So I mean I’d like to find another doctor, but it, it’s really hard to find another doctor.

In this account, the speaker makes a direct link between his doctor’s inability to explain things clearly and his habit of not filling the prescriptions his doctor gives him. One of the other participants in the focus group then offered to share with him a list of doctors who had HIV experience and help him find a doctor whose practice better fit his needs. Let us hope they were successful! Participating in research is rarely of such direct and immediate benefit. One advantage of group interviews is that they offer the participants a chance to learn from and, if they wish, help each other.

CONCLUSION

In this chapter we have examined some of the work PHAs do around their doctors, work that is evoked by the organization of health care delivery as well as by, more broadly, the institutional organization of support for people living with HIV/AIDS. This work involves PHAs in finding appropriate doctors, matching their health needs onto a diversity of health care providers, trying to get their needs met through medical encounters they do not control, educating doctors and monitoring the diagnostic process as necessary, building a relationship with their doctor, and, for some, finding ways to deal with the upsets, insults and confusions that are a routine aspect of their experience of being a patient.

We have also looked at PHAs’ evaluations of their doctors, with a constructive emphasis on what people find helpful and would like more of from the doctors they consult. While this latter discussion departs somewhat from our analytic focus on PHAs’ health work, we have included it because it expresses what was for many of our participants an important dimension of their experience, one that we expect will be of interest to health professionals and ASO staff who support PHAs in their dealings with the health care system.



UNDERSTANDING THE SOCIAL CHARACTER OF TREATMENT DECISION MAKING

ERIC MYKHALOVSKIY

INTRODUCTION

This chapter raises questions about how PHAs come to take combination therapies and other medical treatments for HIV. We discuss some of the conventional ways of understanding how PHAs come to be on antiretroviral therapy then move on to present an alternative based on our own research. Throughout the section we emphasize the distinction between established perspectives and our own work. As conventionally understood, the process of coming to take medical treatments is based on rational decision making. This perspective focuses attention on the individual in isolation or in relationship with his/her physician and stresses the importance of treatment information for making decisions. In many cases, established ways of thinking about treatment decision making involve implied or explicit prescriptions about what “appropriate” decision making looks like.

What makes our own approach different is its focus on the social character of how PHAs get on antiretroviral therapy. Rather than basing our analysis on research that asks people hypothetical questions about their medical care or that otherwise treats them in abstract, isolated terms, we look at how people with HIV come to take treatments in the context of their day-to-day lives. In addition to PHAs’ relationships with physicians, we consider other social relationships that are relevant for how PHAs come to use antiretroviral therapy. A more “social” understanding of how people living with HIV/AIDS come to take medical treatment also locates their activities and experiences within institutional relations of power. This is an important step in complicating the rational decision-making frame, for it puts into view the limits of “choice” for many. The temporal or processual

character of how PHAs come to take antiretroviral therapy and the forms of interpretive work, not captured by the notion of rational decision making that they undertake, are also emphasized in our work.

Most of all we try not to be prescriptive in our analysis. We do not begin from a place that presumes that the health work of coming to be on HIV medication should take a particular form. Rather, we want to describe the different routes through which PHAs come to be on medical treatment for HIV. Making choices or deciding amongst treatment options is only a small part of a complex social process through which PHAs come to use HIV medications. In bringing into view the many dimensions of how PHAs make decisions or otherwise come to be on antiretroviral therapy, we hope to inform new ways of thinking about PHAs' engagements with medical treatments. We hope that a broader understanding of how PHAs come to take combination therapies will aid efforts to support this area of their health work.

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**COMPLICATING THE
RATIONAL DECISION-
MAKING FRAMEWORK**

If I were to go to [my doctor] she would kick my ass. She . . . would say . . . "Start taking them [antiretroviral drugs], what is the problem." And she does not seem to understand that it is not just she saying and me taking.

The process of coming to use antiretroviral therapy is not as simple as it appears to some. Before exploring the work that PHAs engage in as part of this process we offer a brief discussion of established ways of understanding how people decide to take medical treatments. We emphasize the importance that social science research has for developing and sustaining what we call the treatment decision-making (TDM) discourse – a dominant way of thinking about how people come to be on medications. The TDM discourse does not exist simply in the rarefied world of academic scholarship, it is alive and well in various social settings. As such, we describe how it is reflected in the work of ASOs and also finds its way into PHAs' descriptions of their own experiences with antiretroviral therapy. Since our analysis of the social character of coming to take antiretroviral therapy is counterposed against the TDM discourse, we offer this section as background information. Our aim is to describe the main features of conventional ways of thinking about treatment decision making and to indicate the types of exclusion and other forms of limitation that our analysis seeks to redress.

**THE TREATMENT DECISION-
MAKING DISCOURSE AND
SOCIAL SCIENCE RESEARCH
ON HEALTH**

We use the term treatment decision-making discourse to refer to both a dominant way of thinking about how people come to take medical treatments and the social arrangements that support this way of thinking. The term "discourse" as we use it does not refer to discussion or dialogue as it

does in everyday speech. Rather, we mean by discourse a systematic way of knowing something, that is grounded in expert knowledge and that circulates widely in society through language, including most importantly language vested in texts.¹

The treatment decision-making discourse is readily available to most of us. It appears almost as common sense and goes something like this: individuals come to be on medications by making personal choices or decisions about a set of treatment options; they make these decisions in consultation with their physician and on the basis of some form of printed treatment information.

While this way of thinking about how people decide to take medical treatments is diffuse, one of the most important sites where it gets developed and articulated is health-related social science research. Psychologists, health services researchers, sociologists and others experts have produced countless studies that explore people's involvement with medical treatments as a process of rational decision making. In much of this literature, rational decision making conceptually organizes the research through the selection of "patient preferences" as an object of study. Using quantitative methods, researchers have studied patient preferences for many things, including actual treatment interventions, levels and types of information, and roles in decision making (see Guadagnoli and Ward 1998; Mouton et al. 1997; Benbassat 1998).

An overwhelming concern of the literature is to better understand what kind of role patients want to play in decision making and to make changes in physicians' behaviour to accommodate patients' needs. Distinctions are typically made between different elements of decision making (Deber et al. 1996)² and there is a tendency to understand patients' participation in decision making in terms of a hierarchy of involvement. Thus, Degner and Sloan (1992) distinguish between a passive role, in which patients leave decisions to their physicians, a collaborative role, in which they share responsibility for choosing a treatment option with their physician and an active role, in which patients make the final treatment decision.

1. Thus, by discourse we mean more than a group of ideas or formal statements. We use the term to think about how people take up and modify a way of thinking about taking treatments that is based on a rational model of decision making. We are particularly concerned with how PHAs, ASO workers, physicians, health care providers, social scientists, and policy makers come into relation with one another through their engagement with the TDM discourse. For more on this notion of discourse see Smith (1999:133-156).

2. Deber and colleagues (1996, 1999) distinguish between problem solving and decision making proper. They describe the former as identifying the "single correct solution to a problem" (1996:1414) and claim that it has a limited place for patient involvement. Decision making on the other hand is, for Deber and colleagues, a realm of medical choice in which patients can participate. They describe decision making as making choices from among possible alternatives.

Other foci within the literature include the study of how decision aids influence patients' decision-making behaviour (Deber and Sharpe 1999; Kasper et al. 1992; Levine et al. 1992) and the use of experimental methods and statistical models to assess the consistency and adequacy of patients' decision-making abilities (Rosenfeld et al. 1997; Rosenfeld and Turkheimer 1995; Llewellyn-Thomas 1995). Overall, the social science literature produces a way of thinking about decision making that focuses attention on processes of rational choice enacted by the individual patient, at times within the context of a hypothetical physician-patient relationship.³

Very little research has been conducted on how people with HIV make treatment decisions. Reflecting the existing emphases of the broader literature, those studies that have been conducted support the assumptions of the TDM discourse. Thus, Rosenfeld et al.'s (1997) study of treatment decision making is based on an experiment in which HIV-positive study participants were required to hypothetically choose a treatment option from a variety of pairs presented to them on cards.⁴ The cards did not name the treatments but described them in terms of "known risks, benefits, FDA-approval status, cost, dosing schedules, and extent of empirical research regarding treatment effectiveness" (1997:308). Rosenfeld et al.'s study made estimations of people's decision-making ability and concluded that their treatment choices were based on the likelihood of a treatment increasing CD4+ cell counts and on the restrictiveness of a dosing regimen.

A second study, conducted by Catalan et al. (1994), focused on PHAs' preferences for involvement in decision making and information seeking. Drawing on the results of a questionnaire administered to patients and staff at a hospital and medical clinic in London, England, the authors concluded that PHAs had a stronger preference for involvement in information seeking than in decision making. They further noted that staff views about their patients' preferences did not correspond with the views that patients expressed in their survey responses.

Both of these studies contribute to understanding how PHAs come to be on treatments in terms that rely on a narrow representation of what counts as decision making. They support conventional ways of understanding that present health-related decision making as a rational process of selecting between pre-established treatment alternatives. They emphasize patients'

3. These relationships are imagined because some of the research does not ask for people's preferences about specific, actual physicians – their own or otherwise. Other studies involve people who are not "active" patients at the time of the research. Instead, they draw on people without actual medical conditions or people who are not ill at the time of the research.

4. Studies involving "forced pair comparisons" are a staple of the literature.

use of information and suggest that the primary site for decision making is the patient's relationship with a physician.

Of course, the treatment decision-making discourse circulates in social contexts beyond the academic. For example, formal health care policy has become a major site for calls for greater public involvement in health care decision making (Charles and DeMaio 1993). These appeals are linked with hospital cutbacks and other institutional transformations in health services that encourage patients to be responsible for and actively involved in their health care. The expectation that patients will take an active role in making decisions about their health, including the treatments they take, has become an organized feature of the health care system in Canada (Armstrong et al. 2000). Of course, the notion of the individual who is responsible for his/her health is not simply an outcome of health care policy or the contemporary organization of health care services; it can also be linked with the critique of medical expertise made by the women's health and AIDS movements. In recent years, patient empowerment, as developed within these movements, has been systematized within community-based health organizations as advice and education that might assist women and PHAs in making better choices about their health. Finally, popularizing the use of treatment information by people making health decisions can also be linked with heightened pressures to reduce health care costs and a more general move toward market-based approaches in the organization of health care services (Lupton 1997; Grace 1994; Crawford 1986).

As suggested above, the assumptions of the TDM discourse are built into the work of community organizations, including AIDS service organizations. In recent years, the production and distribution of treatment information for PHAs has become an increasingly common focus of activity among ASOs. Certainly, within ASOs there is greater recognition, than in the social science literature, of the complexity of PHAs' decision making, including, for example, an understanding of the emotional dimensions of making a long-term commitment to taking antiretroviral therapy. The very commitment on the part of ASOs to produce and promote the use of treatment information also implies an appreciation of the significance of community organizations for PHAs' decision making that is not a part of conventional approaches. At the same time, however, the ASO advice literature and the organization of ASO treatment information services carry forward the assumptions of the TDM discourse. Both imply and, to some extent require, an individual user of information who is encouraged to make reasoned choices in consultation with a physician.

**OTHER SOCIAL SITES
WHERE THE TREATMENT
DECISION-MAKING
DISCOURSE IS EXPRESSED**

**THE TREATMENT
DECISION-MAKING
DISCOURSE AS
ARTICULATED BY OUR
RESEARCH PARTICIPANTS**

As one might expect, the TDM discourse is also active in PHAs' experiences of coming to take antiretroviral therapy and their ways of describing them. In our research, it was an important part of how some PHAs talked about their experiences of taking or switching to a particular antiretroviral therapy. Here is an excerpt from one exchange concerning the frequency of a person's daily dose of Crixivan.

- I: Who makes decisions about treatments you're going to take?*
P: Me. Nobody else has permission to make. Now if [my doctor] was going to say "I would like you to go on this drug," I will ask him about it. Like, we were talking about the BID thing with Crixivan versus TID.
I: So BID is twice a day ?
P: And TID is . . . three. And he thought it was okay. And I mentioned the fact that I don't have any problem taking three so then he said he'll look it up a little more thoroughly because we're concerned with this over-supply of the drug or under-supply of the drug depending on its half life. But he'll look that up on the internet. . . . So he'll suggest but I'll question and get his reasoning before I'll accept anything.

Note how switching doses is presented in the account as a decision-making process in which information about biomedical phenomena figures prominently. The speaker's embodied preferences do make their way into the story – in his remarks about not having a problem with a more frequent dosage schedule. For the most part, however, changing the frequency of doses is represented in the account as a matter driven by technical, biomedical concerns about the drug's absorption into the body.

The account further articulates an organization of health work presumed and promoted by the treatment decision-making discourse. For example, the work of decision making is presented in the story as a process of considering treatment information that occurs within the confines of the speaker's relationship with his physician. The speaker represents himself as active in this relationship through forms of health work that involve rational, cognitive processes. Thus, he asks questions of his physician and queries his reasoning. The general division of labour suggested in the account – in which a physician seeks out and communicates treatment information to a patient who makes a final decision – is a recurring feature of social science research on shared decision making in medical encounters (see Charles et al. 1997).

Our research interviews included other moments in which PHAs told stories about their experiences with medications that were framed by the assumptions of the TDM discourse.

My doctor goes to conferences and stuff and he usually tells me we will try this because this is what they say works better.

We're going to sit down and, you know, whether [my doctor] wants to make a change in the four combo or whether he wants to stay with the original because I can't take the ritonavir. We'll see how it goes from there. I want to see how it's coming physically . . . It's a decision I can make either way.

I have tried different things. My doctor told me to [take antiretroviral therapy] because my T4 was pretty low.

These and related accounts focused on making choices and keeping up with the latest in treatment information, on consulting with physicians and following their recommendations, or on leaving decisions to one's physician to make. Overall, these stories had a certain flatness of character to them. While they often referenced complex medical problems and decisions that were difficult to make, they presented the work of decision making in fairly simple terms. As conventional understandings would have it, decisions were made with physicians, drew on biomedical information of one sort or another (published research, laboratory test results, etc.) and involved rational choices. It is as simple as that.

Or is it? One of the most interesting features of our research data is how people expressed their experiences of coming to be on combination therapies in ways that went beyond or disrupted the coherence of the conventional focus on rational decision making. In our research, rational choice, cooperative relationships with physicians and an active engagement with biomedical information appeared as components of a language for describing experience that seemed most available and most suited to the social conditions of life of middle-class men. The experiences of coming to be on treatments recounted by others involved much more than making informed, rational choices.

This is not to suggest that people who are disadvantaged or marginalized do not make treatment decisions, or that the TDM discourse fully captures the many dimensions of coming to be on combination therapies as it is experienced by men who live middle-class lives. Rather, it is to underscore the

PROBLEMS WITH THE TREATMENT DECISION- MAKING DISCOURSE

social dimension of language itself. The treatment decision-making discourse, both in its expression in the social science literature and in PHAs' accounts of their experiences, is not a neutral discourse. It does not describe the way things are for all people but, in fact, masks important dimensions of the social process through which PHAs come to be on treatments. In part, this is a consequence of social science research methods that strip the particularity of people's daily lives from what can be known. For example, questionnaires that ask about people's hypothetical decision-making preferences or experiments that test abstract reasoning practices do not map well onto what actually happens in the context of people's daily lives.

Beginning precisely from the place of people's telling of their day-to-day experiences with antiretroviral therapy, this section of our report explores how they come to take or not take treatments. It complicates the limited notion of decision making that gets put forward in the conventional social science literature and that circulates widely as the treatment decision-making discourse. Our research builds a picture of decision making that is based on people's accounts of how they actually come to be on treatments, rather than on how it is felt they should do so, or on experimental reconstructions of cognitive functions. These accounts are not so much about particular choices or decisions than they are about the complex social process of coming to be on treatments articulated as historical narratives.

On the basis of these narratives we offer an analysis of the work that PHAs actually do in coming to take antiretroviral therapy as it is carried out from the varied social locations within which their lives are organized. Focusing on what gets missed by the TDM discourse, our analysis is divided into two main sections. In the first section we briefly explore the institutional relations of power through which some PHAs come to be on treatments. The second section offers an extended discussion of the temporal character of PHAs' decision making. Here we investigate various forms of work as well as interpretive strategies other than rational choice that are important for how PHAs come to take HIV-related medications. Throughout our discussion we aim to make visible how the varied forms of activity that PHAs engage in as part of coming to be on antiretroviral therapy take shape within the broad social conditions of their lives.

**TAKING INSTITUTIONAL
RELATIONS OF POWER
INTO ACCOUNT**

Conventional social science approaches to treatment decision making do not give full expression to the relations of power that shape PHAs' involvement with medical treatments. When they do recognize questions of power, they tend to emphasize inequalities of access to medical knowledge in the doctor-patient relationship that can be remedied by putting information into the hands of patients. But for these asymmetries, social science research and the broader TDM discourse speak little of institutional rela-

tions of power. Our research reorients the TDM discourse by calling into question the notions of individual choice that it rests on, and by displaying the links between PHAs' decision making and broader social and political arrangements.

One of the most striking features of our research involved accounts in which PHAs describe coming to be on medication not as a process of decision making or free choice, but of compulsion. In place of the TDM discourse's focus on people who make choices and consult with physicians, we heard how, for some PHAs, taking or not taking drugs involved various forms of pressure and coercion.

These accounts shed a different light on the organization of medical practice and doctor-patient power relations than that suggested by the rational decision-making frame. They were made primarily by women, urban Aboriginals, visible minorities, people on social assistance, current and former drug users and other participants of focus groups conducted at Two-Spirited People, the Don Jail, 127 Isabella, the Teresa Group, Voices of Positive Women and BlackCAP. In part, their stories of being pressured to take medications reflect the zealous medical enthusiasm for combination therapies that was a feature of the historical moment in which our research was conducted. More importantly, they express how marginalized people are excluded from the TDM discourse even as they are included within medical relations as objects of surveillance and control.

Some of our respondents expressed their experiences of being pressured to take antiretroviral therapy in their stories of doctors who threatened or frightened them as a way of getting them to take medication.

He tried to scare me. He wanted me to keep on these medications, but it is my choice and I just told him "I am not taking them."

That is the same thing with my doctor, too. He suggested right away that I take the cocktail. "I do not think so." He made me feel like I was going to get sick right away.

I am threatened by the doctor. As I understand it, if it reaches the 10,000 [mark] we will talk about medications. And I thought within myself well, you can talk, but I don't have to take. I think it is false hope.

The descriptive language of these accounts – the use of terms such as “scare” and “threatened” – records a social distance between patient and physician that was discussed in the previous chapter. There, we heard the

COMPULSION VS. CHOICE

concerns that some PHAs, those living on social assistance or who were drug users, for example, had over how they were treated by their physicians. We also heard about how physicians generally control the topics and overall form of interaction during medical visits. The remarks above, then, signal forms of physician-patient interaction marked by power differences and social tensions through which some PHAs come to be on treatments.

In our interviews they were elaborated by other PHAs such as those quoted below. Here, two speakers describe being told by their physicians that they had to take medications as well as their reactions to such efforts at controlling what they do.

This doctor was a real asshole. He said "You have to take AZT . . . you get counselling, see a psychiatrist right away." I told him "I don't have to take anything if I do not want to, it is up to you if you want to take medications." He thought I was just some dumb Joe off the street.

I do not want to take something that somebody tells me I have to take.

In a final example, one woman we interviewed talked about how her experience of physicians pressuring her to take HIV treatments had less to do with her own health than with a medical concern for prenatal HIV transmission. Her comments further make visible how social relations of difference (in our research typically of class, gender, and race) can organize coercive processes of coming to take medical treatments.

I felt like she said when she mentioned that she was forced into making a decision. That is why I felt that I didn't last more than six months taking [antiretroviral therapy]. . . . Between my G.P. and specialist, both of them, ganging up on me saying "Take this, take this," . . . that kind of crap scared me. . . . Even now the only reason I am on the medication is because I am pregnant. If I wasn't pregnant. But even now I was forced. I was told, you know "Either you do or your baby is positive."

