

LIVING WITH COMBINATION THERAPIES

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1 May 2002

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In the mid-1990s, reports of the success of new antiretroviral therapeutic regimens for suppressing HIV replication generated renewed optimism that HIV infection was becoming a 'manageable,' chronic condition. Declines in the number of HIV-infected individuals progressing to AIDS, and in the number of AIDS-related mortalities (at least in wealthy nations), provided some warrant for optimism. Articles began to appear speculating about the advent of a "post-AIDS" era and AIDS became more normalized or routinized in the sense that it seemed possible to treat it more as a disease like any other, susceptible to medical intervention.

For those who experienced 'returning from death's door' or at least renewed health and energy, success did not often come easily. Maintaining the therapeutic regimen typically required careful attention to a complex, inflexible schedule of medication with numerous pills and/or liquids having different dosing schedules, restrictions on food intake, and sometimes debilitating side effects (Altice and Friedland 1998; Bright 1999; Jeffe et al. 1998; Sigma Research 1998).

This study reports on the ways in which living with HIV has changed in the half decade since the introduction of protease inhibitors and the widespread adoption of various forms of combination therapy in the treatment of HIV disease. Interviews with thirty-five people taking combination therapies in the Windsor, Ontario region, explored how living with HIV has changed as a result of combination therapies by examining their impacts on work and home life. We also examined how the structures of everyday life, in turn, affected medication regimens, and how adherence to these regimens was accomplished or compromised through solving day-to-day conflicts.

Our findings show a "mixed" set of responses to combination therapies. There is a considerable range of experiences with symptoms, and the impacts of HIV on everyday life and on adherence are strongly shaped by these experiences. One set of study participants remained largely symptom-free. Another group experienced the recovery that has received so much attention in contemporary AIDS narratives: they had often resolved earlier symptoms and were now feeling well, or well enough to participate in work and family life. Others, though, continued to struggle with symptoms that recurred or worsened. Focus group participants expressed considerable skepticism about the use of the term 'chronic manageable' as a descriptor of HIV disease, preferring instead to characterize it as perhaps more 'tolerable' now than in the past.

METHODS

Semi-structured, in-depth interviews were conducted between May, 1999 and May, 2000 with 31 men and 4 women who were taking combination therapies for HIV disease. Study participants were recruited through invitations offered by nurses at the HIV Care Programme at Windsor Regional Hospital and a mail-out to the case list of the local AIDS service organization. The Windsor region functions as a self-contained medical catchment area and these two organizations are estimated to be in contact with at least 96% of the HIV-positive people in the region. A few,

who lived at the edge of this region, received medical services in a neighbouring area. Study participants represented approximately one-quarter of the known sero-positive population in the region. Interviews were conducted by the sociologists on the research team. Open-ended questions were posed in the following areas: treatment history and current pattern of combination therapy, self-reported adherence, issues involved in taking medication on time and/or as prescribed, symptoms and symptom management strategies, daily routines, work activities, finances, social life, household and family activities and relationships, life changes associated with going on combination therapy, 'feelings about life,' and future plans. Interviews typically ran an hour or hour and a half. Study participants were offered a \$30 honorarium for their time and transportation costs.

All participants granted the study team permission to access information from their medical records. Trained nurse-researchers employed by the HIV Care Programme were contracted to gather information from these records. This included: current and former treatment regimens, date of diagnosis, experience of AIDS-related conditions and opportunistic infections, CD4 counts and viral loads and recent changes, CDC categorization, past and recent Karnofsky scores.

Tapes of interviews were transcribed and analyzed to identify descriptions of daily life related to work, finances, personal and social relationships, future plans and expectations. The software program QSR NUD*IST was used to employ a constant comparative analysis of participant narratives.

The completeness of the results and trustworthiness of the interpretations were assessed by mailing a draft of the analysis to study participants who expressed interest in providing feedback. A focus group was held where results and interpretations were discussed; the final report reflects modifications, elaborations and additions recommended by the group.