THE INSTITUTIONAL RELATIONS OF COMPULSION AND CHOICE

In talking about feeling forced to take HIV medications, some PHAs made visible other institutional relations that lay behind their experiences. These accounts complicate conventional understandings of decision making by shedding light on how the various formal organizations that PHAs are connected with shape their experiences of coming to take medical treatments. An understanding of decision making as involving abstract

individuals who make choices outside of any particular institutional context is replaced by an appreciation of how coming to take medical treatments is linked with certain institutional arrangements. For example, in a discussion focused once again on compulsion, a man we interviewed in prison talked about how taking antiretroviral therapy was part of his probation order.

The point is they first said to me “Do you want to use these pills?” And I said “No” . . . and I didn’t take medications until three years ago and I was forced to take them. It was part of my probation order to take my medication. . . . The judge said, the crown said, he is supposed to be on this. . . . Whatever medication they decide to order, I have to take.

He went on to describe how PHAs in prison do not have a choice of doctor. Should they wish to pursue antiretroviral therapy, they often are not offered the range of options available to people who live outside the prison system. Another PHA we interviewed told about how his experience of coming to be on HIV medication involved his coming to the attention of the public health department, which had the authority to require him to treat his HIV.

The thing is with my case I got on [antiretroviral therapy] with the public health department. Because I felt that the reports were wrong – because I had been diagnosed and I haven’t yet had a symptom and so I felt, well, I do not believe their reports – I am not going to believe. I am going to go donate blood to Red Cross. And I went to donate blood and passed the preliminary and it was two weeks later the public health department contacted me and they informed me and I openly, honestly admitted that I knew and went and donated blood. So right then and there the public health department kind of put out a search warrant to find me . . . a public health nurse . . . comes around every two weeks to check up on me. It is not to do with me personally health wise. It is to do with the report, an act I have to follow.

Other PHAs, who did not talk about feeling forced to take medications, complicated the notion of choice that operates within the TDM discourse in other ways. At times they told stories gesturing toward activities occurring outside their immediate relationships with physicians, that shaped how they came to be on antiretroviral therapy. For example, stories of coming to take HIV medications in which the pharmaceutical industry is highlighted bring into view some of the institutional relations that lay in back of

people's choices. These accounts underscore how choices or decisions do not simply follow from the competencies of any given individual. Rather, they have to do with cycles of drug development, processes of drug testing and procedures for government approval that produce different routes through which PHAs come to take drugs and that shape what it is they can make decisions about:

And I know that the capsules are sitting in Ottawa all ready to go they're just waiting for approval. So, that's so frustrating, because I knew that in December, that they were with Health Canada waiting for approval, so here we are taking this liquid.

So I got off the Crixivan and . . . all along while I was on the Crixivan he said "We need you on this new one that's coming out – 1592, DMP 266 and nelfinavir – that's not available yet." It's not available yet, so I tried to hang on to Crixivan – didn't. Finally I had a holiday for a while, began to feel better . . . and eventually one by one they approved that combination and [I had] to wait so I can start them altogether. I started that combination nelfinavir, DMP 266 and 1592, May 25, I know cause it's the day before my birthday. I figured Happy Birthday, Christine, here you go.

[My doctor is] very, very pushy and uh, he looked at many of his patients and in utter frustration, realizing that the drug, uh, availability in this country is appallingly slow compared to Food and Drug, for example, for the [United] States. When Food and Drug, that is to say National Institutes of Health said, they had the centre at Bethesda, Maryland, they were going to have a site where they would test these three brand new drugs, an analog, a protease inhibitor and an RTI. All of which would be fresh to the body and to the virus, never seen before by the virus. They wanted to know what would happen. And by a miracle of some sort I was number three out of the hat.

Understanding people's treatment decision making as a matter of selecting from among a range of alternatives presented through information or by a health practitioner is of limited value. Beginning from the actual historical circumstances in which PHAs engage with antiretroviral medications, our research begins to put into view the broad social character through which PHAs come to be on medical treatment. Not all PHAs come to take HIV medications as the treatment discourse would have it. Relations of medical and institutional power that target marginalized PHAs as objects of scrutiny and surveillance often locate them outside of relations

of choice. And the conventions of medical practice, including medical interpretation of the state of scientific research, and other institutional practices of drug development and approval shape and limit how PHAs can enter into processes of coming to take HIV treatments.

Having discussed some of the institutional relations of power that organize the process of coming to take medical treatments for PHAs, let us now consider more carefully the organization of activities that PHAs engage in as part of this area of their health work. Our research suggests that an important feature of the work PHAs do in coming to take or not take HIV medications is its ongoingness or temporality. The TDM discourse, particularly as expressed in the social science literature, represents PHAs' decision making as occurring in discrete, bounded moments of time. Experimental designs, for example, limit recognition of the temporal character of decision making, by requiring study participants to make immediate choices in artificial settings. In the real time of everyday life, however, decisions about HIV medications are rarely made so quickly.

In our research, the processual nature of treatment decision making appeared most visibly in the language PHAs used to describe their experiences of coming to be on medications. In contrast to the TDM discourse, with its focus on particular choices and isolated moments when decisions are made, PHAs spoke about how they came to be on combination therapies as a temporal process. Often their accounts of how they came to take medication were articulated as historical narratives. By historical narratives we mean extended moments of talk in which people told stories about their lives, in this case through a lens focused on their experiences of dealing with their health and thinking about and taking medications. Often they recounted events that occurred years before they began antiretroviral therapy. Some people told detailed "drug histories," beginning with how they initially took AZT and moving on from there. Even those who were recently diagnosed spoke about coming to take HIV medications through stories that emphasized duration and the extended passage of time.

The following quote offers an example of the type of historical narrative through which PHAs described their coming to be on HIV treatments. While the quote is lengthy, it offers a striking example of how one person's story expresses the complexity of the process of coming to take antiretroviral medication.

So for two-and-a-half years I travelled back and forth every month to come see the doctor down here. And then after I saw him for about four years I wanted to decide to start doing something about it. I do not want to wait for something to happen to me

**EXPLORING THE
TEMPORAL DIMENSIONS
OF COMING TO BE ON
ANTIRETROVIRAL
THERAPY**

before I start to defend myself or go against it. And in those days the theory was that if your T4 count did not go below 200 it was not a prescribed situation. You sort of just went along with the flow until something happened. And I just felt the same way I would about cancer, why wait until you are in a position where they have to cut something out or they have to do something . . . when you can start treating it right away? And all the doctors in those days did not really want to start prescribing anything. Of course they did not have the variety that they have now.

So we got into a big dispute about me wanting to have some treatment and manage my health as well as going on a specific diet or whatever . . . [It] came to a point where I decided OK if this doctor does not want to work with me on what I want to do, then I should find another doctor. . . . I eventually decided, well, I want to do something about this so I went and changed doctors . . .

I work at PWA or volunteer there and there is a list of doctors that you can go through and check with, but I went by word of mouth. Some are heavy duty pill pushers, other ones are absent from pills. They don't want you to take anything. . . . So I switched doctors and after being with him for about six months we went through sessions every month as to pre-warn me what the regimen was going to be like, what I am going to have to be involved with, I was in a position where my counts weren't really too high or they weren't too low and the decision was basically mine. He was happy with the fact that if I wanted to go on medications or I didn't want to go on medications – he was happy with either.

After going through counselling and stuff with him about how to fight back with this and hit it hard and fast before it gets the chance to take a bigger hold – nowadays they are working with that system, they weren't before – so that is why I decided to go on the medications and stuff. And I just started them a couple weeks back and I am starting to experience all those changes too. Physically, emotionally, financially, it is all a big change. Even when I first decided to leave work, I was working full-time two-and-a-half years after diagnosis because I did not want anything to change. I said "Why change anything? My life is fine" and all this stuff and it was sort of denial in a way. But I stayed with my full-time work and then I just started to lose friends. In my groups they started to talk and I decided that I have to do something about this, but I cannot do it in Brampton because I do not have the access to things out there. And that is when I decided to move down here. So my income went from a regular income down to like 350 dollars a month. And it is such a big change emotionally making that decision plus you

are in a position where you cannot do anything with yourself because you don't have the funds.

This person's account vividly displays how coming to be on a particular antiretroviral therapy is about much more than the discrete decisions made by an individual PHA and his or her physician in a singular moment of time. As the speaker tells it, coming to be on antiretroviral therapy involved some six and a half years of daily life. Crucial to the process was a shift in the organization of HIV-related medical care from what the respondent describes as "physicians not wanting to . . . prescribe anything" to a more aggressive and preventive medical response. This change operates in the speaker's everyday life at the level of his search for a physician who will support his preference for a more active therapeutic approach against HIV. For this PHA, then, coming to take antiretroviral therapy involved the work of finding a new physician. It also involved a set of experiences that come into view when the process of deciding to take HIV medications is told through PHAs' experiential language. For the speaker, deciding to take medications was shaped by the geographic organization of medical expertise, by volunteer work at an ASO, by counselling, by changes in employment and by the death of friends. It occurred as part of physical, emotional and financial changes in the speaker's life. All of this occurred over time.

The relationship between the passage of time and deciding to take antiretroviral therapy was expressed in many ways in our interviews. One of the most common of these was reference to the ongoingness of taking combination therapies. At the time our interviews were conducted, many of our research participants had already been on more than one combination of antiretroviral drugs. Rather than speaking about being on HIV medications as involving a one-time decision, they described a flow of events that involved them trying or taking various combinations. Here is an account that displays how coming to be on combination therapies occurs as an extended course of action in which a change or prospective change in medical treatment is associated with side effects and changes in bodily processes. Note how the speaker's account of the process preserves its embeddedness in his movement from paid work to being on social assistance.

If you are like me, you get to the point where you have to take the pills. I am on my third cocktail. The first two I ended up with myopathy, paralysed, could not walk. The first one I was still trying to work and take these pills and I could not hold a job as a waiter. I could not hold a tray; I was always afraid I was going to

THE ONGOING NATURE OF TREATMENT DECISION MAKING

dump in someone's lap. And then I end up on the system, on the Welfare, onto the third cocktail where you did not go anywhere because you are afraid of your bowels letting go. No warning, nothing – they would just go. Now I am a year later I have gained back my weight, my counts are up . . . the viral load is non-detectable and everything else is fine. But every time you get an earache or sore throat you run to the doctor because you are afraid like “Oh God, here we go again.”

The temporal character of coming to be on treatments was expressed in our interview research in other ways. Perhaps the most striking counterpoint to the TDM discourse's focus on the isolated moment of decision making were the numerous descriptions PHAs offered about length of time it took for them to begin taking a particular combination of anti-retroviral drugs.

From the time my doctor started suggesting, to the time I finally agreed to take [antiretroviral therapy] was about nine months I think.

I just started a couple of weeks ago. It was a two month process to make the decision.

It was just a decision, I said that I didn't feel like just sitting and waiting for something to happen before I reacted. I'd rather be proactive and start to attack it. And after about six months discussion with my doctor he said “Okay, let's go for it.”

The time PHAs reported was involved in deciding to begin taking HIV medications reflects the complexity of making a commitment to the long-term use of complicated drug regimens. Taking antiretroviral drugs in combination can be difficult and can provoke substantial disruptions in the rhythms of everyday life. The use of combination therapies is associated with medical recommendations for strict adherence. The drugs can have severe side effects and their long-term efficacy is unknown. In their narratives of coming to take HIV medications, PHAs made visible how these were not “one-off” concerns that could be quickly addressed. Rather, they were objects of reflection that were explored and negotiated over time and in the context of the particularities of a PHAs' day-to-day life:

I'm thinking about [taking antiretroviral therapy] . . . It seems like it's manageable now the HIV, it's manageable so far. And I'm thinking that, just thinking of some of the side effects like nausea

or headaches or feeling tired. And I think, I don't know how I am going to respond to that. I don't know if I'm going to be prone to depression or prone to anxiety because of the way I had responded in life, for some times.

I'm thinking about [taking antiretroviral therapy]. Though just to see like to get some, like at the hospital where I am going now . . . to get a reassessment of my condition. I've had HIV since 1994, and I can't say much more than that it's just that I haven't been taking the pills yet or anything like that so . . . I don't think – I'm not too sure what's going to happen in the future like when I take those pills will I get those side effects and stuff like that.

My decision making involved that this was twice a day as opposed to one other which is one dose more you are likely to forget. The other thing was being able to eat. I did not really want to be restricted to meal times because I live with a partner and that is one of the few times when you sort of spend time together. You know, quality time and I did not want that disrupted by my having to eat at certain times and eating alone at different meal times.

The various concerns that PHAs raised about coming to take antiretroviral therapy were often expressed as part of accounts of the complex and ongoing forms of work involved in such deliberations. For some PHAs, the prolonged work of making a commitment to begin taking antiretroviral therapy was expressed in the familiar terms of the TDM discourse. Here is an account in which the work of timing the onset of antiretroviral therapy is centered in an ongoing exchange with the speaker's physician.

THE FORMS OF TEMPORAL WORK INVOLVED IN COMING TO BE ON ANTIRETROVIRAL THERAPY

[My doctor] has been suggesting to me . . . to think about starting to take medication, the protease inhibitors or the cocktail . . . thing. And I have told him that I am thinking about it but I am not feeling like starting yet. My viral load and T-cells have been stable so far, no changes. Just the last time I had a change in my T-cells, they were down, but they go up and down all the time. So he says it's time to think about starting the cocktail. And I say "Yeah but." He says "Well a year, let's see in a year if you have any changes and then you can start."

In a related way, the person quoted below reveals how his engagement with treatment information led to a further delay in starting to take antiretroviral therapy:

I was very close to taking the step and doing this. And then I went to [province] for a couple of months and stayed with friends and that was great. I came back to the city and [my doctor] was leaving and I had to find a new doctor. And through that as well the information started coming out in articles about the problems around the lack of effectiveness. There were articles coming out saying that they were really only working on 50 percent of the people. . . . So that made me pause and I said "I'll hold off yet again because this isn't the sure shot and I don't want to start this prematurely." And in retrospect I'm glad I didn't because now . . . there's the problem with resistance and the problems with fat distribution in the body and things like that. And what's that going to do over a number of years to people?

THE WORK OF "MAKING TIME"

While relationships with physicians and using information are an important part of deciding when to take or switch medication, much else is involved. Our research suggests that treatment decision making, as it actually occurs among PHAs, consists in specific forms of ongoing work that are not fully recognized by the TDM discourse. It draws upon a variety of social relationships, not simply the physician/patient dyad, and is shaped by the social locations within which PHAs' lives are organized.

One form of work that PHAs engage in as part of coming to take antiretroviral therapy actually contributes to the temporal duration of the process. This is the work of "making time" – of producing a space or extended period within which to reflect and consider whether to begin taking antiretroviral therapy. PHAs' accounts of making time were often told as part of stories about feeling pressured to take treatments. One person spoke about this work as involving a kind of physician management:

That is the same thing with my doctor too. He suggested right away that I take the cocktail. "I do not think so." He made me feel like I was going to get sick right away. Eventually I did have to talk to him. I more or less want to think about it first instead of just jumping on it.

For others, the work of making time was not so much a matter of dealing with physicians, than of negotiating personal relationships with friends and family members. The PHAs in our study described how their efforts to clear time and space for thinking about taking antiretroviral therapy involved extended forms of relationship work. As part of this work people reassured family and friends about their health status and tempered their anxieties about the need to start medical treatment. PHAs also explained to

their family and friends their need to wait, to have time to consider what to do and to start medications when they felt ready:

I happened to be diagnosed around the time that the whole aggressive antiretroviral therapy was being pushed. . . . And I think from various quarters I was hearing the something to do was to go on treatment. You know from my parents – more so my father. . . . From the minute he heard about the new treatments . . . it was like “Well, why haven’t you had a viral load test?” Like it wasn’t happening fast enough for him. And I can remember saying to him, like “Calm down, chill out. . . .” And I remember just saying, you know, “I’m not ready.”

I find a lot of time people say “Well, you should do this or do that. . . . You should be taking medications, we want you to live longer.” I tell them “I realize all that and love you too, but you need to realize this is a decision I have made whether it is a good one, bad one, responsible, irresponsible.” You know, right now, taking care of the baby I am not responsible enough to take care of myself taking my pills.

My friends don’t seem to have a hard time with [antiretroviral therapy]. They think I should be taking the pills and I have to explain to them . . . it’s still my decision whether I decide to take them or not.

Other PHAs we interviewed spoke about the work of timing the onset of antiretroviral therapy in other ways. They described what was involved for them in taking time to decide when and what drugs to start. Their stories about “taking time” focused on how the scheduling of doses and possible side effects and difficulties with compliance posed questions for them about when to best start taking combination antiretroviral therapy. These deliberations might be thought of as a kind of preparatory work in which people reflect on themselves and the demands of different drug regimens.

For some, what was involved was deciding on a antiretroviral therapy that best suited the demands and particularities of their life situation. Consider the process for the woman quoted below:

- P: I can’t go back on it [antiretroviral therapy]. I mean, if I go back on it I will go off again, which is something I do a lot.*
- I: Because of work, or . . . ?*

THE WORK OF “TAKING TIME”

P: Work. Family life. Anything. By the time I finish taking care of everybody I don't have time. Like I came home from work yesterday and I went to bed at 5 o'clock and I didn't get up until 8:30, I was so tired. So that's the kind of thing. And so you miss it [a dose]. And if I work nights it's a different schedule, so you kind of – and I sleep all day. So that's one of the reasons that I'm so scared to go back on it because I want to make sure that I take it the way I'm supposed to, but right now I can't commit to that so I figure I'll go on two instead of three.

For others, taking time meant making changes in their home and/or work life in order to produce the conditions required for beginning the uncertain process of taking antiretroviral therapy.

I: So what happened in September that made you think that it was the time to go on the cocktail?

P: I was really stressed out from work and I was just feeling blah. I felt that I had to take some time off because my stress level was so high. So initially I took six months off work . . . but it's been over a year now and I don't think I'll go back.

I: So you went on a leave of absence in September?

P: Yeah, and that's when I went on the cocktail because I didn't know what kind of side effects it would have or anything so I took some time off just to see, but . . . I didn't want to be taking pills when I was at work all the time and when you do hair you're working really long hours, so.

I: So part of the decision to leave work was around the pills?

P: Yeah.

As with other forms of health work, in taking time PHAs enter into particular sets of institutional relations. In the following example, the preparatory work of taking time is occasioned by a disjuncture between the daily life circumstances of the speaker and drug payment policies of an insurance company. Note how in this example, taking time is not so much a voluntary activity than something the individual is compelled to do by financial circumstances.

I had to make sure I was covered for the new drugs because they were fairly new and very, very expensive and I was not sure if they would be covered . . . I sent a letter off; they didn't get it, etc. Fortunately, I . . . keep a copy of everything for myself. So I sent it through the fax machine . . . If you call them on the phone and say "My doctor might prescribe a drug" then they say "Do you have a drug iden-

tification number?" Well then they say "We really need you to write a letter and then we will reply back to you." It is time, a little bit here, a little bit there . . . [My doctor] wanted to start six months prior but it is just getting everything. The thing that really worried me was I did not want to get the first prescription, get it filled, pay for it up front, on my credit card, then have the problems with benefits when they say "No we won't cover you," then I am stuck with 3000 dollars and then I cannot afford to continue, then I have to stop.

Among the most striking narratives in our research were accounts of taking time made by PHAs with mental health issues and/or histories of substance use. These life circumstances present unique complexities for the process of coming to be on antiretroviral treatment and, in particular, the work of timing the onset of antiretroviral therapy. One person we spoke with who had used injection drugs off and on for a number of years described how the bodily experience of taking medication presents particular challenges for some people with histories of recreational drug use. He described taking pills as a "hard time" and noted how they figured into his drug use:

- I: I dread it every time I have to take another pill. Because it does affect me. It affects my energy level. It affects my capabilities of you know, just fatigue sets in really easily. So it fucks up my addiction too because of taking all the pills.
- I: How so?
- P: It gets me wanting to use pills that really do something that feels better for me, that give me an effect that I want.

For this person, matters were made worse by medical suspicion of his complaints and reluctance on the part of physicians to prescribe medication for pain.

PHAs experiencing mental health problems also described complex experiences of timing the onset of antiretroviral therapy. One individual we interviewed had been considering beginning antiretroviral therapy for years. He had been prescribed antiretroviral therapy on two occasions, had brought the treatments home but, in the end, did not take them. His concerns focused on potential side-effects and on the possibility that depression would interfere with taking antiretroviral therapy:

I actually at times warmed up to the possibility. Right now I have saquinavir, d4T, and 3TC ready to take, well they've been in my fridge and cupboard for the past, let's say six months. It's a big decision for me and the main reason I haven't taken that junk is

fear of side effects must be my biggest reason . . . I know I may not have side effects, but I'm just kind of trying to stretch out the time. 'Cause one thing that has stopped me from taking medications in the past has been depression. And I always told my doctor that unless depression is under control I'm going to not be able to maintain the regimen, you know, the three, four times a day. You have to really want to be on these medications, take them when you should and I always over the years have been of the mind that you have to take them and stick with them, and it's a long term deal. So, it's been a while and then there's been periods of time when . . . I could not really believe that I could stay on these the way I should.

Not fully visible in the quote is the ongoing work that this person and other PHAs with mental health issues undertake as part of the decision to begin antiretroviral therapy. In our research, PHAs struggling with depression talked about the array of appointments they kept with therapists, physicians, psychiatrists, social workers and others as part of prolonged forms of “self-work.” More than other PHAs their lives are embedded in relationships with experts and health care providers through which they work at coping with everyday life and at transforming the “self.”

This work of self-reflection and transformation seems provoked and heightened by the prospect of taking antiretroviral therapy. For example, for the individual quoted above, the demands of pill taking occasioned an ongoing period of reflection on how depression might impact on taking HIV medication. For him and other PHAs with depression, timing onset was not simply a matter of choice. It involved intense self-scrutiny marked by prolonged reflection about one's self in relation to depression and the demands of pill taking. It also often involved efforts to get depression “under control” before embarking on antiretroviral therapy. Deciding to begin antiretroviral therapy takes time for these PHAs for they engage in extended efforts to produce their lives and “selves” in ways deemed required to manage the complex drug regimens of antiretroviral therapy.

Recent clinical research has highlighted the importance of addressing depression in people living with HIV/AIDS and its potential impact on treatment adherence and clinical outcomes. Our research underscores the importance of dealing with depression.

THE WORK OF “INFORMAL LEARNING”

A second form of activity that is an important part of the temporal character of coming to take or not take antiretroviral therapy is the work of informal learning. The TDM discourse emphasizes a relationship between decision making and abstract reasoning processes. PHAs' accounts of their experiences tell a different story. They display how people learn about what to do

about taking medications through informal observation that goes on as part of day-to-day living:

And I have seen that with some friends . . . that I see. The treatment is working for them but not for all of them – for some of them. Some of them cannot tolerate the treatment. One person got cancer already. And I have seen those changes.

I have watched a couple of people go that way. They did not know what they were doing. I have the information that people get living with this and I have to base my knowledge on what I have seen.

PHAs' ways of talking about this work emphasize its everydayness and informality. For example, in discussing his concerns about taking antiretroviral therapy, one person we interviewed described watching the weight changes of PHAs on HAART who lived in his apartment building. Another described how he "compiled two years of hearing things about other people's side effects" as part of an ongoing process of considering when to begin taking antiretroviral therapy. In the following account, the forms of connection through which learning through observation occur are registered in the terms "seeing" and "eavesdropping."

I'm a bit leery because my [doctor] doesn't want to do anything. And I see other people with roughly the same T4 number and they're in a totally different situation than I am. So I'm wondering "Well what do I do?" So with those three doctors I'm waiting and from what they say and their response, I'll go in that direction . . . The vitamins, sure they help and they're good for me. Sooner or later, I've had [HIV] for eleven years, something should be done. I'm always eavesdropping when people are talking about it. Just process it and think about what I should do next.

For many of our research participants, observing and listening to what was happening with other PHAs was an ongoing process. It was a regular activity integrated into patterns of everyday life that some had engaged in for a number of years. As the above quote makes visible, the possibility of this kind of work follows from people's immersion in extended networks of other PHAs. Some people spoke about these networks as "community" or as "friendships," while others emphasized the importance of ASOs for providing opportunities to meet and share experiences with other PHAs. The following person describes the character of relationships and forms of interaction involved in this kind of informal learning:

Because you are HIV-positive sometimes it sort of puts you into a community setting where you are part of a certain group. Almost all of your friends and associates are HIV-positive or involved with something that has to do with HIV. A lot of it is word of mouth, conversations, experiences they have had . . . sitting and talking.

The significance of accounts of observing, watching and talking with other PHAs in people's extended narratives of coming to take antiretroviral therapy underscores the importance of an interpretive practice and forms of association that support it that are not expressed within the terms of the TDM discourse. PHAs' accounts of informal learning are not about discrete rational decision making in the abstract. They are about social relationships and interpretive practices that produce a form of community knowledge. This knowledge circulates among friends and associates through talk and observation and is an important outgrowth of the activities of AIDS service organizations. Even our focus group research provided a site for some to engage in informal learning:

That is one of the reasons I am here. I wanted to hear other people's experience.

Like I said, I'm not taking any medication, so for me, I really don't inquire about it. But I get information from here, basically sitting here. Because right now I'm getting information, and I listen to her for my information, and listen to you for my information, and so when my time comes where I'm supposed to be on medication, then I know how to handle it.

CREATING EMBODIED KNOWLEDGE

As one might expect, much of the knowledge PHAs share with one another was described by them in ways that emphasized its embodied character. From the perspective of the treatment decision-making discourse, people with illnesses make health choices on the basis of medical information whose nature does not change through their engagement with it. From this perspective, HIV/AIDS-related treatment decision making involves PHAs meeting up with and using static, unaltered information. Our research participants' stories about informal learning suggest more complex ways in which PHAs interact with treatment information. Rather than simply using information unchanged, they engage in interpretive practices and ways of making sense that translate medical information into experiential terms. In our research, one recurring example of this type of translation of medical knowledge was referenced in people's talk about interpreting the significance of laboratory test results in ways that privileged bodily experience:

It has been mounting somewhat in the last year because my count has dropped down below 200. I do not know where they are right now. In the support group I was in at the time a lot of people had come to the conclusion that this CD4 count did not mean a lot. Some people had practically none and were doing fine and other people when they had 500 were in deep trouble so, I have to listen to my own body.

I went undetectable, and my count went up to 480. Yep, number wise, of course! It worked but it made me feel bad. And for some people that happens, some people I've talked to some people and they don't have a problem with it at all. The numbers, I'm telling ya, for me they never worked, it's like the numbers are good, doesn't mean I feel good at all, and I think they're putting too much importance on the numbers.

The translation of biomedical knowledge also appeared in people's accounts of learning about side-effects. In the following quote, for example, note the contrast between a medico-scientific articulation of diarrhea and diarrhea as it comes to be known through PHAs' informal learning.

P1: Everyone wants to talk about their medications and I am quite happy to hear it. People tell you all different side effects and how it affects them and all kinds of information . . .

P2: And it is based on actual individual experiences and not based just on reports and statistics . . . It is important to have the actual. The side effect of this may be diarrhea. Okay, he [referring to P1] is telling me he can spend the whole morning and be afraid to leave the house. That is a little different than "diarrhea." This is hours and hours and it is real and the whole thing is there. The whole story is there.

P1: I have shit my pants at my door because I did not make it.

In addition to the forms of self-reflection, informal learning and translation of biomedical knowledge noted above, PHAs engage in other forms of interpretive work as part of coming to be on antiretroviral treatments. These are generally more complex than the models of rational choice promoted by the treatment decision-making discourse. Among the most striking of them, is a form of temporal reasoning PHAs engage in that is shaped by medical uncertainty about the long-term efficacy of currently available treatments and the ongoing development of new drugs. This way of thinking involves considering and fashioning present circumstances

THINKING AND ACTING IN LIGHT OF THE FUTURE

in light of future eventualities. It was expressed in various ways in our research.

In the following quote, for example, a PHA already taking antiretroviral therapy talks about his reluctance to make changes in his drug regimen. Note how his stance of maintaining his current regimen is made with a view to preserving future options in the event that his present drug treatments fail:

I don't want to fiddle around with changing it and risk a whole lot of cross resistance and fiddling around with this and fiddling around with something else. And you know you never know what's going to happen in two to three years from now. I may have to go off ritonavir. It may stop working or something and I'll need those other ones to. . . .

PHAs who had yet to begin taking antiretroviral therapy also engaged in forms of forward thinking or looking. A number of people we interviewed spoke about having an eye toward what treatments were “coming down the pipeline.” Others, such as the PHA quoted below suggested how deliberations about treatment were made with a keen awareness of how current choices bear upon the future.

I was fortunate enough to be a volunteer at PWA which handles all of this and there is a specialist there who has been on a cocktail for years and years and I think he is pretty much immune to all of them. And if you have the change and it doesn't work and they try another combination, eventually they run out of combinations . . . I listen to his opinions, not necessarily the opinion I will choose but I will listen to his side of it.

Still others spoke retrospectively about how particular decisions and actions around treatment are linked with subsequent possibilities:

And I think as it turns out this is probably the best one to have got on to in case it didn't work. Because it's left the most avenues open to go on to something else. If I'd done it another way, I know there's a couple if I had chosen those I wouldn't have been able to go on to ritonavir if they hadn't worked because they would have done something to conflict with the ritonavir.

At different moments of the process of coming to be on antiretroviral therapy PHAs engage in forms of thought and action that align the present with the future. This way of acting and thinking comes into view through

PHAs' detailed talk about their experiences with HIV medications. Rather than an abstract and universal form of rational choice it is an active reasoning process shaped by the organization of scientific research on HIV/AIDS and the forms of popular and medical knowledge that circulate among PHAs about how antiretroviral therapy will likely work over time.

By describing the forms of health work that PHAs engage in as part of coming to take antiretroviral therapy, this chapter of our report has complicated the established models of treatment decision making that increasingly inform the health promotion work of AIDS service organizations. In writing the section, we have intended a particular form of intervention. We have wanted to displace the TDM discourse's focus on decision making as an individual event of rational choice and put in its place an understanding of the broad social process through which PHAs come to be on treatments.

The TDM discourse does not fully appreciate the institutional relations of power that organize PHAs into taking antiretroviral therapy through various forms of compulsion. It also passes over the complex forms of work that PHAs undertake in their day-to-day lives as part of coming to be on antiretroviral therapy. In this chapter we have tried to describe how, from their varied social locations, PHAs engage in the work of coming to be on HIV treatment. We have underscored its ongoing character and emphasized the work of making and taking time. We have discussed how PHAs engage in informal learning through their association with other PHAs and described the forms of temporal reasoning they engage in. We hope the overall picture offered by the chapter helps ASOs support PHAs' health work in ways that are informed by their actual experiences of coming to take antiretroviral therapy.

CONCLUSION



CHAPTER THREE

FROM COMPLIANCE TO MEDICATION PRACTICE

MICHAEL BRESALIER

LIZA MCCOY

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I remember the first night of laying out the medications, like putting them in the dosette, and then the first morning of taking them was just, it was scary because, it's this whole piece around . . . faith and hope . . . pinning my hopes, on . . . whether . . . these pills would . . . do what they were supposed to do. And . . . realizing that the first time I took the pills . . . that this was not something that I was going to be doing for a week, or two weeks, but basically until, until further notice. This was going to be a part of my life.

INTRODUCTION

A principle aim of our research has been to open a window onto the everyday work PHAs do in managing their health and illness. Integral to this work is the management of medications. As is well known, most PHAs in Canada follow one or another medication regimen that can involve taking large numbers of pills daily. While the type of medication can vary from antiretroviral combinations to vitamins, most PHAs take some form of medication on a regular basis. This is a significant, if not critical dimension of PHAs' health work. Such work requires not only some degree of reorganization of an individual's life around medications, but it also requires individual PHAs to establish and link into social networks that facilitate, support and even govern the taking and management of medications. As such, the work people do to manage their medications is not done in isolation, but is very much a social practice that necessarily connects PHAs to friends, doctors, clinics, ASOs, pharmacists, drug companies, information sources, and a variety of other service providers.

The actual work of managing medications is an aspect of living with HIV/AIDS that has not been the subject of much social scientific investigation. Nor has it been taken up by health care providers and primary caregivers as an important dimension in the development and delivery of treatment information. Our research provides a partial corrective to this gap. The principle objective of this chapter is to explicate the largely unnoticed work and social relations that are part of PHAs' management of their medications. As our research makes evident, taking medications for HIV and AIDS is not a simple matter of regularly popping pills. Medications play a crucial role in the ongoing organization of people's lives. Balancing the demands of different regimens reflects the difficult work of managing medications. By looking at this activity our research emphasizes the importance of attending to the everyday experiences of PHAs and the social character of these experiences.

OVERVIEW OF THE CHAPTER

Without doubt, the issue of compliance is an overarching theme found in medical and non-medical discussions of HIV and AIDS medications. As will be discussed below, compliance not only shapes how physicians, ASOs, health providers and information sources have come to speak about and look at the use of HIV and AIDS medications, but it in turn places a particular set of demands on PHAs. It should therefore come as no surprise that some version of compliance discourse figures into most people's accounts of their experiences with medications. While it is likely true that people understand and act upon compliance in multiple ways, it should also be remembered that "compliance" is a medically-defined practice (as opposed to a patient-defined practice) that strictly delimits what a person can and cannot do when taking medications. Compliance can act as a rather stable regulatory framework of behaviour that people use or resist in the management and evaluation of their medication practices. Our aim here is not to specifically lay out the various meanings of "compliance" expressed by our informants; nor is it to determine what "compliant" or "non-complaint" behaviour looks like. Rather, we have sought here to put into view what can be called "the work of compliance."

The work of compliance needs to be viewed as but one facet of the more general work PHAs develop and employ in relation to their medications. As it is defined within medical discourse, "compliance" refers to a narrow set of practices organized around following – or "adhering to" – a drug regimen. However, much of the work people actually do around their medications does not fit neatly into this definition. So, while a type of work or practice might be shaped and informed by compliance discourse, it might not be intelligible as "compliance" to either health care providers or PHAs. Indeed, it is interesting to note that, when asked about how they understand what they "do" in relation to their medications, most informants did

not immediately refer to “compliance.” Rather, people spoke of a variety of practices and meanings associated with their medications that come from outside compliance discourse. For this reason, we have tended to place the work of compliance under a more general rubric of people’s work on medications. Making such a shift has the effect of extricating our interpretation from the normative framework offered from within compliance discourse.

Our discussion of PHAs’ medication practices is organized into two main sections. In the first section we describe the ongoing work that PHAs engage in as part of taking antiretroviral therapy. We want to move beyond the notion, implicit in compliance discourse, that pill taking involves simply following a set of instructions, in order to unpack the cluster of activities PHAs describe as relevant to taking medications. In our discussion, we describe the institutional context of PHAs’ medication practices. We also explore the work of “realizing the medication day,” by which we mean PHAs’ efforts to translate idealized medical instructions into embodied routines and activities. Here we emphasize the work of recognizing medication time and of acting on that recognition to get medications into bodies. As part of this discussion we look at the emotional and social character of taking pills and the activities PHAs engage in to adjust and modify their medication schedules.

The second section extends the first by looking at how PHAs miss medication doses and/or stop taking antiretroviral therapy for extended periods of time. While we do not view these activities as occurring apart from the work of taking medications, the importance with which they were spoken about by our research participants requires us to treat them in some detail. Once again, our concern is to move beyond the compliance framework and so we do not understand missing dosages as a failure on the part of individual PHAs. Rather we explore it as purposeful activity that can be an attempt to maintain a commitment to a medication routine as well as a form of resistance to the temporal regulation of everyday life. In describing how PHAs go off antiretroviral therapy we look at the clash between embodied and biomedical ways of knowing health as well as at the social circumstances of daily life that render compliance unworkable.

Since much of our discussion of PHAs’ medication practices is made in critical dialogue with established social science perspectives on compliance, we offer a brief discussion of research on compliance before turning to the discussion of our research.

The issue of medication compliance has been present in the HIV/AIDS epidemic since the introduction of antiretroviral mono-therapies such as AZT. However, with the advent of HAART in the late 1990s, compliance and its relative, “adherence”, have come to occupy center stage in the medical

**HIGHLY ACTIVE
ANTIRETROVIRAL
THERAPY (HAART)
AND THE ISSUE
OF COMPLIANCE**

management of HIV. HAART has received qualified, but nonetheless enthusiastic support from the medical community, most AIDS service organizations, and the media as the most effective means of controlling the development of HIV disease and AIDS. HAART has also raised the hopes of many PHAs, but responses have been notably more ambivalent and diverse (Weiss 2000). There are numerous possible explanations for such ambivalence and variation: HAART does not work for all HIV-positive people; it produces numerous negative side effects; it is expensive; and its overall long-term effectiveness is unknown. As is evident from our research, equally important to PHAs' responses is the fact that HAART introduces significant, new demands on people's daily lives. HAART requires very high levels of adherence to what are complex regimens. People must take three or more antiretrovirals at specific times of the day, in conjunction with meals and other medications. According to research into the effectiveness of HAART, little margin for "error" exists for those on such regimens. The common view among medical scientists is that "less than excellent adherence may result in virus breakthrough and emergence of drug-resistant (HIV-1) strains" (Carpenter et al. 1997). It is suggested that even short term "non-adherence" can potentially result in viral resistance and re-population. While previous antiretroviral therapies required high levels of compliance, protocols governing HAART demand near perfect compliance.

HAART therefore calls for a high degree of vigilance on the part of PHAs in the management of their medications. Perhaps not surprisingly, only a few of our informants actually spoke of being "perfectly" compliant or adherent. Those describing themselves as compliant typically held the view that following a prescribed regimen is not only "mandatory," but a full-time life commitment that requires will power and personal vigilance:

Overall, my attitude about compliance is that everything I do is, of course, mandatory. There is no other avenue I would consider . . . I love organization and I consider this, without being melodramatic, unquestionably the biggest challenge of my life. And that's to stay alive. So, I've got to do everything, throw everything I can, and nothing must get in my way. And I will not permit anything to get in my way. I'm busy, busy, it's full-time.

I had a very clear sense of taking the medication and taking it as prescribed, when prescribed, how prescribed and not missing doses.

Both of these informants take up the position of being "compliant" and, in turn, articulate a version of the standard concept of compliance as requiring rigid adherence to drug regimens. From this position, they not

only reveal an awareness of HAART requirements and the dangers of non-compliance, but as the person below suggests, they also tend to take up a common view in compliance discourse of “non-compliance” as both physically dangerous and morally problematic:

[M]ost people I have talked to, they say “Oh, I don’t like taking all those pills everyday.” Fine. I’ve a got simple, straightforward answer: you can commit suicide at whatever rate you choose. You know, if you want to do it now, fine . . .

I’m aware that you don’t mess around with these things. What’s the point . . . ? [Working in HIV-related health services] . . . I witnessed . . . what would happen with people’s blood work if they took their medications, what would happen if they took it sporadically, what would happen if they went on drug holidays on anti-retroviral therapy. So I think I went into it very much with an awareness that this whole piece around compliance, adherence, whatever you want to call it, was incredibly important. Because I had seen blood work results and the . . . clinical manifestations of not being rigid.

The above accounts help to give a basic sense of the nature of compliance discourse, its particular imperatives and what it looks like when a person holds onto compliance as model of behaviour.