ANALYSIS

Study participants were sorted into four groups reflective of their past and present illness experience:

- *asymptomatic*: current CD4 counts >200, viral load <1000, Karnofsky rating ≥ 90 , never had an AIDS-defining condition. N=8
- *improved*: current CD4 counts >200, viral load <1000, Karnofsky rating ≥ 90 ; have had ≥ 1 of the following: CD4 counts <200, viral load >1000, Karnofsky rating ≤ 80 . N=11
- *symptomatic (less severe)*: currently only 1 of: CD4 counts <200 or viral load >1000; in addition, no more than 1 of: AIDS-defining condition, current Karnofsky rating ≤ 80 , CD4 count declining. N=8.
- *symptomatic (more severe)*: current CD4 counts <200 and/or viral load >1000; in addition, ≥ 2 of the following: AIDS-defining condition, current Karnofsky rating ≤ 80 , CD4 count declining. N=8

There were no significant differences in the age or gender distributions of study participants across symptom categories. There were differences, however, in other participant characteristics. People in both symptomatic groups were more likely to be diagnosed before 1994; whereas, those who were *asymptomatic* or *improved* were approximately equally distributed before and after 1994. Of the 11 longest term survivors (diagnosed prior to 1990), 6 were found in the *less severe* symptom group with the remaining 5 spread among the other illness experiences.

At the other extreme of diagnosis date, 4 of 5 diagnosed since 1996 were categorized as *improved*, with the remaining participant categorized as *asymptomatic*. In reviewing interview transcripts it was clear that the relatively newly diagnosed *improved* participants were diagnosed because they were experiencing symptoms related to HIV. They were immediately placed on combination therapy and all responded well. For other years of diagnosis there were no apparent patterns or clusters within any of the illness experience groups.

Table 1: Characteristics of Sample Interviewed

Symptom Category	<u>Asymptomatic</u>	<u>Improved</u>	<u>Less Severe Symptoms</u>	<u>More Severe Symptoms</u>	<u>Total</u>
N=	8	11	8	8	35
Males	6	11	8	6	31
Females	2	0	0	2	4
<u>Age:</u> 30-39	5	6	5	5	21
40 and older	3	4	2	3	12
<u>Date of diagnosis</u> before 1994	4	6	6	5	21
1994 or more recent	4	5	2	3	14
<u>Employed:</u> FT	6	5	5	1	17
PT	1	0	1	1	3
unemployed	1	6	2	6	15
<u>Live with:</u> partner	3	5	7	3	16

family	2	2	0	1	5
alone	3	4	1	4	12
<u>In Relationship:</u>					
yes	4	6	7	3	20
no	4	5	1	5	15
<u>Sexually Active:</u>					
yes	6	5	5	1	17
no	2	3	6	7	18

With respect to employment in the paid labour force, the majority of both *asymptomatic* and *less severe* participants were employed, compared to approximately half of those who were *improved* and only one with the *most severe* symptoms. As will be discussed later, this pattern is strongly related to the ability of participants with different illness experiences to remain in the labour force.

The two most common ‘living’ patterns were with a partner or alone. These were almost equally common in all illness experience groups except the *less severe* symptom group where a majority lived with partners. Relationship status showed a similar, though not identical pattern with *asymptomatic* and *improved* people equally split between those who were currently in and not currently in a relationship. Those with *less severe* symptoms were primarily in relationships as compared to those with *more severe* symptoms, most of whom were not in relationships. As will be discussed later, living and relationship patterns reflect a combination of factors including personal choice, illness experience, and the outcome of prior relationships.

Participants’ narratives were separated into groups based on differences in personal illness experience with comparisons drawn across these different contexts. Discussions of stigmatization, experiences with the medical and social system, and location in the history of HIV were examined and compared within each of the daily life activities and illness experience contexts.

VOICES OF WOMEN

For the most part, the experiences of living with combination therapy did not vary significantly by gender. The four women who participated in the study were very different from each other but similar to men with whom they shared similar illness and life experiences. Two women were asymptomatic and working full time, one in a factory and one in a professional position. Both had been diagnosed in the 1990s. Two women were experiencing more severe symptoms and were unable to work full time though each engaged in some form of part-time labour for pay (occasional housecleaning and sale of handmade crafts). One had been diagnosed before 1990 and one since. One woman had grown children and was no longer in a relationship; one was considering having

children with her relationship partner (who was also HIV+); two others were single and children were, at most, a distant consideration. The two with more severe symptoms who had been living with HIV for a longer time period were in regular contact with the local ASO and relied on it for a variety of services. The two who were asymptomatic had had minimal contact with any ASO. Their contact was concentrated right after diagnosis and was primarily for the purpose of obtaining information. One of these women had searched for a support group for herself and her partner but declined joining those that existed because she did not feel she and her partner shared the same life experiences with those attending. All four women spoke of wishing there were support groups for women in different circumstances.