While the majority of our informants would not fit into the ideal model of the compliant patient, it is nonetheless evident from our research that the discourse of compliance – and its demands – infuses much of what people do in relation to their medications. This suggests that one important effect of the advent of HAART has been the extent to which it has made “compliance” and “adherence” into central preoccupations of both the medical community and PHAs. However, as is evident in our findings on the work PHAs do in relation to medications, a considerable disjuncture exists between standard medical definitions and assessments of compliance and how PHAs actually take up and put compliance into practice. In order to better grasp this disjuncture it is useful to quickly outline some general characteristics of the discourse of compliance.

Within medical, academic and ASO constituencies, compliance has very much been the dominant discourse through which PHAs’ use of medications is both organized and evaluated. On the one hand, compliance can be viewed as a “medically-prescribed practice” that is set-up and administered by physicians and which patients are meant to strictly follow (Conrad 1985). As a practice instituted by the medical scientific community, compliance therefore establishes basic guidelines for the use of medications. Any

person seeking to go onto HAART will confront these guidelines and ultimately have to develop ways to integrate them into their lives.

Compliance discourse thus functions as a model of behaviour that PHAs and healthcare providers utilize in medication management. As we shall further see, PHAs regularly employ notions of compliance to regulate, evaluate and understand their activities. In a different register, ASOs and other agencies draw upon the discourse of compliance in the development of information for PHAs, as well as for counselling and assessment around people's behaviours.

Compliance has also guided most medical and social scientific research looking into the medication behaviours of PHAs. The principle concern of such research has been to examine and evaluate medication "behaviours" with a view to determining the extent to which people actually adhere to prescribed regimens. A central issue in compliance research is not so much defining what is "compliance," as norms of compliance are generally assumed as already given by medical science. What has occupied most attention is the problem of "non-compliance" – specifically, why people do not follow norms of compliance. Non-compliance is generally construed as a problem in need of solution. While this emphasis on understanding and solving "non-compliance" is partly indicative of the very real concern over drug resistance, it also reflects a more general tendency in medical, behavioural and social scientific research to look at people's medication-taking behaviours or practices almost solely in terms of variations of or deviations from compliance. For the most part, the aim of such research has been to explain why people do not comply with a given regimen, to evaluate non-compliant behaviour and, in doing so, to provide an empirical basis for developing ways to improve compliance.

Critics of compliance research have noted a number of problems with this framework. To begin with, the very notion of compliance has a medically-centered orientation. As Conrad notes, the concept has been developed from the doctor's perspective and "conceived to solve the provider-defined problem of non-compliance" (Conrad 1985, 1987; Trostle 1988; Lerner 1998). Conrad argues that in a considerable portion of research informed by a concern with compliance, the problem of "non-compliance" is construed through the rubric of deviance. Working from the point of view of the physician, compliance research often assumes a moral stance in relation to the non-compliant behaviours it describes. The result is that research is rife with undertones that are both morally evaluative and prescriptive.

Some important corrections to these tendencies have been developed in the social and behavioural sciences (Stimson 1974; Hunt 1989; Holm 1993). These correctives have started to creep into research focused on HIV/AIDS

(Eldred 1998; Gallant and Block 1998; Hecht 1998; Kelly et al. 1998; Lamp 1998). A great deal of this research has sought to look at “compliance” from the patient’s perspective, rather than from the perspective of the medical profession. While quite nuanced methodologically, the majority of patient perspective approaches have tried to shed light on how individual attitudes and beliefs of a patient – along with other factors such as patient-provider relationship, nature of the disease, and type of regimen – influence their perceptions of medications and might, in turn, affect their levels of compliance in relation to a specific regimen. Much of this research is predicated on the assumption that “negative attitudes about medications or illness may also interfere with patient adherence” (Metha et al. 1997:67; Catt 1995; Attice 1997). Interestingly, while emphasis is placed on the “patient’s view,” a principle objective of much research in this area has actually aimed at developing a basis for correcting the problem of adherence by exposing its individual determinants (attitudes, beliefs, perceptions etc). In this sense, research on the patient’s perspective actually does not move beyond the interventionist and corrective nature of compliance research. Indeed, like other forms of compliance research, it too can slip into a moralistic or normative stance on people’s attitudes and belief.

While facilitating ways to improve medication adherence and examining its individual determinants is by all means important, from the point of view of our research concerns, the tendency in patient perspective studies to individualize beliefs and ignore their social character is a serious shortcoming. Important questions of where people derive their beliefs have been rarely asked in this research. In addition, the pervasive orientation in patient perspective research towards explaining individual motivations behind people’s medication behaviour – and particularly, motivations behind non-compliance – overlooks significant aspects of what people actually might be doing in relation to their medications. Looking for motivations of behaviour is not the same as explicating both what people say they are actually doing and the social dimensions of their doing.

Overall then, we can identify some important problems and limitations with compliance research for examining what people do with their medications. Historically, the research has been doctor-centered, relying on medical norms of compliance to evaluate people’s medication behaviours. The discourse of compliance therefore tends to set up an either/or dichotomy, whereby people’s behaviours or beliefs are viewed as either compliant or non-compliant. In this sense, the discourse has the capacity to be both normalizing and moralizing: non-compliance is viewed as deviant behaviour that requires correction. It also limits what can be legitimately construed as PHAs’ medication practices.

**MOVING BEYOND
COMPLIANCE RESEARCH –
MEDICATION PRACTICE**

By using the concept of work to organize our data, we have sought to avoid the prescriptive and evaluative nature of most social scientific research informed by a concern with compliance. However, the intention of our research has not been to level a critique of compliance. This has been done elsewhere (Conrad 1985; Trostle 1988). Rather, by noting the limitation of the frameworks of compliance research, and by focusing on the actual work PHAs do in relation to their medications, we have wanted to put into view the wide range of practices associated with taking medications. Such practices are crucial to PHAs' everyday management of HIV and AIDS, and for this reason should not be side-stepped with the aim of understanding why they do or do not adhere to certain medically-prescribed regimens. We look at these "hidden" practices not only in terms of elucidating what individual PHAs do, but also in terms of making visible their social character. That is, we have sought to present both the kinds of work on medications people engage in and how this work is socially organized. The concept of "work" shifts the emphasis from determining what constitutes compliance to what people do (and how people do what they do) to manage medications.

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**MEDICATION PRACTICE
OBTAINING MEDICATIONS**

HIV medication is expensive and few PHAs can afford to purchase it out of their disposable incomes. A crucial area of work, therefore, involves hooking up to the institutional work processes (insurance companies, social services, clinical trials) that control access to drugs or to money that will pay for drugs. This work varies considerably, depending on the particular access route to medications available to an individual. People with private insurance, for example, deal continuously with reimbursement paperwork and sometimes need to learn about the intricacies of unfamiliar bureaucratic processes, as in the following account:

I keep a file [on drug payments]. For tax purposes as well . . . There is a lot of photocopying. It is funny because you mention the amount of time, but a lot of these activities you just incorporate into your schedule, like making trips to the pharmacy, picking up drugs, making phone calls, filling in applications – all administrative . . . but if you were to sit down and you were to say, add it all up, that time could be a fair bit. There was a whole lot of time spent researching just how Trillium¹ works – the idiosyncrasies of that system and how it meshes with the private insurance . . . It is

1. "Trillium" refers to the Trillium Drug Program, a public reimbursement program for people with exceptional drug costs.

just like running a small business, there is all this administration, all this paper work, and my partner complains because my desk is just covered completely. Photocopies of prescriptions, and just keeping track of the whole mess.

The other institutional work processes every medication-taker must engage with are those of doctor's offices, hospitals and pharmacies, which function as gatekeepers and distribution points for the actual medication supply. If a PHA is to avoid running out of medication, she or he must not only monitor the amount of medication on hand, but do so in a way that takes into account the scheduling practices and dispensing routines of others, and the cost and effort involved in making trips to the clinic or the pharmacy.

You have to remember that you gotta keep it planned – “Oh, I’m running low, gotta make a doctor’s appointment” . . . You run out [of medication] and you can’t see him for a week.

Another time-consuming thing is actually pharmacy hassles. I had to wait at [hospital] pharmacy for two hours once . . . and now they have even changed their policy and you have to book an appointment now with the research pharmacist to get research meds.

You have four drugs that come in four bottles. What you want is for all of the pills to run out at one time so then you can go get the next batch. The problem is that some come in weekly bottles and the other drugs they will dispense for 30 days. So what happens is they start coming out of sync, meaning that you will run out of one drug long before you run out of others. So just keeping – you don’t really think about it, but devising a little system so that, you know, you won’t be making three trips to the pharmacy.

Some of the people who spoke with us described periods in their lives when they obtained their medication through more haphazard routes – from a sympathetic doctor dispensing samples or from an ASO. Getting medication this way depends heavily on the individual’s contacts with doctors and ASOs, it is less predictable and, therefore, less amenable to routine planning or semi-conscious monitoring systems on the part of the PHA. (As we saw in Chapter Two, for some people the choice to start HIV medication hinges on first successfully establishing reliable access to money for drugs.)

However HIV medication is obtained or paid for, the daily work of taking it according to medical instructions has only just begun. This is work that makes considerable demands on the medication-taker, requiring new

kinds of conceptual knowledge and some sort of strategy for undertaking the mental, physical and emotional work of what can be quite a complex regimen.

Your medicine cabinet looks like your grandmother's. You have so many prescriptions for this and this . . . At seven a.m. you start – you are not finished until eleven. Some of the pills you have to take with meals, others on an empty stomach, others you cannot take with this one because it will react the wrong way . . . all kinds at different times. You have to remember all this, you almost have to be a medical doctor to be sick.

I have this container full of different drugs, right? And then drugs in the fridge and other drugs in bottles in a cupboard. And people say, how do you keep track? Like how do you know what you have to take and how many and when? You learn, it is part of your life, it is an everyday thing.

But what is involved in making medication “an everyday thing,” a “part of your life?” This is what we set out to understand. The second speaker represents herself as perplexed at her friends’ requests that she explain how she manages with all those pill bottles. You just do, she says, you learn. When we talked with our research participants about their medication work, we found variation in the extent to which participants were able or willing to articulate their medication practice in terms of conscious strategies. As one of the speakers above put it, when talking about monitoring his medication supply, “you don’t really think about it, but devising a little system so that, you know, you won’t be making three trips to the pharmacy.” This account suggests a kind of ongoing work that slips into and out of conscious focus, where sometimes it is the main business of the moment and at other times it recedes into the background, while still somehow getting done.

Other participants had apparently put a lot of conscious thought into their medication work and so were more readily able to describe in detail what they did. But everyone had something to say, often lots to say, about some aspects of their medication work and the experience of taking HIV medication. Generally, it seems, what people talked about the most easily were those aspects that caused them some difficulty and therefore required them to do conscious emotional or planning work if they were to carry out the treatment regimen.

Earlier in this section, we introduced the notion of medication practice as a way of sidestepping the normative notion of compliance in order to look with fresh eyes at what people actually do around their medication.

Concepts such as compliance or adherence incorporate unexamined assumptions about the work of taking prescribed medication, in addition to taking up a stance within biomedical relevances. We can see this in the terms themselves, which evoke images of following, obeying or sticking to a given set of medical directions. Carrying out a medication regimen under one's own autonomy is a much more complex and active set of activities than such terms suggest. The notion of "following instructions" doesn't get at what people who "follow instructions" are actually doing. When we jettison such terms, how then shall we talk about what people are doing? We begin by unpacking a cluster of activities as described by the participants in our study.

Each medication comes with its own instructions, adjusted for the individual patient – how many pills or ccs of liquid to take at any one dose, how many doses in a day, how many hours apart, whether food should or should not be taken with the dose. These instructions in abridged form come affixed as a label to the medication bottle; more extensive instructions may have been given verbally by medical personnel or pharmacy staff; there may also be accompanying patient information literature. People on antiretroviral therapy take at least two different medications; three or four antiretrovirals are common. They may also take medication to treat the side effects of antiretroviral therapy, medication for HIV-related illnesses and medication for other, unrelated chronic or short-term health conditions, along with vitamins, supplements and homeopathic treatments.

The different instructions for all these medications are somehow combined into a schedule, either by the PHA or by someone else (nurse, pharmacist, friend) into an ideal "medication day." People with complicated drug regimens described actually creating or receiving a written schedule or chart; others keep the schedule in their heads. This schedule operates as a plan, an ideal plan, of how their pill taking should be done, often in combination with scheduled eating and fasting.

Seven in the morning I take d4T, 3TC, and indinavir – three – and then I can't eat for an hour. And then three in the afternoon I take indinavir, so I can't eat after one in the afternoon, and then I can't eat until four in the afternoon, and then seven at night is 3TC and d4T and it doesn't matter in terms of food, and then eleven o'clock at night is indinavir so again I can't eat after nine at night.

This was not an uncommon schedule among our participants. Below is another person's account of his medication day, one that includes medication for another chronic condition. This account references both the plan –

REALIZING THE MEDICATION DAY

the how it should be – and gives a glimpse of the embodied activities through which the plan is realized on each occasion, day after day.

I start out in the morning with Crixivan and my 3TC and my d4T. I can take them on an empty stomach without food or I can take Crixivan with certain types of food. But I take them and my uh, diabetic medication and then I have to sit around and have some coffee or I might go back to sleep for an hour or so. And then I'll get up and breakfast and then I don't take any more medication till the middle of the afternoon, which again is the diabetic medication and the Crixivan cause it has three doses, for most people anyway. And then at bedtime, I repeat again. Although I take Crixivan at midnight cause I try and keep it every eight hours.

When we talk about the work of “realizing the medication day,” we are talking about the way people translate medical instructions into routines and activities that they can repeat day after day, although not as automata: the schedule may be fixed, but each day is unique. The medication taker must actively find or create, in the ongoing flux and action of each unique day as it unfolds, appropriate or propitious conditions for pill taking. “Following,” “complying” or “adhering” hardly get at what it takes to do that.

Based on what people told us, we could see that taking prescribed medication involves two distinct clusters of activity. Although sequential and related, the first does not automatically ensure the second. This first activity is largely mental: it involves recognizing or becoming aware of scheduled pill time at various moments throughout the day. In everyday language, this is often talked about as “remembering to take one’s medication.” Within the flow of each actual day, the medication-taker makes a match between the medication schedule as a plan, carried in the head or written down on paper, and the clock or activity time of the actual moment. “It’s almost three o’clock, and at three o’clock I take Crixivan” or “It’s bedtime, I’m about to go to bed, and at bedtime I take Zithromax.” Medication takers find in the here and now of their lived experience, the categories that evoke their pill schedule (7:00 a.m., 3:00 pm; bedtime).

There is complex work involved in supporting the recognition of pill time as a routine feature of the evolving day. This work entails for some people the development of a new consciousness of self in relation to measured clock time.

I usually pretty much keep an eye on the clock through out the whole day. The trigger for me is usually when I'm hungry, my immediate reaction is wow, where am I in relation to my next

dosing, and can I eat now or can I not? and usually that keeps me on track, 'cause I'm like hungry at least three or four times during the day and I have a pretty good idea where I am on my schedule . . . Um, so but that's when I'm feeling well, otherwise I set alarm clocks to remind myself when I have to take pills, usually whenever I wake up, whatever time I've been sleeping, first thing I think about is do I need to take medication.

I: So, it's a constant schedule in your head?

P: Yes. Something that I'm like at least subconsciously aware of all the time.

But some people didn't find it easy to keep a subconscious awareness of the pill schedule in combination with a sense of passing time.

It's very difficult to have a regimen of keeping on the medication all the time. . . . I mean, you're sitting there and then all of a sudden it's four o'clock [and] you're supposed to take it at two o'clock.

Sometimes you find time goes so fast and you think, oh, my pills! . . . or sometimes you fall asleep and get up and you maybe should have taken the pills when you were asleep.

Participants described having developed specific routines, particularly of waking, sleeping and mealtimes, so that the doing of an activity became associated with taking pills, and thus triggered their recognition of pill time. People also described various strategies that arranged for some kind of exogenous signal to call their mind to their medication schedule. Beepers were used by many, although we heard a range of comically-told disaster stories about beepers going off in restaurants, theatres and work meetings, a situation that generally occasioned embarrassment and some kind of damage control on the part of the medication-taker.

The following speaker uses the programmable capacity of the television to organize his activities and bring his mind back to the schedule.

For the morning I've got the TV. I've programmed so it can turn on, and it's blasting, throughout the whole house, so I have to get up to turn it off because my neighbours are probably sleeping. So then when I get up I take my meds . . . The TV's programmed to go off at eleven. When I see the TV go off [at night] then I know it's time to take my meds.

Others described transferring some of the reminding work to other people.

P1: *Do you have problems remembering to take your meds?*

P2: *No, I got a good caretaker. (Laughs)*

I: *So someone gives you your meds then.*

P2: *Well, well, a friend of mine, John, he comes and usually medicates [me] on time.*

The unofficial agreement that we have in our house is that he takes care of the vitamin question – we both take those – so he lays out the morning dose or evening dose at the dinner table. So, I don't even have to think about remembering to take those. I manage the antivirals, the pain killers or whatever else is going on in terms of prescription drugs and the diarrhea, but he has taken over managing the vitamin part.

Notice in these accounts that the friend or partner does not simply remind the medication-taker that it's pill time; implied in the first account, and described in detail in the second account, is the other person's work of readying the dose, laying it out on the table at mealtime or, perhaps, handing it to the pill-taker with a glass of liquid. As we shall see further on, readying doses several times a day is a tedious task. Having it done by someone else, at least part of the time, and making pill taking into a companionable event within a friendship or intimate relationship, went a long way toward lightening the burden of pill taking for some people.

In order to realize their pill schedules, medication takers usually need more than an internal or external mechanism for keeping track of where they are in the medication day – they often recognize the need for a set of routines that privilege the requirements of the schedule. A significant change for many was that their activities became more scheduled and less open to daily variation and spur-of-the-moment decisions. Participants described altering their routines and planning their daily movements, especially their comings and goings, so that they would be in a convenient place when pill time came around.

I live around them [medications]. Cannot leave home without them kind of thing or have to come home for a certain time because I do not like to travel with them if I do not have to, so I will go to a friend's house and then I will have to leave to take my meds. So it cuts my day a little bit.

Another participant, who had a scheduled dose at 11:00 p.m., described how he used to forget that dose if he went out to a bar earlier in the evening. "By eleven o'clock, it's totally slipped my mind." He addressed that problem by delaying the time he went out so that he would still be at

home for pill time: “If I go out to a bar, what I’ll do is I’ll wait till after eleven to go out.”

Others described attempting to devise their medication schedules in ways that would better fit the preferred rhythms of their lives, so they didn’t always feel they were living around their pills.

I had a chart and I’ve helped a few other people do it. The druggist will do it. Your doctor will do it . . . I made up my own because I wanted the pills to fit into my lifestyle as much as possible so that I would have to make as little change . . . A major change was I quit sleeping till noon . . . Now I have my mornings and I don’t go out late at night. It’s just pointless anyway most of the time except maybe on the weekends.

What became apparent in the way people talked about taking medications was that becoming aware of medication time was only the first step; while crucial, recognizing medication time in the present moment did not necessarily result in the achievement of the regimen on any given day. People still had to act on the recognition, to get the medication into their bodies. To do so they had to carry out a cluster of activities that could involve: readying the appropriate dose (opening bottles, shaking out pills), overcoming dread and revulsion, preparing and eating a substantial meal, if recommended to accompany the dose, concealing the pill-taking from others, and of course, actually putting the pills in the mouth and swallowing them. Our participants talked about difficulties that could arise around all of these activities. By examining these difficulties, we can get a sense of the work involved in completing the medication sequence. (The emphasis on troubles is not meant to suggest that completing the sequence is an event the realization of which is unpredictable for most medication takers at most times; rather, by examining these “trouble stories” we gain an appreciation of medication work that otherwise goes unrecognized, such that “remembering to take one’s pills” comes to gloss and conceal all the work that actually gets the pills in one’s mouth and keeps one’s social relationships intact.)

Some people reported occasions when they didn’t have trouble recognizing pill time, but found themselves balking at the next stage:

The pill bottles were too small and I would open every bottle every damn time and it would make me mad and sometimes I would miss doses because I had to open every bottle.

I will be honest, I do miss a couple doses because I just get tired of taking them.

COMPLETING THE MEDICATION SEQUENCE

I woke up at three o'clock and I thought I'm not getting out of bed to take some pill so forget it. I just shut the alarm off and went back to sleep. I said screw this.

Later in this chapter we examine people's accounts of missing doses and present a way to view missing as something other than failure or deviance. Here our interest is in understanding pill taking as an ongoing struggle, for some people, with anger, frustration, inertia and revulsion. We see that pill taking requires a willingness to interrupt pleasurable activities, such as sleep, as well as constant manipulation of a proliferation of pills and pill bottles – the materiality of the bottles and the pills figured strikingly in people's accounts.

Below two focus group participants talk about how the act of swallowing a particular drug was a prolonged challenge.

P1: Well apparently ritonavir has some kind of [?] or something

P2: Yeah, exactly.

P1: It's one of the ones . . . where I would literally gag . . .

P2: Yeah, gag . . .

P1: Even – even thinking about them took me like half an hour to take my pills.

P2: Yeah.

P1: In the morning . . .

P2: I would take one and then go do something . . .

P1: Just to get them down.

P2: Yeah, yeah.

For other participants, the difficulties they faced were practical ones:

P: I've been a street person most of my life . . .

I: Does that make it hard to take your medication?

P: Of course, of course. Like, walking around with a pack sack on and I've got freaking half of it filled with medications and just trying to find water to take them is sometimes not easy. Sometimes I didn't have food the times I needed to take it [medication].

Given the cluster of activities involved in taking any one dose, and the difficulties that could arise, participants also described a range of strategies undertaken to enhance the likelihood that, when they recognized pill time, they would be able to complete the sequence and swallow the pills along with whatever type of food or drink was recommended. These included planning-ahead strategies, such as having pills and water with them wher-

ever they went or preparing a week's batch of doses at one time, to cut down on the hassle of opening pill bottles.

A lot of it is just being super organized. Having your cupboards laid out, keeping it all together – it is a bit of work. Devising little systems, remembering to take your stuff with you, look at your calendar for each day “Oh, I have got to go to a meeting tonight, I better make sure to take this with me” and that kind of thing.

I have this huge thing from the drug company and there is a platter of pills and it has three compartments, but like if you have five [doses] you run into problems. It works fine. I cannot put my vitamins in there . . . it would have been great to just set them up and be ready for the week. I find the week goes fast though. I just have to open my vitamins every time. I usually do that in the middle.

A problem for some people arose when successfully recognizing pill time and acting on that recognition could be accomplished without much conscious attention on their part. If pill taking becomes too automatic, too routinized, how do you know whether you took that last dose? Thus some people described strategies oriented to making clearly visible where they were in the intersection of the ideal plan and the actual day:

In the morning I put all my pills and my supplements together so as I'm going through the day I see what I've taken and what I haven't . . . because sometimes before that I was worried about missing a dose and just forgetting about it or not knowing if I had taken it or not, so with this pill box it allows me to see what I've taken or what I haven't taken. If I'm questioning whether I took a dose or not I just have to count them.

Taking HIV medication is a conflicted experience for many people. As mentioned in the previous chapter, some people do not experience being on medication as wholly their choice. Others may have chosen medication in the belief that this is the best available way to maintain or improve their health, yet the daily experience of taking medication can feel contrary to the project of looking after their health. The medication has harsh side effects; some, like nausea, occur soon after taking a particular dose, so that the pill taker, in swallowing the pills, is knowingly making her or himself sick. Carrying out an HIV medication regime calls for the PHA to ignore the strong bodily experience of side effects in favour of the more remote

**EMOTIONAL WORK:
COACHING THE
RELUCTANT SELF**

information obtained through laboratory blood tests that document the diminishing prevalence of an otherwise imperceptible virus.

Living with a diagnosis of HIV is an emotional challenge. People with HIV often do emotional work around staying cheerful or at least relatively hopeful about their future; they may try to live well-rounded lives that are about much more than their health status. Yet the work of carrying out a medication regime necessarily enshrines their HIV as a central organizer of their daily lives, even when they are otherwise asymptomatic – or were, until they started getting side effects from the medication.

I find that the HIV medications constantly remind me of how sick I really am.

P: I do not like taking the pills.

I: What is it about that you do not like?

P: Just the pills. Just the idea that this has control over my life rather than me having control over it. So then I get very angry.

Thus, many people recounted a kind of emotional work they did to overcome their dread or resistance to the pills, in order to ensure their realization of the medication day. This work often involved the development of a particular form of consciousness, a new relationship to self and body. We see it expressed in the following accounts, where a knowing, managing self subordinates or cajoles the experiencing self and body:

I know they make me nauseous but I just take them.

I open this one cupboard and it is like a pharmacy but then I look at them and I say “OK, do your job” and then I take them.

A similar kind of mind-body subordination occurs around eating. HIV medications can make some people lose their appetite; others find it a challenge to eat meals according to the requirements of the medication schedule, rather than following the patterns of their own hunger. Some people describe forcing themselves to eat.

I struggle every day, every meal, I don't want to eat anymore, ever.

A particularly complex work of emotional self-management was described by people who were trying to overcome addictions to narcotics.

P: I'll be taking my meds at 4 o'clock and I'm not looking forward to it. I dread it every time I have to take another pill . . . It fucks up my addiction too because of taking all the pills.

I: How so?

P: It gets me wanting to use pills that really do something that feels better for me, that give me an effect that I want.

Not only does the speaker work to make himself take pills he dreads taking because of how sick they make him feel; as a consequence he has to work to keep from taking unauthorized pills that *will* make him feel better.

Given the emotional challenges of medication, it is not surprising that some people reported having enlisted professional expertise to learn how to develop habits of mind better capable of subduing or neutralizing the resisting, experiencing self, as in the following account:

I struggled with this compliance issue for a while and then finally, it was actually one of the residents, she said to me . . . “I do not think we should start you on a new cocktail until we get your head around this problem that you are having because you could screw that up and you are running out of options.” So I went to a psychiatrist briefly and worked my way around the issues with compliance and then I started on a new cocktail last July which was Crixivan, delavirdine, and EPOT and then everything since then has had amazing results I never dreamed of. And compliance is almost perfect, almost.

Even among people who did not describe having sought professional guidance, the accounts they gave of their pill taking and the challenges they faced suggested that they had put thought into attempting to understand their emotional responses, the better to circumvent them.

The issue of other people came up frequently in participants' talk about taking medication. In many people's lives, taking medication is, at least some of the time, an activity that happens under the gaze of others and that, at times, has implications for family and friends. The scheduling demands of antiretrovirals are so strict that people who come into the orbit of a pill taker's daily trajectory may find themselves also, to a degree, living the schedule. The following speaker describes what was for him a process of accepting and normalizing that situation:

When I first went on the drug regime, it felt very oppressive, and it felt difficult for me having to ask for accommodation around when we would eat, if I was with friends and, you know, let's say a dinner party or something. And, I mean I'm over that now, because to me again it feels so routine, and friends just know that . . . if they're having a dinner party and Cory is invited, you have to stop

THE SOCIAL CHARACTER OF MEDICATION PRACTICE

eating by nine. Well, they can keep on eating but, like I can't, and the interesting part of it is just the progress of time, my reaction to that is very different than it was before. I mean now it's just, well, that's the way things are.

For some, the combination of other people and scheduled doses produced a potential hazard of discovery; it could easily happen that pill-taking time coincided with the presence of people who were not to know about the pill taker's HIV status. This was often a problem for people who held paid employment. Participants talked about various strategies of concealment, as well as the anxiety these situations provoke.

Certainly at work, that is why the three o'clock pills are particularly difficult to take because I run to the washroom every day at three o'clock, and they start to think, wow, he is really regular.

I stayed with my sister for a month . . . during the ice storm. And I had to wait until they were out of the house and then I did up my little pillbox and in the morning before I would appear, I would take my pills and I am glad they had another bathroom.

The following speaker cannot conceal her pill taking from her children; instead she conceals it conceptually, by presenting her pill taking as related to a health problem other than HIV.

I: Do your children know?

P: No

I: So what do you say?

P: That I have to take. "Because why?" "For me." First of all they thought I was sick, they thought I was losing my mind but they saw I take medicine and start to ask questions and I have to tell lies and I do not like to tell lies, it is hard.

Thus, for some people, realizing the medication day also involves delicate work negotiating the demands of the medication schedule in relation to the presence of other people, as well as managing other people's reactions to the sight of the medication.

I just had ingrown toenails surgically removed and the nurses that came to attend to me seen me take all my pills and I said to them jokingly, how do you like my breakfast?

Women who have children at home and responsibility for the care and feeding of others often find they must do an extra layer of work to carve

out the time and conditions they need to realize their own particular medication and eating schedules (which usually differ from those of their families). As we will see later, the expectation for women to privilege the needs of family members also shapes how they come to miss or go off antiretroviral therapy.

For many people, the experience of taking HIV medication is as much about coping with side effects as it is about realizing the pill-taking schedule through daily life activities. HIV medications can have strong side effects such as nausea, vomiting, diarrhea, constipation, neuropathy and fatigue. These side effects can last for weeks or months after the introduction of a new medication; for some people they endure for as long as the medication is taken. One side-effect, lipodystrophy, changes the shape of the body through the redistribution of fat and muscle mass, and marks the inscription of HIV-medication on the body in enduring, visible ways. Taking antiretroviral therapy thus brings some people into close acquaintance with an out-of-control body.

TIMING, PLACE AND THE OUT-OF-CONTROL BODY

I'll get up in the morning and I'll have a cup of tea and then the next thing you know is that my face is in the sink and I'm throwing up because I don't feel good.

Coping with this becomes an additional factor in the work of realizing the intersection of the medication schedule and other life activities, especially those that involve going out in public. The strategic timing of doses can be crucial.

I usually have it [nausea] in the morning and because I have somewhere to go every morning I make sure I am dosed early enough so that if it is going to happen it happens before I leave the house.

Others spoke about the humiliation and messiness of sudden episodes of diarrhea in public places:

Like every now and then having an accident in public, like thinking you're going to fart and you don't fart. It's not gas, and sometimes leaving my buggy in the middle of the store and, you know – getting home and cleaning up.

When the diarrhea couldn't be predicted to occur at particular times of the day, people reported that they ended up staying home until the diarrhea became less of a problem: "You do not go anywhere because you are afraid of your bowels letting go. No warning, nothing – they would just go."

Some people described altering their routines and developing a new knowledge of public spaces, especially the location of public washrooms and fast routes to get there.

I stopped going to the Y. I had a program there and I complained because they only have a washroom in the basement, they don't have one on any of the other floors and the workout area. So filed a complaint there. I had to become more pro-active in that way. So they will give me a key to the elevator if I'm not well enough, so I can get through places quicker.

The anticipation of possible side effects and their drastic limitation on mobility was an important consideration for people planning a change in medication:

Every time I change it's worse . . . you have to have a totally blank calendar for four to six weeks when you change a cocktail because you don't know what's going to happen . . . Plan to be at home, be stocked with toilet paper and paper towels and just be totally stocked so you don't even have to go shopping for six weeks. You know, friends can pick up fresh stuff.

The dramatic physical side effects of antiretroviral therapy can also reach into and demand alteration in people's practices of choosing and preparing food:

I am developing food allergies [on the medication]. You buy your groceries and then you find out you're allergic to half of it. You cannot really afford to replace it. I developed an allergy to milk so I have to take lactase pills and then that allergy passes and then it might be tomatoes – that was a big thing for a while; then beans upset your stomach, but you never know. It just changes your body chemistry.

THE COMPLIANCE DISCOURSE AND MEDICATION PRACTICE

Although it was not our intention to introduce the compliance discourse as a normative standard into our interviews and ask participants to assess themselves in its terms, it was evident that most of our participants drew on that discourse as a resource in assessing and carrying out their medication practice. People's accounts of their strategies often referenced the compliance discourse, explicitly or implicitly, as grounds for self-critique or as an ideal they attempted to realize:

I am usually pretty well on schedule. I mean I take my pills say, 10:30 a.m. and 10:30 at night, every twelve hours, just twice.

Sometimes I may forget. If I am going out I will take my morning dose early like nine o'clock which you are not supposed to do because that is an hour and half off schedule and then I will take them at nine at night. It should be consistent twelve hours, every twelve hours. You should be almost exact.

The compliance discourse was also referenced as authorizing people's pride in successful pill taking, especially following times in which they had found it difficult to realize the medication day:

P1: I do not like missing doses. I have been doing pretty good. A year and a half ago was hard, but now I have got it right down and I hate missing a dose.

P2: I think with me, I was sat down because I was not doing it either and she explained it to me in no uncertain terms, you take them on time as close as you can, just because you missed, unless you are not going to be able to get them, if you miss them for an hour, still take them.

Despite the importance of the compliance discourse in structuring people's accounts of their medication practice, it was not always the case that people attempted to realize, unquestioningly, the pill schedules they were given.

People talked about their work translating received biomedical instructions into the activities of their daily lives, but they didn't necessarily treat the instructions as unalterable. Many people's accounts of their medication practice interpret or recast medical instructions as allowing degrees of flexibility. Often this is described as an orientation to pill taking that evolved from a previous, more rigid orientation.

The following speaker describes a day-by-day adjustment of pill taking within the parameters of an overall plan that has been reconceptualized to allow for greater flexibility:

P: You know, there's no real complexity in terms of when I take them. For a while I was concerned with having to have them at exactly the same time everyday. I sort of strayed from that. You don't necessarily get up the same time every day and sometimes I find working downtown, I don't get home until seven versus six type of thing. I fall into the routine of taking them when I have breakfast and when I have dinner. I don't think an hour here or there is going to change it too much.

I: So you don't have that worry any more about precision?

ADJUSTING THE MEDICATION SCHEDULE – AS PLANNED, AS LIVED

P: The response has been fairly good so I don't think it's had a huge impact.

Here is another participant's account of a flexible "medication day:"

I am on a very easy one, once in the morning and once at night, very easy, eight to twelve hours apart, there are times I take 15 hours apart or seven hours apart. I just – you know what? I don't think it is imperative at this . . . I do not feel like I am going to die. I know my body I know when I am not feeling well.

The following speaker describes occasional adjustments to fit pill taking around his plan to get an early night.

Then the eleven o'clock one, like sometimes – like if I go to bed at nine I say "Okay I'll pop that one."

The work of interpreting how tightly a pill schedule needs to be reproduced in actuality draws on the PHA's knowledge about recommended doses but also his or her bodily experience and ongoing health monitoring. People often seem to tie medication flexibility to their sense of their health status, however measured – whether through biomedical forms of knowledge, such as lab results, or through their own experience of their bodies. We can see this above, where the first two speakers justify their flexible strategies by appealing to the good state of their health.

Some people described adjusting the entire pill schedule as a plan that would be easier for them to realize day after day, that would better fit their own life rhythms and habits, or that would be easier in its side effects on them.

The clinic set me up with the computerized print-out – this is when you eat, this is when you take this so that you can eat. Well, I am sorry but my life does not work that way. Because I do not always eat at five and noon so I had to readjust. Even with what pills I am taking I readjusted the combination of pills that I took at a given time because I found that if I took one of the pills out the nausea was not there. I did that experimentally.

They had me on Septra in the morning and I found it better at night.

Many of the people who spoke to us treated biomedical expertise, especially regarding dose timing and dose missing, as provisional and evolving

rather than authoritatively fixed. PHAs seek treatment in a medical context shaped more by experiment and discovery than by established convention. Thus, some people approach their medication with a similar orientation.

I have a basic distrust for the medical profession and I am getting a distrust for the clinic that I attend in that I am not sure anyone really knows what they are doing with the drugs . . . I take AZT three times a day, that is the prescribed dosage. Then I find out that you can actually take the six pills twice a day – so three and three rather than two, two, and two. This is not coming from the medical profession, but what you call the street or from the underground community. The community is saying that you don't have to take them that way.

In the preceding discussion we have unpacked and examined some of the work that goes into carrying out antiretroviral therapy for the treatment of HIV. For the concept of compliance as a normative standard we have substituted an alternative concept, that of realizing the medication day, which directs our attention to what people are actually doing when they take prescription drugs. Most of the people who spoke with us took up a position within the compliance discourse and presented themselves as wanting to take their medication in a way that would be good for their health – although as we have seen, people sometimes brought their own judgment into determining what that good way might be.

Throughout our study we have been continuously aware of a tension in our participants' accounts between biomedical and experiential forms of knowing. It crops up in discussion of the work of using information and making decisions about treatment; we can see that it also features in the work of managing a treatment regime and evaluating its results in balance with a person's project of living a life that goes beyond and has other goals than pill-taking. In the following section we see that tension surface again in people's accounts of missing doses and stopping medication.

People described a variety of situations in which they missed a scheduled dose of their medication. A number of participants reported missing a dose that they made up a short time later. Others described missing dosages altogether.

From a compliance perspective, missed medications signal deficiencies in PHAs' individual behaviours that can be understood through scientific research. One participant in our study described his involvement in one such effort:

SUMMARY

MISSING MEDICATION

Right now I am on a study with the pills and they put a counter on my bottle and I bring it back at the end of the month and then they will know what kind of schedule I follow and if I miss them. And they are trying to figure out how people are coping with taking the medications. I had managed with a pill bottle to be pretty much on schedule, an hour's difference. I usually take them at three but some days at four or 3:30 type of thing. About once every two weeks I might forget.

The forms of research that this person describes generally treat missed dosages as mistakes, errors, or forgetfulness on the part of individual PHAs. They focus on what PHAs do as a problem and seek to offer people new skills to enhance or alter what is considered inadequate coping or, in the extreme, deviant behaviour. Our research suggests a different way of thinking about what is happening when PHAs miss medication dosages. Our approach emphasizes how missing medications can involve purposeful activity that is not well grasped from within the moral framework of established compliance discourse.

FORGETTING

Of course, some participants did describe missing doses as a simple matter of forgetting. However, even these accounts display how missing medications fits into the broader health work PHAs engage in. From a perspective emphasizing PHAs' work of taking medications, forgetting emerges out of situations where the work PHAs do to develop and maintain routines is put off. Rather than simple mental error, forgetting becomes a matter of disruptions in PHAs' daily rhythms of pill taking or of cues that are missed or misread. Consider the following example:

I was out working in the garden in the backyard and it was like nine o'clock. And I was thinking "God it's nine o'clock, why hasn't my pill beeper gone off?" I have to take my pills at nine o'clock and I took them, I took pills at nine o'clock and what I had taken were my eleven p.m. pills (laughter) and then I was like, the minute I swallowed them I was like "OH FUCK! WHAT HAVE I DONE!" And I was, I was getting confused. Because nine o'clock is when I can't eat anymore, I can't eat after nine p.m. And I was out working in the garden "Isn't this weird the beeper hasn't gone off, but something happens at nine o'clock, I'm supposed to take pills." So I think in almost two years of being on medication, twice I've had like a mix up.

In other people's stories, forgetting is even more clearly tied with active work. For the PHA quoted below, missing a dose occurred as a result of sleeping through an alarm. What is interesting in his account, however, is

how, upon waking, the speaker deliberates over whether or not to transform a delayed dose into one that is missed completely. What makes the dose a missed one is a particular negotiation of compliance discourse. There is interpretive work here, a kind of tempering of the call for strict adherence that is quite different from the organizing presence of compliance discourse in the experience of the speaker quoted above.

Everything that I've read says that it's not good to miss a dose because then you become resistant to the drugs . . . But I thought, "I'm not going to sit there and worry about it." I've been pretty lucky so far and my regime has been, I haven't really altered it. And every once in a while, like once in a blue moon, I wake up – you know. Let's say I have to take my dose at one o'clock in the morning 'cause I take it three times a day every eight hours. So let's say I take it at five, I have to take it at one cause usually that's when I take it 'cause I usually take it either seven, between seven and nine hours later. And I missed it, you know, I woke up at three o'clock and I thought "I'm not getting out of bed to take some pill so forget it . . ." I said "Screw this."