This profile is not unlike that of the men who participated in the study. When we compared experiences in the area of work, relationships and medication adherence, we could find little that distinguished the women from the men. Similarities and differences among participants were related primarily to their experiences with HIV. Those who were asymptomatic shared similar dilemmas and experiences regardless of gender as did those who were experiencing more severe symptoms. Additional variations among participants depended on whether they were working full time and whether they were in long term relationships.

In the text that follows we have generally chosen not to specifically identify those who speak by gender. However, in the few cases where a dilemma or experience was distinctive to the women we interviewed, we do identify it as such. The voices of men and women are represented in the quotations approximately proportional to their representation in the sample.

WORKPLACE ISSUES

Those working full-time came exclusively from the *asymptomatic*, *less severe*, and *improved* groups. People who had not had symptoms or had *less severe* symptoms and were working full time, rarely had to have a break in employment related to HIV. HIV had not resulted in an AIDS-defining condition and symptoms had never been severe enough to jeopardize employment.

For the improved group, a break in employment depended on when they had been diagnosed. Although almost all those who were recently diagnosed had had an acute illness that did not respond to conventional treatment; time out from work was short and did not result in termination of employment. In comparison, those diagnosed prior to the availability of combination therapies had often left the labour market because of an AIDS-related condition. With the introduction of combination therapies, their health improved sufficiently to re-enter the labour force. Those in the *more severe* symptom group were all unemployed and supported by disability and pensions.

Staying employed

For those who were *asymptomatic*, work was described as simply something they did; consideration had not been given to leaving the labour force. In comparison, for those in both the *improved* and the *less severe* symptom groups, working full-time required a specific commitment. People in both groups reported various degrees of physical difficulty in maintaining full time employment. For some, extreme fatigue restricted their lives to work and rest; all other aspects of daily living had to be sacrificed in order to continue working. One study participant described a

lengthy period of extreme fatigue:

I still worked five days a week, twelve hours a day. I would go home and sleep until it was time to go to work. I would work and sleep. (improved, management level job)

For others it meant finding ways to cope with symptoms such as nausea or diarrhea while on the job. Several acknowledged that the only reason they could continue working was because their jobs were not physically demanding. People in physically demanding jobs, such as factory work with swing shifts, often had to cut back on their work or hours. This could restrict or eliminate chances for promotion or advancement. Even when medical justification was provided to reduce shift changes, coworkers, supervisors, and often unions were not supportive of such change.

I was on two [rather than the usual three] swing shifts because of my illness and then the union was getting after me because people were complaining that I was working two shifts when I should be working three ... But when I got onto the midnights, then I just couldn't sleep. Then it was interfering with my medication also. I couldn't figure out when to take it or if I'd taken it. ... I wrote a letter to the one guy, the plant chairman. He didn't do anything to help me. He more or less went against me. (less severe, unemployed)

Travel, as well as shiftwork, produced problems. A truck driver spoke of cutting back from long-haul to local driving because of problems with diarrhea, medication schedules, border-crossing and the changes in daily routine and sleep patterns. This effectively changed him from a full- to a part-time worker. A manager, who could no longer participate in the work and living requirements of international assignments, was restricted from advancement in his corporation.

At home I can set my schedule. I can cook my own food and I know what my limitations are ... [when working in another country] these are 14 hour days. An hour on a bus, a GO train for a little more than an hour, then a van that brings you to the plant, and then you work 14 hours, then you do the same thing and go home. No English ... The food is very different ... That's why I don't want to go, for fear of becoming ill. So yes, it [HIV] has impacted on my career because I limit myself. I've become very choosy as to what I will and won't work on. (improved, management position)

Not everyone we interviewed found it necessary to reduce their work schedule. Some worked hours that would be exhausting for the most healthy person and are indicative of the demands of the new economy.

I didn't get out of work until almost 10 o'clock this morning and I started at 8:30 last night. That's a long shift. Yea, but it has to be done right and I can't leave until it is. (less severe, factory supervisor)

Yesterday and the day before I had to work 14½ hours for two days in a row and then I'm tired and I only went to bed for 3 hours and then today I worked 11 hours... I work 60 or 70 hours a week. (less severe, food industry)

A break in employment related to HIV, and especially to AIDS-defining conditions, was common in the improved group. Leaving jobs, moving home to live with family, and divesting

oneself of property and other capital resources often occurred as part of coping with progressive illness. Some described themselves as ‘preparing to die.’ A return to full time employment could represent an important sign of overcoming poor health and re-establishing independence, and those who returned to work were following the prescribed course for someone who has recovered from an illness.

You have to feel like you can be successful at something and you think in the back of your mind, yes I can beat this. (improved, technical/managerial job)

Working full time can be so important that moving from a highly skilled technical or managerial position held prior to illness to a comparatively lesser skilled or unskilled labour (at times with no opportunity for advancement) once health improved, was acceptable, so long as it was work. One study participant who had held a highly technical job in the printing industry described how he became a pizza delivery driver:

I'd become friends with the owner at this pizza place ... and he asked me, “Why don't you come [do deliveries] for me?” I started off just delivering Wednesday, Thursday, Friday, and Saturday and now it's 6 days a week. It gives me something to do, structures my day.

Better than just sitting around. (improved, delivery)

Renewed health and the desire to prove to self and others that health had returned provided the motivation for some to take on the challenge of rigorous training or an apprenticeship period in new fields.

As I said, I moved on very fast and just needed to submerge myself in anything else but this [HIV].. Soon after I was into this [job]. And in this job you have so many courses and your licence and in those two years you have three more mandatory courses. Well I continued, and I laboured through those last courses because I was tired. (improved)

I just became a workaholic. My whole focus in life was truly working. (improved, technical/managerial job)

Goldstein and Goldbaum (1999) observe that incentives or assistance with the transition back to work are virtually non-existent. If anything, there are disincentives in the form of friends and support group members questioning the wisdom of returning to work, loss of government subsidies once one is in the paid labour force, concerns about handling medications at work and how the stresses of work would affect health, and whether it would be possible to get back on disability if returning to the labour force didn't work out. As one PHA who had recovered from serious illness and wanted to return to work said:

I wasn't on welfare because I wanted to. I wanted to work and do everything. Why isn't there any kind of program to help a disabled person get back to working? (improved, salesman)

Coping with seropositivity and the process of survival and recovery from a life threatening illness were often accompanied by periods of existential reflection (Adam and Sears 1996; Weitz 1990), sometimes resulting in a different perspective on life and the place of paid employment in one's life. For some this meant a rebalancing of their lives to spend less time at work or to leave

the labour force completely. For others it resulted in reflection on their relationship to their work. One participant reflected on his thoughts and feelings while in the process of interviewing for a job:

I'm sitting here thinking, I bloody well got here, this is a miracle...I don't care about all your crap. They were so dead serious. I don't think these people ever had an awakening or a challenge. It was very odd to be sitting there, looking at this and thinking "You don't even know where the hell I came from." (improved, took on new area of work after health improved)

Acceptance of the dominant cultural script that prescribes paid employment for healthy adults together with a strong commitment to work may make it difficult to empathize with other sero-positive people who are perceived as able to work but choose not to.

I see that the turnaround has affected many people. People have spent their money, some people are so burned out trying to cope they'll never be the same. But I do know there are a lot of able-bodied people that are well, with little motivation. They can do whatever they want to do. I don't care if it's do this or do that, but do something. Go to school, do something instead of staying on the system... They're sitting there frustrated 'cause they'd like to move ahead, but they're too afraid to and there's no reason for them not to do it. (improved, took on new area of work after health improved)

Disclosure

For those in the labour force, decisions around disclosure loom as large now as they did earlier in the epidemic. Concerns about potential discrimination, loss of employment, stigmatization and breaches of confidentiality continue to deter people from disclosing their sero-status. A waiter who was actively engaged in AIDS education in schools reflected on the effect of his public visibility on his job:

I was doing talks at high schools and then I started to notice that there were people [coming into the restaurant] who were tagging me as the guy who had AIDS and that was an issue. I started to realize that my being out about my HIV status and being a waiter in a restaurant -- it's one thing to smile and shake my hand in a school setting but quite another when I'm putting a plate of food down in front of you, and you're wondering how much of that food did I touch. (asymptomatic, currently unemployed)

It was rare for those who were employed full time to have informed coworkers or employers of their HIV status. They were often dissuaded by the advice of others.