For many others we spoke with, missing medications was not a matter of forgetting, but of more deliberate activities. Participants often spoke about missing doses as something they did to temper the difficulties and demands of strict treatment regimens. The sheer volume of medication, the frequency and difficulty of swallowing pills, and harsh side effects made taking pills a trying experience that some PHAs dealt with by occasionally missing a dose. As one person said "Sometimes, I will be honest, I do miss a couple doses because I just get tired of taking them."

It is important to understand that in the context of long-term medication use, missing doses is not simply an error or a failure to comply with a treatment regimen. Instead, it can be an active feature of PHAs' work of staying on treatments. Faced with the prospect of taking antiretroviral therapy for an indefinite period, some PHAs permit themselves a break or lapse in their routines as a way of maintaining their very commitment to those routines:

Sometimes I will miss purposely. Like I really do not feel like taking the pills, I do not have the energy to go and gather them all up and I won't. And then the next day I think, better get those pills into you today, don't miss anything.

The movement in and out of scheduled pill taking and its association with particular forms of reflection and work on the self are further

ACTIVE MISSING

suggested by the PHA's comments below. For this person, sticking to a treatment regimen is made difficult by the requirement to take pills with food. While he manages to take pills as prescribed during the week, he permits himself a break on weekends. He talks himself "out of it" and, like the speaker above, does a kind of self-coaching to get back on track. His account suggests how missing a dose or taking pills in ways other than as prescribed can be a deliberate effort. It can become a form of temporary relief from the strictures and self-monitoring of pill taking that becomes integrated into PHAs' medication routines.

I force myself [to eat]. It's particularly bad in the morning when I'm already [not] a morning person to begin with . . . The past year or so I've been trying to eat in the morning . . . I have really got to force myself to get through the breakfast . . . When I'm going to work it's better. Monday to Friday I'll get up in the morning and I'll eat breakfast, although it's awful and I take the pills and go to work. On the weekends, I usually manage to talk myself out of it. I'll just take the pills without any food, even though I know I'm not supposed to be doing that. I'll eat later in the day, at lunch or something. And then at dinner, I'll eat and take the pills, which is what you're supposed to do.

MISSING DOSES AND RESISTANCE TO A REGIMENTED LIFE

In their talk about missing doses, research participants also referenced their resistance to the forms of self-regulation that are a part of adhering to complex treatment regimens. This resistance was implicit in people's stories about needing to produce flexibility in their medication routines. However, it was also spoken about in direct ways that further demonstrate how missing doses is about much more than the shortcomings of individual PHAs.

The speaker below, for example, uses the language of the workplace to articulate what is required of pill taking and to position himself as someone who stands outside the forms of self-discipline and regulation required of strict compliance. For him, and others we spoke with, missing doses is not a personal failure, but arises out of a confrontation between ways of being. It is a form of resistance to the requirement to lead a particular kind of disciplined life:

P: Because I am not home I am not a clock puncher. So three o'clock in the afternoon those two pills are the ones that are most likely to be missed. It is easy to get up and take the pills or take them before you go to bed, but it is the ones in between that I find difficult to remember.

I: So it is a question of remembering?

- P: *Yeah and wanting. I think that the desire, because I really do not want to do it. I do not like taking the pills.*
- I: *What is it about that you do not like?*
- P: *Just the pills just the idea that this has control over my life rather than me having control over it, so then I get very angry.*

This speaker's use of the clock punch as a metaphor for the external imposition of temporal regulation in one's life resonates with the comments of other research participants. In the account below, for example, the person uses the notion of the military drill to reference the temporal organization of daily life necessitated by strict compliance. While he does not express his resistance to such strictures as anger, he echoes the quote above in how he positions himself as a kind of person who lives in contrast to what is required of the compliant subject. While he refers to himself as failing and fucking up, his comments suggest how missing medication doses is about much more than this. Rather than simply registering personal failure, his remarks suggest a rejection of a particular way of monitoring and tracking one's self and one's activities over time. From this perspective, missing arises out of a discord between the organization of PHAs' day-to-day experience and the rational, calculative and self-regulated life of the presumed subject of compliance discourse.

I'm really glad that people are relaxing about it because that military drill, when the things first came on the market, it was really painful. And some people like that, you know. But I've never been any good at military drill at all. I failed big time at any of those macho things and so telling me I had to do this at eight and something at four and then something at six and something at twelve I just knew I would fuck it up. So I thought I'd just do my best but I knew I would fuck up.

While the interview excerpts above indicate how some PHAs miss doses not because they are personally deficient but because they lead lives that are not organized around temporal self-monitoring, they also tell us something else. They suggest how missing doses can be linked to changes in the social presence and force of compliance discourse in the lives of PHAs. Some people we interviewed spoke about how, particularly as they took antiretroviral therapy over time, they adjusted their initial concerns and anxieties about following recommended treatment regimens in a strict fashion. Time and experience with medication routines seemed to produce a certain ease around occasional missed doses:

**THE CHANGING FORCE
OF COMPLIANCE
DISCOURSE**

When I was on ritonavir, every time I was on ritonavir I had to eat first. So I had to make sure I was awake so I could eat something that I could recognize, you know. So it was . . . when I missed a dose, it didn't, well put it this way, it's not that I started off that way. It didn't take me long to get used to being able to miss a dose. It wasn't something I had a problem with for a long period of time.

For some participants, a changed assessment of the consequences of non-adherence was related to particular forms of self-observation over time. The remarks of the following speaker show how knowledge of one's health developed through prolonged interpretation of medical test results can lead to a more relaxed relationship to an occasional missed dose.

We talk about adherence right. If you are taking your pills on time and stuff. I mean I am usually an hour, an hour and a half, sometimes two hours off time. But with my blood work and stuff it really has not shown any drastic drop, or I have always maintained. That would show if you have been off schedule it would be affecting the virus. That is what I thought. And you know, my viral load is very, very low and my CD4 count is reasonably high so I must be doing something right.

People's changed relationships to compliance discourse, the tendency on the part of some PHAs not to "buy in" to strict adherence, and a certain normalization of occasional missed doses are not individual accomplishments but social phenomena. The intensity of compliance discourse and the admonishment to strictly following medication regimes emerged in our research as a historical moment, something that while continuing today, was at its height at the time antiretroviral therapy was first introduced. Over time, as PHAs have followed their lab results and shared their experiences of taking antiretroviral therapy with one another their assessments of the need for absolute compliance has shifted:

I: Do any of you feel that pressure from anywhere, like from the physicians anymore or from other places around compliance or is that sort of passé now?

P1: Not anymore.

P2: Not anymore.

P1: At the beginning it was bad. I actually talked with [a friend] before I went on the drugs because I was freaking about thinking oh it's so rigid and stuff and [a friend] talked me out of that way of thinking.

I: *That's really interesting.*

P1: *It got to the point where, I remember when I missed my first dose and it was like "Oh my God I can't believe it," you know, it was just like "Okay that's the end of the world . . ."*

P2: *I know it's insane.*

P1: *And now it's just, now I miss a dose about every 80 to 100 dosages so about once every six weeks I'll miss one and it's like well I've missed a couple already and my viral loads are still undetectable so hopefully it will continue that way. And if not I get a viral load every three months so I'll catch it quick enough. [Laughter].*

As part of our interview discussions, PHAs also told stories about going off antiretroviral therapy. These accounts were not focused on intermittent missed dosages, but on extended periods of time during which people stopped taking their treatments. Some people spoke about not taking their medications for a few days after which they started up again. At the time of our interviews, others had completely stopped taking antiretroviral therapy for a number of months. A repeated cycle of taking medication, then stopping for a few weeks or months, then resuming and stopping again was also described.

In some respects, people's accounts of why they stopped taking antiretroviral therapy were similar to the stories they told about missed dosages. For example, side effects and the difficult logistics of taking multiple drugs formed part of the backdrop to stopping medication as well as to missing doses. In addition, the resistance to temporal regulation that was a part of people's stories about missing an occasional dose also featured prominently in their accounts of going off medication altogether:

I decided to quit taking pills because taking pills takes over your life and you have to take them three to four times a day. I threw everything in the garbage and said "To hell with it. I am healthy right now."

It is important to recognize, however, that going off medications is something that comes about and that is experienced in ways distinct from just missing the occasional dose. It is a unique experience that is tied to a particular set of social circumstances. Our research suggests the significance within these circumstances of a sequence of activities organized around changes in PHAs' experiences of their bodies that can lead to stopping medications. Consider the following example.

GOING OFF MEDICATION

COMPLIANCE, EMBODIED KNOWLEDGE AND PLEASURE

Just prior to this Christmas I became violently ill again. A lot of vomiting and headaches and that's when I decided "No use taking these because they're not staying down." And then when I finally got to see my doctor I just told him that and he said "Well maybe that's a good idea," because maybe it's the medication that's making me vomit as well. And then in two weeks it cleared up and I was feeling fine and I didn't go back to my doctor, I guess because I didn't want to. Because I felt so good and I didn't feel that fatigued feeling anymore. So I stayed off the medication and I did that for a couple of months and then I started feeling guilty and I went in and had my blood test.

This speaker offers a complicated narrative about how he came to stop taking antiretroviral therapy. An important feature of the story is how going off medication is something that occurs over time. It is useful to consider his account in sequence and in some detail.

The account begins with a description of illness and or side effects – in this case vomiting and headache – and the speaker's decision to stop taking medications. But that decision is not strictly speaking personal or definite. Indeed, the changes in the speaker's health and, likely, his stopping medication prompt him to see his doctor. With his physician, a certain amount of joint interpretive work around the question of stopping antiretroviral therapy happens. That work affirms and extends his earlier decision. Next, his account registers a set of bodily experiences that resonate in the comments of many of our research participants. Once he stops taking the treatments, the speaker begins to feel the vitality of his body in new and renewed ways. His symptoms clear, he has newfound energy and he feels "so good."

This experience of the body presents a set of rather profound changes that occasion a predicament. What is the speaker to do? Feeling "good" invites the further extension of not taking drugs. But what about the requirements of compliance? While the speaker does not directly articulate his experience as a moral dilemma, his account renders the pleasures of the "vital body" as forbidden, to the extent that they are associated with not taking medication. His account suggest how, as part of a series of activities that support going off antiretroviral therapy, a certain clash occurs between a felt experience of the body on one hand and biomedical knowledge and the dictates of compliance on the other hand. In the end, the speaker opts for pleasure and stays off his drugs, if only for a couple of months, for the authority and organizing presence of compliance discourse in this person's life are strong. He feels guilty about not taking his drugs, a guilt that keeps him away from seeing his physician and that, in the end, returns him to the world of biomedicine.

The sequence of activities and experiences represented in this story – illness and/or side effects, an initial cessation of medications, visiting physicians, pleasurable embodied experience, continued stoppage of drug taking, avoiding medical authority, guilt, and return to the biomedical domain – were repeated in different ways throughout our research interviews. For the PHA quoted below, for example, going off medications does not last as long as it did for the speaker above. His account also does not reference the health work of visiting a physician. Still, his story suggests how going off antiretroviral therapy proceeds through a sequence of activities in which a privileging, if only temporary, of embodied knowledge and pleasure is paramount:

I got sick, like some gastral infection and I just couldn't take any pills. I couldn't even look at the pill bottles, I was getting so sick. After a couple of weeks I was better. I thought oh God, I don't feel weird – because you do become accustomed to the fact. I mean you can't tell me like taking five kinds of pills everyday you become accustomed to it, but in its absence you notice this huge difference. Now it's an illusion because really your viral load is going up and you know you're playing with fire but there is this very brief, you know it's kind of like smoking pot for the first time, it's like wow I kind of like this, it's weird but I like it. And there's this guilt thing and you go back and go "Well, it was interesting, a little reprieve from gastrointestinal torture but now I'm going to go back."

Once again stopping medication emerges out of illness and takes hold within a confrontation between compliance discourse and embodied knowledge. More specifically, once the speaker initially stops taking anti-retroviral therapy he experiences a “huge difference” in his embodied sense of health that propels him to continue not taking his medications. This embodied understanding of health lies in tension with compliance discourse and biomedical knowledge which exert their influence as organizers of his experience in the form of background knowledge about how “viral load is going up.” The discourse of compliance is also a source of the guilt through which he relocates his understanding of and action on himself within a biomedical framework.

These two accounts are striking for how they position bodily pleasure in relation to not taking medications. In both stories, an initial stoppage of pill taking becomes a more prolonged cessation of treatment on the heels of a renewed sense of bodily vitality and health that it brings. Rather than thinking about going off medications as an error or deficiency on the part of individual PHAs, our research suggests how it is associated with an everyday experience of feeling good and alive that runs counter to and in

some sense resists a biomedical way of knowing about health. Here is another example of how this works:

It was a decision made on my own. One day I was home and just said “Well I don’t need this.” And then a couple of days went by and I didn’t really notice it and then I’d say probably about a week or two weeks afterwards I started to eat better, I started gaining a little bit of weight, I got more energy, I’m doing things. And I didn’t tell my doctor for like eight months to a year. He just assumed that I was on the pills . . . I was constantly seeing him and he said “You’re gaining a lot of weight, you look great, the pills must be working” and of course I’d lie and say “Oh yeah, the pills are working.” And then it got to the point where I couldn’t lie no more . . . I just recently gave blood [for health monitoring] and there’s nothing like sitting here going “Sure, life’s perfect, you know my viral load’s huge,” so I just basically told him. I told him.

GUILT AND GOING OFF MEDICATIONS

A further feature of PHAs’ stories about going off antiretroviral therapy is how the authority of compliance discourse resonates in them much more strongly than in their accounts of missed dosages. While people expressed a relaxed stance toward compliance in their narratives about occasional missed medications, their descriptions of going off medications registered a strong organizing presence on the part of compliance discourse. As already discussed, in our research, compliance is part of a biomedical way of knowing health that stands in contrast to what emerges as an experience of “forbidden” embodied pleasure when PHAs stop taking antiretroviral therapy. The moral dimensions of strict adherence further present themselves in research participants’ accounts of guilt. Guilt operates as a curious organizer of what people do. On the one hand, PHAs’ guilt at not taking their medications keeps them away from their physicians. Or, such as for the person quoted above, it leads them to provide accounts of themselves that fit the compliance frame, even if they are not following their treatment regimens. On the other hand, guilt organizes people back into biomedical treatment and biomedical ways of knowing the body and how to act on health. The following quote offers one example of how this is so.

P: I was questioning “Well, so what if I don’t take my medication?” I feel great. So my viral load goes up and my CD4 comes down a bit. What’s, that’s just what I have to give to actually start feeling normal again. You know, not to be rude, but to have a normal bowel movement is just heaven. And it’s like once I got into not taking the medication I sort of felt normal

again. But the guilt started coming in and I thought well, I guess I should start going to see the doctor again.

I: And the guilt was strong enough that it made you take the medication?

P: Yeah. Oh, I go through medication guilt every day.

Our research also suggests that going off antiretroviral therapy arises for PHAs out of situations in their day-to-day lives that make taking medications simply too difficult to manage. We have already spoken about the considerable work that PHAs do to develop and adjust pill-taking routines, to manage medications with the demands of their social relationships, and to deal with the side effects of antiretroviral therapy. When people's medication practices are understood in the context of their everyday lives and the other forms of health work they engage in, stopping antiretroviral therapy can be understood as involving much more than failure or incompetence. It arises out of the interface of the organization of people's daily lives – with all its emotional, personal, social and practical complexity – and the formal requirements of compliance. Put simply, PHAs stop using antiretroviral therapy when they are immersed in social circumstances that render the work of compliance unmanageable.

One set of experiences that makes taking antiretroviral therapy extremely difficult, is dealing with serious emotional problems. In our research, PHAs coping with depression spoke in detail about their deliberations over whether they were at a place in their lives that would permit them to follow complex treatment regimens. Others dealing with depression spoke about how they had stopped taking antiretroviral therapy. In the following quote, for example, the speaker is describing a situation in which he elected not to tell his physician he had stopped taking medical treatment for HIV:

I: Did you tell [your physician] that?

P: No. I knew what his response would be like . . . No particular reason at the time, but I was really stuck. I was living one day to another. I really didn't care about anything at the time. And also, you know, it changed my mood. You know, drop dead tomorrow it really didn't matter to me.

Below a PHA describes a related set of emotional circumstances. In this instance, changes in how the speaker feels about her self and her life are connected with a pattern of going on and off antiretroviral therapy. In the account, she tells how the already difficult work of pill taking becomes com-

THE SOCIAL CIRCUMSTANCES OF GOING OFF ANTIRETROVIRAL THERAPY

COPING WITH EMOTIONS

plicated by the emotional adjustment that comes from recently learning about her HIV-positive status. Stopping medication also arises for her out of the emotional complexity of a relationship with a partner who would prefer that she not be HIV-positive.

I am not very good at taking them [AZT and d4T]. I get mad every couple of days and fire them away and it takes me about four days to fish them out of the garbage. I find that it works with other factors in my life. Like love factors type of thing. Like things are not going too well “To hell with it, what do I want to take the pills for, I do not need to live long.” I do not know being so new I am still on the emotional roller coaster. I have heard of people taking it so bad and I do not really, but I fell in love with someone who really does not want me that way and I do not know how to cope. I have never had these feelings about anyone and I do not want anyone else and without this one I do not want to live quite literally.

FAMILY AND PERSONAL RELATIONSHIPS

The quote above suggests how, in the context of day-to-day life, going off antiretroviral therapy can be connected to the demands of personal relationships. This connection was voiced by other research participants in our study, particularly by HIV-positive women. Having and raising children, for example, presented women with demands made of them by other people that complicated the self-regulation required of the work of compliance. As one PHA put it,

I was missing some so I stopped. My son is small and I had to take care of the baby and I was always forgetting them.

These simple remarks begin to open up for view important features of PHAs' experiences of going off antiretroviral therapy. Like many other research participants, the PHA quoted above stopped taking medications because her day-to-day life was not structured in ways that allowed her to follow the requirements of “proper” pill taking. Rather than displaying incompetence or inadequate behaviour, she demonstrates a keen awareness of the prevailing biomedical understanding of the consequences of not being compliant. The quote points to how stopping antiretroviral therapy can arise out of the work of self-reflection through which PHAs come to recognize their lives as currently too complex to support the requirements of compliant medication use. Of course, for the person quoted above, what “gets in the way” are the demands of childrearing. Her remarks begin to suggest how stopping medications is shaped by a gendered organization of family life in which women's lives are partly structured by the needs of other people.

This feature of how going off antiretroviral therapy comes to be is further suggested by the following remarks:

I'm thinking I really have to go back on the medication because it did a lot of good. I mean I'm asymptomatic, but my viral load was undetectable for a long time, my CD4 went up, so I knew it was doing me what it's supposed to do. And I had no side effects so I didn't mind taking it. But I don't mind going back on it, but my schedule is crazy and I can't go back on it. I mean if I go back on it I will go off again, which is something I do a lot. Like by the time I finish taking care of everybody I don't have time. Like I came home from work yesterday and I went to bed at five o'clock and I didn't get up until 8:30. I was so tired. So that's the kind of thing, and so you miss it. And if I work nights it's a different schedule . . . So that's one of the reasons that I'm so scared to go back on it because I want to make sure that I take it the way I'm supposed to. But right now I can't commit to that.

For this person, stopping medication use is not about illness or side effects; as she puts it, she doesn't mind taking antiretroviral therapy. Instead, the problem arises out of a disjuncture between the pill-taking requirements of an ideal treatment day and the realities of her daily life. She describes her daily routine as crazy, a characterization that likely arises out of a combination of the demand she faces to care for others when at home and a changing shift work schedule. In this example, stopping medication use is about a kind of temporal clash. The speaker's lived world is shaped by gendered expectations to prioritize the needs of other family members, which becomes all that more complicated by an organization of paid work that has a changing schedule. The orderly, regularly timed pill taking required of compliant medication use simply does not fit the realities this person's life. And her reflection on and appreciation of this discord is what keeps her from resuming treatment.