I felt very compelled to tell my supervisor... and Dr. A kind of stopped me in the beginning and told me to really think about it and find out from a legal standpoint before I made a decision. ... I spoke to somebody in law and she put me into perspective by saying that my relationship with her and my doctor is a relationship bound by confidentiality, where my relationship with my boss is not really and things do leak and I wouldn't be protected. (asymptomatic, professional)

Even some people with drug coverage through workplace insurance did not disclose their status to their insurance company, foregoing the financial benefits rather than risking negative

consequences of disclosure.

I have a drug plan at work and I choose not to use my drug plan. I go through Trillium except for drugs like acne medicine and new eyeglasses, those that aren't related to HIV. (improved, sales)

Not all, however, felt it was necessary to hide their HIV status from employers and coworkers. Disclosure did not appear to be a problem for those who worked for employers who were 'AIDS aware.'

So I'm wondering, just why they [employers] are so good. It's because they work so much more close to the danger. They have to be aware of all pathogens that are potential. Airborne tuberculosis is far more contagious. Meningitis is far more contagious and it is a danger of their profession. ... And being a professional environment, they are personally aware of the AIDS awareness campaigns that have been launched over the last fifteen, twenty years.

I: How about medical and drug benefits?

Excellent, I have excellent benefits. I even have psychological coverage as well as my full medical. (less severe, service industry)

Alternatively, some employers who were not 'AIDS aware' were willing 'to be educated.' These employers were described as generally understanding, flexible, and approachable even before disclosure. One man, who did not work in an 'HIV aware' field took on the responsibility of educating his coworkers about HIV risk in their own lives:

What had happened is that several women in the last year have left their men and are of course back out there dating and of course I had to educate them because they're not using safe sex. So it's interesting. It's a thankless thing sometimes, it's like, "Oh god, I've got to educate these people again and again." (M6, improved)

Part-time or no employment

Those who were unemployed or working part-time stopped their regular employment because of HIV. This was either because of severe illness such as pneumocystis carinii pneumonia (PCP) or Kaposi's sarcoma (KS) that made it impossible to continue working, or because employers did not want someone with HIV in their employ. For those in the most severe group, returning to work was impossible. Though few were acutely ill at the time of this research, fatigue, diarrhea, mood swings, headaches, memory loss, the emotional and physical after-effects of having survived life-threatening conditions, declining CD4 counts and/or rising viral load, and other symptoms related either to treatments or HIV were debilitating. As one participant said, 'living with HIV is a full time job.'

For me to hold down a job would be impossible. There's too many doctors appointments, too many mood swings and depression, different side effects from the medication like this on my legs. Where a person with diabetes normally can hold down a job for quite a period of time, this is different. (improved, sales)

Unlike the *more severe* symptom group, many of those who were unemployed in the *improved* and *less severe* groups spoke of wanting to return to work. Three barriers stood in their way: finding a job, paying for drugs, and uncertainty. Finding a job of the same or similar calibre to the one they had left – including similarities in skill, responsibility, and income-- was difficult. Having a lengthy ‘gap’ on a resume, or advising a potential employer of being HIV-positive were both seen as impediments to locating suitable employment. The limited number of openings in any specific area, and the size of the local community restricted opportunities and meant that “everyone knows everyone else.” Those we interviewed who had had highly skilled, technical, or managerial positions, or positions that involved particular kinds of contact with the public viewed the possibilities of returning to such positions as non-existent and the alternatives as demeaning. This respondent complained of an

inability to go back to work and function at the level that would even be inspiring. I am not going to go back to work for the sake of going back to work, ... not when I was making the money I was once making and the education I have. It doesn’t seem right. (less severe, former technician.)

People, who had taken advantage of early retirement plans, found their financial and insurance needs were well taken care of, but their ability to return to work was curtailed.

I was off work off and on, then Dr. B signed a note to put me on disability. I went to the company doctor and he read the thing and said, “Let’s retire him.” (improved, former factory worker retired in his early 40s)

For others, employers had made it clear that they did not want them back.

They don’t want somebody with HIV coming back. I was management so I know the little tricks of the trade that were going on in the branches with some of these managers ... no advancement. Some were outright wicked and complaints went to head office in regards to one manager I know who was above me. I’d hear that she was doing this to somebody who was HIV, not even somebody in her branch, this was somebody who worked in another branch ... and she was doing this just because they were HIV. (improved, formerly in banking)

The second barrier was drug costs. For those who are unemployed, drugs are covered through government sponsored plans. Many expressed concern that if they were to return to the labour force they would lose their drug coverage and that it was unlikely that they would be able to obtain adequate (or potentially any) coverage through their employer. Some described themselves as “trapped on disability” because of the medical coverage it provided.

It’s basically all covered [drugs]. With that I feel like I’m trapped sometimes because I feel like I can’t do what I want because of the coverage. (more severe, unemployed)

Concerns about being able to ‘get on’ disability pushed one asymptomatic man, who wanted to spend time with his HIV-positive partner in the United States, to quit his job and file for disability when he heard the criteria for acceptance were going to be tightened.

C came up to me and said that they were going to be revising the categories and the parameters for going on disability, so if you want to do this so that you have coverage,

then now is the time to do it. So I went into my doctor and said, “Will you write me off for depression?” and he said, “Absolutely.” (asymptomatic, unemployed)

Clearly, the contemporary fashion in government of reducing the number of people benefiting from social programs by applying more stringent eligibility criteria may have the opposite-to-intended effect.

The final barrier to labour force participation was uncertainty: uncertainty about how long the relatively good health would last, whether it would be possible to maintain a full-time job, whether an employer would be flexible with ‘time off’ requirements for sickness or medical appointments, what the long term effects of the drugs would be, whether it would be possible to get disability pension and medical coverage again if returning to work didn’t work out.

I: Do you think that is something you would want, to go back to work?

I keep thinking about it and I don’t know if I would. I would go back because of the money, but health-wise I don’t think it would be a good decision. If I knew I was going to be healthy enough to do it, but seeing how I am right now I don’t think I could handle it. (less severe, steel worker)

For those who had been out of the labour force for a long time, there was the additional obstacle of reorganizing their lives yet again. Leaving the labour force had been accompanied by a re-evaluation and reorganization of life. Prior research has described this as a rebalancing of priorities that includes developing an identity and lifestyle that does not include work, along with a drastically modified set of expectations regarding the present and the future. The Sigma researchers (1998) described the loss of skills, training and commitment to work as having “lost the foundation for work”. Given the uncertainties about the long term effects of medications, the effects of work stress on health, the stigma and discrimination that would have to be dealt with in returning to work, and the risk of losing benefits, it is perhaps unrealistic to expect a return to work to be seen as the logical and necessary consequence of improved health.

Medication and work

Keeping a job and taking medications can pose a series of contradictions that are not always easily resolved. Two major work-related problems around adherence to medications arise from the interviews. The first concerns the difficulty of reconciling a medication schedule with the demands of shift work. Industrial and health care workers, in particular, often face a moving work schedule where work, eating, and sleep times change frequently. Fitting together the demands of timing several different medications with meal times, sleep, and in some cases highly regimented work where little time flexibility is permitted on the job, creates cross-cutting pressures that pose barriers to adherence and generate the conditions for forgetting. One shift worker outlines his strategy to resolve conflicting schedules:

I try to go with the schedule. I want to stay alive too so I do take them. I try to take them on a regular basis. I know it fluctuates a lot....I try to shift them. I push them four hours each way depending which way I’m going. I push them four again,

and four again, within three days. I know it's four hours early but it's better than one great big push.

The other major concern is the problem of taking medication at work. Where dosing and work schedules require that pills be transported to work and taken there, adherence difficulties mount.

As one respondent remarked,

I have to worry about hiding it and how am I going to take my pills? Or having to worry about taking the pills and having the shits for an hour and can I get to the washroom which is way down the hall?