The social circumstances out of which PHAs come to stop using antiretroviral therapy extend beyond the gendered family obligations and forms of paid work noted above. One important example of how compliant pill-taking is out of synch with PHAs' day-to-day life circumstances emerges from our discussions with people who experience themselves as having problems with alcohol use, who use injection drugs, or understand themselves to have a drug problem. For these PHAs, going off antiretroviral therapy can arise out of bodily responses to taking medical treatment while taking alcohol or using drugs. It can also be a matter of the everyday activities they

DRUG AND ALCOHOL USE

must undertake to support a drug habit. Others we spoke with stopped taking antiretroviral therapy as part of the health work of changing their drug use. We heard a number of accounts of how, through visits with physicians, social workers and counsellors made as part of efforts to “get their lives together,” PHAs stayed or went off antiretroviral therapy.

The following quote suggests some of what can be involved in going off antiretroviral therapy for PHAs with drug and alcohol problems. The speaker is offering a retrospective narrative of change from noncompliant to compliant medication use. The account is interesting for how it positions stability in relation to taking antiretroviral therapy and associates stability with changes in a personal relationship and drug use.

P: With all the medications I tried before it was hard for me. It was yo-yo all the time. I would do it for three or four days and then miss for weeks. Sometimes I would just be so angry I just would not take them. I would look at them and get angry and say “No I am not taking those.”

I: How come you changed?

P: I was in a hectic relationship for years and I left that guy and I have been in a stable relationship for over three years now. The first year and a half I had lots of problems to work out. A drug habit to kick and an alcohol problem and well, in the last two years it has been getting better and this last two years have been excellent. I do not have, since I started on 3TC and whatever, I do not have problems because I do not have a drug habit and I am not hung over half the time. Because taking the meds with alcohol is very hard and I found that out the hard way.

SUMMARY

In contrast to the established discourse of compliance, this section of this chapter shows that missing doses and going off antiretroviral therapy have to do with much more than failure or error on the part of individual PHAs. Rather than approaching PHAs’ medication practices from the moralizing and individualizing framework of compliance discourse, our research explores these activities as part of the overall health work that PHAs engage in. We do not treat missing doses or stopping treatment as something that is wrong and that for this reason needs to be explained. Instead, we have tried to describe how PHAs actually come to skip doses and stop using antiretroviral therapy and how this is socially shaped.

From this perspective, intermittently missing dosages comes to be understood as purposeful activity that can be part of an effort to maintain a commitment to a medication routine. It also emerges as a form of resist-

ance to the temporal regulation of everyday life. Going off antiretroviral therapy can be understood as part of a temporal sequence in which embodied ways of knowing and experiencing health temporarily overwhelm the biomedical framework of compliance. It also emerges as a practical solution and response to the social circumstances of daily life that render compliance unworkable.



SYNTHESIZING INFORMATION ABOUT HIV/AIDS AND ITS TREATMENT

DARIEN TAYLOR

INTRODUCTION

From very early on in the AIDS movement in North America, links were constructed, often by people with HIV/AIDS themselves, between active engagement with treatment information on the part of the person with HIV/AIDS and improved personal health outcomes. A mastery of treatment information was seen to lead, on the level of the individual, to such benefits as informed decision making, optimal treatment, increased quality and length of life and a more equitable relationship between doctor and patient, and on the level of the community, to such things as the ability to influence clinical practice, drug research and drug approval/marketing agendas. Implicit in this set of assumptions linking an individual's health to activities undertaken on their own or their community's behalf are fundamental societal beliefs in the good of activity and work, particularly self-directed and self-initiated activities and work, and the worth of personal attributes such as independence, mastery and assertiveness.

People with HIV/AIDS were thus characterized by those institutions that sought to influence their behaviour and health (ASOs, treatment resources, gay magazines, health care providers, activist organizations, etc.) as actively seeking and considering treatment information and using it in order to make well-informed treatment decisions that extended their lives. Or, they were exhorted to become such a person, and through these institutions offered tools for doing so: workshops on treatment information, easy-to-read information packages, web sites, updates from conferences, etc. (McClure 1995; Patterson and Robichaud 1996). The attempt was made to forge associations between treatment information, decision making and

improved overall health (which includes an enhanced sense of self-efficacy), themes brought together by one of this study's research participants.

Information is a powerful thing. It is a choice for me. I can choose to do this, this, this, or this because I know. If I do not know, I do not have a choice. If I do not know that there is an herbal remedy or there are vitamins or all kinds of other stuff that I can do, I am stuck with one choice and that may be someone else's choice.

The intention of this research project is to examine the work undertaken by people with HIV/AIDS in maintaining their health and managing their illness. The work involved in relation to information about HIV/AIDS and its treatment (which will simply be called "treatment information" in this chapter, though "treatment information" may at times include information about HIV itself, its symptoms, clinical or diagnostic information, and may include drug and non-drug treatments) is considerable, involving people with HIV/AIDS in activities such as the seeking, obtaining, reading, considering, translating into other languages or easy-to-read formats, and the further dissemination of treatment information. In our research, people with HIV/AIDS describe the work that they do to understand complex medical information, to attempt to reconcile opposing points of view or conflicting information about this disease and its management, and to take general information about HIV/AIDS and apply it to their particular situation.

People with HIV/AIDS have also played an important role in working to create treatment information through an emphasis on the importance of the role of lived experience and the accumulation of anecdotal information.

Assumptions which have often guided the development of treatment information intended for people with HIV/AIDS: that it is easily read and understood, that people with HIV/AIDS want or need it for the purposes of informed decision making, that it positively contributes to understanding, well-being and decision making, will be examined in this chapter.

All research participants whom we interviewed described some degree of work and involvement in relation to information about this disease and its management. Indeed, it is hard to imagine how a person could come forward to participate in a study such as ours that requires an understanding of oneself as HIV-positive, without some interaction with information about this disease. The manner in which most people are tested for HIV involves at least a minimally informative interaction supplied by a health care worker or counsellor and designed to produce an understanding in the person being tested about HIV, its transmission, and its treatment. The process by which an individual comes to understand him or herself as a person living with HIV/AIDS is set in motion by an engagement with treatment information.

The activities which are required by people with HIV/AIDS as they acquire and consider treatment information bring them increasingly into contact with those agencies, institutions and other sources which produce and regulate this information: doctors and other health care workers, clinics, hospitals, community-based AIDS service organizations, pharmaceutical companies and other people with HIV/AIDS and with various systems for the dissemination of information: conferences, workshops, the internet, print material, notice boards and treatment phone lines. People with HIV/AIDS engage with these information sources and providers often over an extended period of time, often in varying states of wellness and in a variety of roles, as patient, client, consumer, peer, advocate and example.

In the past two decades, the role of people with HIV/AIDS in the creation of treatment information has changed. In the early days of the epidemic, when the scope and manifestations of it were as yet unknown, people with HIV played an extremely important role as sources of information and in its dissemination. Doctors learned about AIDS in part through the self-reporting of their patients. People with HIV/AIDS sought to get information about the disease out as widely as possible to affected communities, through a variety of grassroots media. Over time, the creation and dissemination of information about HIV/AIDS and its treatment became increasingly the responsibility of organized institutions, as opposed to more loosely knit community or activist groups.

Research participants had much to say about what works and what doesn't work for them with regards to understanding and accepting treatment information, and how to facilitate their roles as receivers, interpreters and actors on this information. Their suggestions and recommendations will be incorporated into this chapter.

People with HIV/AIDS interviewed in the course of our research provide various accounts of the type and amount of work that they do in seeking out treatment information. They each occupy a point on the continuum of the relationship to treatment information, decision making and treatment uptake, from those who actively seek and use treatment information in decision making through those who experience confusion or "information overload" as they seek information, to those who "do not want to know" about the treatments they are using or being offered.

Some of the people with HIV/AIDS interviewed in this study spoke about the pursuit of treatments and treatment information as a responsibility or duty with a very strong personal imperative. One participant in an early focus group said that seeking information about possible HIV treatments was ". . . something I felt I had to do." Other participants in the

**POINTS ON THE
CONTINUUM OF
SEEKING TREATMENT
INFORMATION**

focus group agreed: “[T]his is a very scary disease, so you do whatever you have to do” and “you have to get off your ass” in dealing with HIV/AIDS.

Yet other research participants admitted that they were “confused,” “embarrassed” and “lost,” experiencing difficulty in actively acquiring or understanding treatment information, retaining or recalling information or making decisions based on it.

A lot of times I do not understand what I am reading. It makes it very uninteresting and difficult to get through.

I don't understand anything about the new wave of testing of the viral load and stuff. I have no idea what they are talking about. I think 90% of the people don't. It's all numbers and stuff. It's 6,000 of this equals 100 this and 10,000 of that equals 200 of that. And I mean I'm completely, completely lost.

In addition to those who experience difficulty in acquiring and understanding treatment information, there are those participants who feel that it simply takes too much work. One research participant characterized himself as “not the type” to do the work required to engage fully with treatment information and the actions for which it calls.

I just am not the research type. I'm not a comparative shopper. If I want something I just go out and get the first one. So I guess I don't do a whole lot of work if I don't have to.

The pursuit of treatment information takes place in the context of the shifting priorities of daily life. Prioritizing the work of pursuing treatment information may be difficult for some people. They may be juggling other priorities such as illness, employment, family responsibilities or leisure activities that take precedence over the work involved in treatment information. For some, engaging with treatment information requires a degree of self-discipline and mental preparation, as illustrated below where the research participant describes how he tries to motivate himself to do treatment research on the Internet. It is work that this person believes that he should be doing but which he postpones through procrastination.

I've been thinking like now that [a local AIDS service organization] has this computer, I should go up there, and wouldn't it be fabulous and stuff. And whenever I walk by, it's sort of like “Oh yeah, I've got to do that” and I keep walking.

**HOW MUCH
INFORMATION IS TOO
MUCH INFORMATION?**

The question of how much information is enough information is at the heart of discussions about the delivery and reception of treatment information. Treatment information on many given topics is seemingly endless: how does a person with HIV/AIDS know when to stop? Or for that matter, where to begin? Is knowledge about one's health and treatments good in itself or is it better to limit one's knowledge of treatments to those that are directly applicable to one's specific illness? The research participants in this section pose and consider these and other questions.

The interview participant below discusses the considerable work in trying to understand treatment information and how this work of deciphering leads him not toward knowledge that results in a decision, but to "know[ing] too much that I still don't want to do."

And then [while reading about HIV/AIDS treatments] I have to get the dictionary out and then the dictionary will say something that I don't know . . . It just seems like a whole lot of work getting to know too much that I still don't want to do. I'd rather go out and have a coffee with my friends and talk about something else.

Another research participant expressed his doubts about the drive to master treatment information which is often lauded as a virtue of an empowered person with HIV: "I mean, there's self-empowerment, but when [researching treatment information] becomes your 100% . . ."

In the quotation below, the research participant describes the strategy for absorbing treatment information that he has found successful. It is important to note, however, that it is a strategy which is the result of training in information management, training that is not widely available to people with HIV/AIDS.

I: How can you absorb all this information?

P: Well, [ASO] trains me in the bibliographic means by which one sets up files so that follows that I set up my own files for my own health.

Some people with HIV/AIDS interviewed in our research attempted to solve the problem of how much information is necessary to know by seeking this information on what could be characterized as an "as-needed basis," wherein the individual attempts to master the portion of treatment information which they feel that they need to know at the time and in relation to a specific aspect of their illness. One research participant noted,

I tend not to accept information until I need it because it just doesn't penetrate and/or I don't want it to penetrate – one of the two – so it is only when I need it [that I accept treatment information].

Another research participant describes a similar approach, seeking out treatment information “really only when I need it . . . I don't need to be a walking library or dictionary for anybody.”

The research participant below attempts to characterize “the information I think I needed to know.”

P: [W]hat is 3TC?

I: It's a reverse transcriptase inhibitor. There's 3TC, AZT, d4T, ddI . . .

P: Yeah, I think I know that they're that category. And ritonavir, saquinavir, indinavir and nelfinavir are all protease inhibitors. See, I know that. But I don't know much and I don't know if I need to know much. I'm not a news person. I don't watch the news, I don't read the newspaper. I love to read but I only read fiction. I will read some non-fiction but it's got to be telling me a story.

I: So you're the new kid on the block. Everybody else . . . in your group of friends, talking this language that goes in one ear and out the other, that you aren't even interested in.

P: Well, I was interested because it was happening to them. And I recognize certain, you know, like PCP pneumonia. I knew what that was . . . I knew what you were supposed to be doing to prevent getting this or giving it to someone else if you already had it. I knew about high risk and the low. I knew what I think I needed to know.

In contrast to those research participants who actively sought and considered treatment information and those who sought it, but with some limitations upon the extent of the information they were willing or able to acquire, some research participants said that they did not want to know about their illness and the treatments for it. Regarding her interactions with her physician with regards to information about HIV and its treatment, one participant said “I did not ask any questions. I did not want to know. I do not want to even take pills.” Another admitted “. . . to tell you the truth, a lot of the time I'm just pretending to listen [when other discuss HIV treatments] . . . I just don't want to talk about it. I don't want to hear about it.”

Some noted that assistance in the work of selecting relevant treatment information which some health workers used to provide before budget cuts

or health care restructuring is now more difficult for people with HIV/AIDS to access:

- P: *[T]he social worker, she used to keep up-to-date on anything she could find [on HIV/AIDS] . . . but the girl they have now, you have to page her. God only knows where she is.*
- I: *She is just half time now, right?*
- P: *Yeah, but the other one used to be there. She had clinic four days a week and she was there four days a week. Cutbacks, though.*

In response to the amount of work which some people with HIV/AIDS were doing in order to stay current and informed with regards to treatment information and the difficulties which some report in acquiring and understanding this information, the provision of “clear language” formats of such information became increasingly institutionalized and centralized in AIDS service organizations and HIV clinics. Some research participants expressed frustration that with so many HIV-related services available to them, they continue to have to do a great deal of work in order to receive information:

There are 50 [AIDS service] organizations and if I do not ask, no one tells me anything. I have to sit and read it and look up this and that. I find it very strange.

In spite of efforts on the part of community organizers and health care providers to encourage people with HIV/AIDS to engage actively with treatment information for the purposes of decision making, it is evident that only a portion of people with HIV/AIDS are actually able or interested to do so. For others, a number of barriers stand in their way, including personal feelings such as embarrassment about their diagnosis, personal judgments and opinions about the role of treatment information and active decision making in influencing their disease progression, the lack of a friendly support network, the lack of institutional supports, the lack of training opportunities, institutional barriers, the language and style in which information is delivered and lack of interest, motivation or “self-discipline.”

There is a great deal of work done by people with HIV/AIDS in attempting to inform themselves about available treatments, particularly in the process of decision making. Many research participants indicated that they are suspicious of information delivered from sources that they consider to

**ASSESSING THE
RELIABILITY OF
INFORMATION SOURCES**

be unreliable, sources that include health care professionals, pharmaceutical companies or advertising and marketing agencies. Research participants judge these sources as unreliable in part because of bad experiences with health care providers or certain medications in the past. Thus, they work to assess the reliability of their sources of information.

Some research participants' distrust of the medical system is rooted in negative messages about their life expectancy that they received from their doctors or others at the time of their HIV diagnosis:

I have been told for twelve years that I was going to die. They were wrong. They were wrong that I had 18 months to live. So my philosophy is, they could be wrong about this [i.e. the recommendation of new treatments].

Pharmaceutical companies have long been characterized by AIDS activists as profiteers. Early experience in the HIV community placebo-controlled clinical trials and with the early high doses of AZT, which made people ill and often appeared to do nothing to extend their lives, consolidated this view. Two research participants below discuss their suspicion of information they perceive to be in service of drug companies.

P: [P]eople need to hear [about treatments] but it's who's telling it, too. Like, is it the pharmaceutical companies or is it the people that are living with it?

I: And you see that there's a difference there?

P: Oh man, big bucks is big bucks, eh? . . . Excuse me, someone's making a hell of a lot of money on that stuff. They don't want the information out about the other stuff. "Mine's the best" you know. How many people want a cure? Not too many. Not those pharmaceutical companies because that one pill is going to cost maybe a thousand dollars but they're making a hundred thousand. "Let's not fight this too hard."

I just started losing faith in what was being written . . . I started to perceive it like a planned obsolescence, right? Well, this [drug] might work for six to twelve months then you'll have to get this new improved model. Which is fine. I mean, it's what we do with computers.

However, the arrival of protease inhibitors may have had a moderating effect on the negative opinion among some people with HIV/AIDS of pharmaceutical companies and their products.

I'm not paranoid but I notice a great deal of skepticism, especially when the drug companies report this, this and the other thing. I'm not anti-drug company by any means. These people have saved a lot of lives. I don't give a shit how much money they make. If they weren't making that money, none of these drugs would be available. Pure and simple. That doesn't mean that they're god, or that they don't lie, or anything like that. Of course they do sometimes.

Not only are people with HIV/AIDS continually assessing the reliability and credibility of their sources for treatment information, they are engaged in ongoing adjustments in the dynamics of their relationships with doctors and other health care providers and their assessment of their role in providing treatment information. Community-based AIDS service organizations have defined their role in AIDS by distinguishing it from that of health care providers and by questioning the importance of traditional notions of “expertise” in health care. Subsequently, many people with HIV/AIDS have accepted the notion of an alternative form of expertise conveyed by the experience of living with the disease.

[M]y doctor says we're the experts . . . That's what he says. He says we're the experts: "You are the ones who are teaching me."

The doctors that we go to . . . they don't know a lot of stuff. Like, we're just as informed as they are on upcoming stuff, like upcoming medications and upcoming cocktails and trial studies and stuff like that. A lot of us, because of different ways of getting information like the internet . . . we know just as fast or as much as they do about all the medical stuff. So we go in knowing just as much as they do. I mean as far as new information, we are just as important as they are.

[S]ince my diagnosis my opinion of doctors has changed. They are no longer on pedestals for me and I do not trust anything they say. I mean, I have a good rapport with them but I would just as soon read [about HIV and its treatment] myself . . . I sit there and contradict myself and say I read, but I do not read much anymore, to tell you the truth, because I am not really interested except in a cure. But I take the time to read about what I am taking and certainly read enough about what I need to know to make fairly basic decisions. I feel I know just as much as your average physician, if not more. I won't make that claim about my specialist . . . [but] with your average physician, I would not trust their decision.

However, some interview participants pointed out the problems inherent in a dismissal of the expertise of doctors and in a valorizing of treatment information that is delivered informally through friends and support networks which may be based on popular misconceptions or outdated information:

P: (discussing people who get their treatment information from friends) . . . most of the people they know don't have accurate information . . . So I try to steer them to their doctor . . . I don't like seeing people lose their lives because of ignorance.

I: For example?

P: . . . when they slammed AZT because it's a toxic drug that kills everyone that takes it . . . It's such a gross overstatement, it's ridiculous. [It's] based on a very valid perception that arrived ten years ago [but] the world has changed a helluva lot since then.

**CREATING A
COMMUNITY-BASED
LANGUAGE OF
TREATMENT
INFORMATION**

One of the ongoing, collective tasks of people living with HIV/AIDS and the service providers who interact with them in the provision of treatment information is to create an accessible language of treatment information, one which conveys nuance with clarity. This undertaking continues to be an important one, as research participants spoke of the difficulties which they experienced in understanding the language level and style in which much treatment information is written or conveyed. It is important to note that this difficulty was said by some to extend to information produced by community organizations.

[T]his is going to sound stupid but if you're going to tell somebody "This is a horse", [then] call it a horse. Don't call it a supercalifragilisticexpialadocious. And then you say "What the hell is that?" "Oh well, that's a horse." You know, that terminology.

Other interview participants were critical of what they saw as a lack of scientific rigour in the community-based presentation of trends in HIV/AIDS.

I'm . . . increasingly . . . wanting data. I'm tired of going to meetings with other AIDS service providers who . . . in a histrionic way . . . talk about how this is happening and that is happening, how we've had a huge increase in this and that. And there's nothing to back it up.

Some participants experience what they call “information overload,” which they define as a combination of too little time and too much information of a “dry” or “irrelevant” nature. Some research participants referred to the sheer physical volume of paper reference materials when speaking of this phenomenon.

I did plan to give them [AIDS treatment organization] another call because I wanted them to send me what they had [on a certain treatment topic]. And so to avoid talking [with them] for an hour, [I said] “Just send me the information so that I can read it.” . . . I wanted to see what they’re going to send me . . . because in the past they have sent me a lot of dry stuff that nobody wants to read. It is a lot of gobbledy gook. I just want a definition and . . . good knowledge of what it is. Symptoms, prevention and what’s in the pipeline for new drugs. But they’re going to send me a massive booklet on a lot of stuff I don’t need.

I didn’t find [AIDS treatment organization] useful at all when I called up. I mean they were very nice . . . but they basically looked up stuff on the net and printed it and sent it to me. I looked at it and looked at maybe three [packages] of 400 sheets of paper . . . and then I ended up throwing it away because . . . I’m not going to read that. I found them very reluctant to do any actual counselling or talking on the phone. It was more “Well, I can send you this information.”

Initially the mastery of treatment information by “non-experts,” people living with HIV/AIDS, was a challenge undertaken and organized at the grassroots level through community clinics, newsletters, advocacy organizations and nascent AIDS service organizations. As the delivery of treatment information became increasingly institutionalized and increasingly complex as well, it was produced as a service which could be delivered to people with HIV/AIDS. Some of the “work” that an individual person with HIV would have to do in order to access, understand and use this information was taken out of the process, and the person with HIV/AIDS became less of an active participant in it and was established in a more passive role as a client or recipient.

Research participants distinguished between the problems caused by too much information or what was often called information overload, and those caused by conflicting or inconclusive information. They articulated

“INFORMATION OVERLOAD”

DEALING WITH CONFLICTING OR INCONCLUSIVE INFORMATION

alternative strategies for making decisions and understanding treatments based in personal networks. Conflicting information was often presented as paralyzing or inhibiting decision making.

. . . but as far as information overload, it's not so much the amount of information, it's like [another focus group participant] said, it's the contradiction in information . . . You read this guy saying this and you read this other doctor saying this, and you don't know who to believe.

I was getting a lot of my information from American magazines like The Advocate and POZ . . . I found that I had to stop reading the stuff because it was just too much conflicting information every month. And I relied more on just knowing a few people that I knew personally were doing the same things, and discussing stuff.

I had to get to a place in my own mind where, in spite of all the uncertainty, . . . I had to be ready to pin my hopes on the drugs. I had to be ready to suspend my disbelief . . . I knew for myself that I couldn't [start] these pills doubting them.

**WHAT WORKS FOR
PEOPLE WITH
HIV/AIDS IN
TREATMENT
INFORMATION**

Although research participants tended to have more to say about those aspects of treatment information of which they were critical, they also described the attributes of treatment information sources which they found useful and appreciated. These attributes included specificity, diversity, relevance and practicality.

P1: I get most of my information from [a local treatment organization], and there's an organization in Oakland, California . . . and they send me the subscription and I read a lot of it because it's geared to women and I like that.

P2: Geared to women? That's good.

P1: Yeah, it's all about women, so that's why I read it a lot. Because I get firsthand, not an experiment that was done with only men. So I like it and it's very multicultural. There's a very diverse group of women, so that's OK too.

I like to go through POZ magazine because it generally gives me stuff that I haven't heard of . . . I'd like to see a Canadian version because a lot of the stuff advertised in POZ, drug-wise, aren't available in Canada. Or there's an American bend on a lot of stuff. I know this guy who was considering doing a POZ Canada.

But I like POZ 'cause I get a lot of practical issues [about] people who have HIV including the edit . . . the guy that runs the magazine. He talks about his experiences, what's going on. He publishes in the magazine his current blood work and what the doctor thinks of this and that drug. So it's very practical. But also, people are writing about issues that they're dealing with so it's kind of . . . one of my favourite places right now to look at on a regular basis.

A widely-used strategy among research participants for acquiring information about HIV treatments and for making decisions about treatments appears to be personal observation of others. Even among research participants who described using a wide variety of treatment information sources, personal observation was valued very highly.

P: I was on AZT and ddI. I stayed on that for about six months and [then] I . . . made a contract with my doctor, saying that if I was ever to get sick . . . under no circumstances am I to go on any of the HIV medications. I said no life support, blah, blah, blah. And it's only been in the past couple of years that my attitude towards that has changed.

I: . . . How did you have that shift in your attitude take place?

P: Well, I'd seen a friend of mine practically on death's door, then go on the cocktail while in hospital and then totally come back. I was like "Holy shit!" I hadn't seen [the beneficial effects of protease HIV drugs] prior to that. And then I said "I'll give it a try" because my counts weren't up to what I wanted them. They're a little under 300. My viral load was quite high. So I said "Okay, I'll give them a try." My CD4 is over 800 now and the viral load's undetectable, so something's working.

Some research participants pointed to the problems with this method of assessing the credibility of treatments. An anecdote repeated by a surprisingly large number of people who participated in our study concerned negative experiences in the 1980s with AZT. This negative experience continues to affect people with HIV/AIDS strongly in their assessment and decision making with regards to treatments.

I watched people in the beginning of the epidemic go on AZT, when they were prescribing 1200 mg. a day, and get poisoned by this stuff and die due solely to AZT. . . . I have met people in the clinics

**PERSONAL
OBSERVATION
AS A SOURCE
OF TREATMENT
INFORMATION:
SEEING IS BELIEVING**

who, before they took the cocktails, they were fine . . . I watched them go from people you would not know had AIDS to people who look like they are dying from it. . . . This really influenced me through the years. I refused to take anything.

Observation as a way of acquiring information about the effects of treatments includes self-observation. In the situation of self-observation or self-monitoring, the person with HIV/AIDS is at once a person experiencing the disease (the role of “the patient”) and a person working to manage the disease through observation and timely intervention (the role more commonly attributed to the doctor or researcher). This double perspective is evident in the quotation below where, watching himself as “a lab rat,” the interview participant occupies the positions of both patient, or perhaps guinea pig, and doctor/researcher:

[Monitoring my situation with regards to HIV] gives me the chance to put on, while I am watching myself, . . . a white lab coat and . . . put on the microscope. . . . I treat myself as a lab rat.

.....

**PERSONAL
EXPERIENCE IN
THE DELIVERY OF
TREATMENT
INFORMATION**

People with HIV/AIDS interviewed in the course of this study tended to be more receptive to treatment information which was delivered in a format which was personalized. Time and again, research participants articulated their need for other people with HIV/AIDS “stories” and faces in the delivery of information about HIV, for face-to-face contact or for someone to talk their issues over with rather than something to read.

I would rather hear her story, her story or her story than read the stats, because the stats don't mean shit.

I can read the pamphlet and stuff, and it gives me some help but if I don't have someone talk to me who knows their stuff, I don't quite make the connections.

The studies done by drug companies . . . there is no face on them.

. . . [A] lot of places where I see presentations, you know where they get their information? From books. They don't get people like us that are actually living with the illness to present. And I can talk about my illness because I'm living it.

I just wanted to talk to someone to actually tell me verbally about these medications and what they do . . . I don't want to

read, especially when you get overwhelmed by a package that comes to your door.

Personalized treatment information is described variously as being delivered by another individual, preferably by someone with the qualities of a peer or equal rather than those of an expert. An important aspect of personalized treatment information is that the person who is delivering it, rather than being rushed, has time to give the person with HIV/AIDS information and deals with that person's individual situation.

I: So what does [discussing your treatment options with your friends] give you that a doctor doesn't?

P: Information. I'm sorry but like, my doctor is fairly good if you sort of tell him what to do, but I go in for a 15 minute appointment, he's usually three or four minutes late for that and there's ten people in the waiting room, so I feel very rushed.

Personalized treatment information may also involve a person with HIV/AIDS telling their personal story in an effort to provide assistance or information to others. As with the research participant below, some said that this form of information delivery was related to enabling decision making for them.

[W]hat I find is more helpful is firsthand information. A couple of times I'll call [a treatment information organization] and they'll say "Oh, it's you, Pat. Have you tried this new medication?" And the person will tell me "Well, this has been happening with it." That's how I decided to end up taking it: just getting information from other people and just hearing what they have to say and things. And you make a decision.

The following lengthy quotation details the value that one of the research participants in this study described feeling in talking with peers about treatment information and issues of living with HIV/AIDS. This person emphasizes the optimism, sense of humour, support and sharing that are part of a support group for people who are HIV-positive and trying to contend with the new sense of future brought about by protease inhibitors.

P: . . . [T]his past year . . . I was part of a . . . group of people who are HIV-positive and who are relatively healthy, or some of the guys have been ill but are now quite healthy and functioning. We met this week after the eight or ten week course – we continued to get together informally ourselves. . . . The idea

was to sort out – you know, for years with HIV we were all trying to figure out – I think you’re more conscious, and not to be lacking in optimism, but you’re being prepared, you know – it could be a short life, right? And now we’re at a stage where we don’t want to get cocky about it, but we’re getting prepared for more longevity and maybe retirement. I’m going to be 45 in ten days, right? So at 33, little did I know I’d make it to 45. At 33, it was a little bit of a death sentence, because at 33 I watched a news broadcast . . . where it basically said that anybody who had HIV was going to be dead, and that wasn’t too encouraging back then. And a lot of them are dead, but for a number of us, and especially those of us who have been infected within the last few years, it’s much more optimistic, so the group focused on . . . What are we going to do now? Are we going to go back to work, are we not going to go back to work? Like, some of the boys are out buying condos, and it’s kind of, you have to have a sense of humor about it as well. I mean here is a group of people who you thought had a death sentence hanging over their heads, and not that we’re out of the woods, and not that we’re naive, but there’s more optimism, so that it does lead people to reevaluate and reassess what they can do.

I: *Was it helpful?*

P: *Yeah, it was. It was very good. It was an excellent group of people, the participants were terrific, and they were very capable of sharing their experiences and being very open. It was quite insightful to see what’s going on in other people’s lives, to realize that you have a lot in common with your feelings about things and just to learn how they have dealt with what’s been a fairly stressful health factor in their lives. Because a lot of these fellas have been HIV-positive for a number of years as well. So, jokingly, yesterday as we were having lunch, actually, I said, “I hope we’re doing this for another ten years.” And we might be. Yep.*

I: *So information is also through other HIV positive persons?*

P: *Yes, certainly, by getting together with these guys from my group. . . . There’s this exchange of information too. You know, I’m not doing a cocktail but some of these men are so I can learn about what their concerns are with the drugs, what the side effects are that they’re dealing with and that kind of thing. So on a practical level it’s very informative to me that way. And it does have kind of a support element, just interacting with them.*

CONCLUSION

Although the intention of this research report is simply to raise questions about certain assumptions concerning the role that people with HIV/AIDS assume in work related to their health, the insistence by research participants on the importance of the personalized delivery of treatment information must be underlined. One of the only recommendations that our research points to is that providers of AIDS treatment information, both in institutions and in the community, should review and reconsider the methods by which they deliver treatment information in an effort to incorporate, wherever possible, more personalized methods. Print-based information sources (including much computer-based information), unless personalized in innovative ways, are unlikely to be a useful information source to the majority of people with HIV/AIDS.

Given the insistence by many research participants that they benefit from, and make decisions on the basis of personalized treatment information, the complexity of decision making outlined in Chapter Two, the benefits to many of antiretroviral treatment, and the experience and success of community-based peer programs, an effort to provide more personalized treatment information appears warranted. Face-to-face, unhurried discussion of the individual person with HIV's specific situation and options, community-based peer treatment counsellors, question-and-answer and discussion opportunities at workshops and conferences, opportunities for people with HIV/AIDS to tell their stories, telephone counselling or support groups, real-time internet treatment chat lines, treatment information and support groups, peer treatment training – these are all methods which are not entirely new to HIV/AIDS but which are labour-intensive and will require both structural and financial support to implement.



CONCLUSION

ERIC MYKHALOVSKIY
DARIEN TAYLOR

This report arises out of our efforts to bring together the resources of the university and community to produce an active knowledge about the health work of people living with HIV/AIDS. Our goal has been to contribute to ongoing discussions within AIDS service organizations and among health care providers and policy makers about how to support PHAs' health during a time of dramatic transformation in medical treatment for HIV/AIDS and in the overall structure and delivery of health services.

Our report contributes to these discussions an analysis that insists on understanding health work by beginning from the day-to-day experiences of PHAs. As we have noted throughout the report, much HIV-related social science research does otherwise. Established frameworks for authoritative research on the health activities of PHAs draw on concepts such as compliance, behaviour, patient preferences and decision making that may obscure what is actually going on for people. Research of this sort generally informs ruling discourses by glossing over the complexity and multiplicity of PHAs' experiences with an abstract, individualist and overly rational perspective on how PHAs do health work.

Our research offers an alternative that starts with the complexity of people's experience as they recount it. Our aim has been to provide a detailed mapping of the varied ways in which PHAs from different social locations look after their health and how that work is shaped socially and institutionally.

Our discussion centers on the interconnected forms of health work that PHAs do in a variety of areas including finding and dealing with

doctors, coming to be on combination therapy, taking medications, developing and adjusting to medication routines and working with treatment information. Throughout we have tried to challenge authoritative social science perspectives by drawing out the complexity and variety of these forms of work.

Our discussion of the work PHAs do with their doctors does not treat PHAs simply as “consumers” who receive a service. Nor does it otherwise conceptualize them as objects of professional work routines. Instead, our analysis opens up onto the extensive actual work PHAs do with their physicians which includes finding appropriate doctors, educating them about their experience living with HIV, building ongoing relationships with health professionals, and coping with insults, confusion and discrimination within the health care system.

Our research further begins to put into view some of the distinct ways that PHAs do health work that have been occasioned by the fairly recent introduction of combination antiretroviral therapy. Formerly, public health/health management interest was centered on the notion of “risk behaviours,” with the aim of intervening in and decreasing the transmission of HIV. With antiretroviral therapy there is an increasing health management focus on the “behaviours” of PHAs – behaviours that relate to treatment decision making and adherence to complex pill-taking schedules. Here, existing discourses on medical decision making and compliance/adherence, already used to study people with other diseases, have been expanded to study PHAs.

Our own research has not been defined by an epidemiological and managerial/public health concern with ensuring that PHAs take the “right” drugs the “right” way. Instead, we have tried to create a picture of some of what PHAs’ health work looks like under circumstances of widespread use of combination antiretroviral therapy and have tried to describe how that work is socially produced.

So, for example, in Chapter Two, we explored how PHAs come to take combination therapy as a social process. Our research showed the institutional relations of power that shape how PHAs come to take combination therapy and the forms of compulsion they experience as part of starting medical treatment. Chapter Two also pointed to the central importance that informal learning and embodied knowledge have for PHAs as they come to take combination therapy. Attending to the variety of PHAs’ experiences means that our analysis called into question the notion that all PHAs are engaged in a process of rational decision making around medical treatment and indeed that such a straightforward process exists at all. Instead we highlighted the processual and social character of how people come to be on antiretroviral therapy, which involves much more than individual preferences or choices.

The advent of combination antiretroviral therapy has also meant that many PHAs in Canada are engaged in complicated and consequential medication regimens that must be taken over the long term. In exploring PHAs' experiences of combination antiretroviral therapy, once again our research works against the moralizing framework of much contemporary social science research. For example, in Chapter Three, rather than drawing on the prescriptive term "compliance" we used the term "medication practice" as a way of registering and making visible the range of work people do around their medication. In Chapter Three we also detailed the invisible work that goes into "following instructions" and the emotional and social character of being on combination therapy. An important contribution of our discussion is a reframing of the compliance literature's approach to PHAs' departure from the intended scheduling of medication regimes. Rather than viewing missing doses or stopping medication as problematic behaviour that needs to be fixed, we detailed its purposeful character.

A final focus of our report is the work PHAs do in relation to treatment information. The production and dissemination of treatment information was an important initial foundation of AIDS activism and community-based AIDS work in Canada. Recent transformations in health care which promote individual responsibility for health and the widespread introduction of combination antiretroviral therapy, complicate earlier models of individual empowerment through information. Chapter Four contributes to a reimagining of this work by opening up for view how PHAs interpret and experience treatment information. In Chapter Four we drew attention to the ambivalence of PHAs toward treatment information. We also described the work PHAs do to assess the reliability of HIV/AIDS information, their experiences of "information overload" and the crucial role of peer experiences in gathering and assessing treatment information.

Throughout this research report, a number of important tensions informing the work of PHAs have been uncovered. The point of our research has been to highlight these tensions rather than to resolve them. Our research speaks to the tension within AIDS service organizations between "institutional capture" and grassroots activism. AIDS organizations mediate uneasily among activities considered community-based such as critiquing ruling relations, producing health information as a tool of empowerment, or advocating on behalf of PHAs on the one hand and, on the other hand, taking up perspectives and approaches that enter them into ruling relations and that reproduce professional and managerial discourse.

Our research has also shown tensions that exist between more PHA-centered forms of health activism and health policy or managerial models of self-care. The latter are further characterized by an internal tension such that upon entering the formal health care system, in some circumstances

PHAs are expected to look after their own care, while in other circumstances they are expected to respond as a more traditional patient.

Another tension around which our research has taken shape is that which exists between biomedical as opposed to experiential ways of knowing the body. As we have also shown, PHAs are also pulled between idealized images, promoted by safer sex campaigns and pharmaceutical company advertisements, of the “good” PHA – one who is assertive, well-informed, compliant, and sees health as a personal responsibility – and the harsher realities of their lives and priorities.

Our research has attempted to disengage these tensions from a moralistic framework, examine them in operation and consider their consequences for informed and humane policy and for PHAs’ lived experience.

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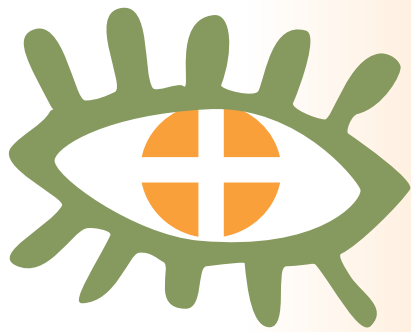
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MAKING CARE VISIBLE

I remember the first night of laying out the medications, like putting them in the dosette, and then the first morning of taking them was just, it was scary because, it's this whole piece around faith and hope, pinning my hopes on whether these pills would do what they were supposed to do. And realizing that the first time I took the pills that this was not something that I was going to be doing for a week, or two weeks, but basically until, until further notice. This was going to be a part of my life.

Drawing on interviews with 79 PHAs from varied social backgrounds living in Toronto and surrounding communities, *Making Care Visible: Antiretroviral Therapy and the Health Work of People Living with HIV/AIDS* gives a detailed look at the experiences PHAs have looking after their health.

Dealing with doctors, making treatment decisions, managing the demands of compliance, and using treatment information are the main topics covered. Throughout, a focus is placed on describing PHAs' actual experiences and exploring how they take shape within an institutional field that involves the health-care system, AIDS service organizations, social service agencies, pharmaceutical companies, and other sites.

Making Care Visible: Antiretroviral Therapy and the Health Work of People Living with HIV/AIDS is the only in-depth exploration of the health practices of PHAs published in Canada since the introduction of combination antiretroviral therapy in the mid-1990s. It is intended to open up discussion about such notions as decision-making, compliance, empowerment, information, and individual responsibility for health. It will be of interest to PHAs, ASO workers, health care providers, social service workers and others committed to supporting PHAs in their efforts to look after their health.

MAKING CARE VISIBLE

ANTIRETROVIRAL THERAPY AND THE
HEALTH WORK OF PEOPLE LIVING WITH HIV/AIDS