The mid-afternoon dose is often the hardest dose to take regularly and on time, a finding reported elsewhere in the research literature (Proctor, et al.1999:539; Erlen and Mellors, 1999). Work-related demands often make it difficult to remember the dose, or the dosing time occurs when a work task cannot be dropped. The requirement that large quantities of water be drunk, for example to prevent crystal formation of Crixivan in the kidneys, may also be difficult to carry out at work.

RELATIONSHIPS

Barry Adam and Alan Sears (1996: 75) describe the "inventive diversity of relationships" displayed by people living with HIV in their study. The same diversity was present in this study. Relationships included those of traditional couples who live together and are sexually and emotionally intimate with each other; couples who have been sexually intimate in the past but are not currently; roommates who share considerable emotional intimacy and mutual interdependence, but no sexual intimacy; and singles who live alone or with family. The nature of relationships and sexual partnering in particular varied across illness categories, principally in relation to the severity of symptoms and the history of experience with HIV.

Couples

All participants spoke of how HIV and combination therapies had influenced their intimate relationships. Among those whose relationships predated sero-conversion, the most common theme was one of being drawn closer together by HIV and of appreciating the mutual caring and caretaking shared with a partner. Care of partners received high priority. Several people moved to new cities or left jobs specifically to be with partners, especially if the partner's health declined. The enduring nature of relationships and the commitment to being in relationships was evident in the duration of relationships that spanned between five and twelve years. The comment of one man about his partner of eleven years reflected the feelings expressed by many:

He's a great guy. Totally devoted. He is also probably the biggest influence in my life. When it comes to other than medication I motivate myself. I do what I have to do but he feeds me with power, devotion, and totally making me happy and food and love.

According to him, he is the reason I am alive, so how can you argue that? (improved)

The importance of and desire for relationships is also seen in the initiation of new relationships, or plans to increase the commitment involved in existing relationships. Even those who had provided care for partners who died as a result of HIV and who had resolved never to partner

again usually changed their resolve after a period of time and entered into new relationships:

I never thought that it would be like this, 'cause I remember a time when I said I would never date someone HIV-positive because in my two previous relationships my partner died and I will never do this again. (less severe, in a relationship with an HIV-positive partner)

For some who had been 'confirmed singles' prior to sero-conversion, HIV brought a desire for relationship. One man had moved from singlehood to a relationship which he described as "taking our time before moving in together":

I didn't want the one thing that probably got me HIV positive, and that was one night stands. I was sick of that and I didn't want it. Meeting somebody nice is so hard. Meeting somebody who you get along with, who you find attractive, and has a personality and a sense of humour, all these things, it's hard. I don't know if it's different in your way of the world or my way, but there's liars and cheats and just awful people. (improved).

HIV and combination therapy may also place, however, a strain on relationships that cannot always be endured. Disclosing HIV status in a heterosexual relationship may disclose bi- or homosexuality, as well as possible infidelity, in what is often assumed to be a monogamous partnership. Adam and Sears (1996: 84) observed that HIV creates disparate life courses in discordant or asymmetric couples, violating the common assumption that a shared life course or common fate is part of being a couple. While combination therapy can re-synchronize life courses by restoring health, it may allow an HIV-positive partner to leave a relationship where the partners have been out-of-step with each other for some time:

It was very awkward for six years for me being positive and him being negative and it was too different. He went to school and got two masters degrees and was planning his whole future and I think I was very resentful and it was like "Wow, you have all this and you are building a future and I could fucking die." ... I want someone who is going to be there with me all the time and I was having a really hard time making the decision because I was asking myself if I was worthy... and I woke up one day and D told me, "You deserve whatever you ask for ... Go for what you want." And I said, "Yeah." I'd been asking myself, "Do I deserve better? You're damn right I do." (less severe)

Sexuality in couples

Earlier studies describe a drop in sexual desire, or even revulsion with sex soon after diagnosis (Adam and Sears 1996). This experience was most common in participants who were living as a couple at the time of sero-conversion:

Towards the very beginning, it [sex] was almost non-existent. We were afraid to. Now we're getting back to our regular sexual relationship--protected sex and it's much better now than in the beginning. (female, asymptomatic)

It was very scary. Sex scared me. I was like, I felt like I was shooting poison bullets out

there. ... It was very scary and I didn't want to make it worse. I didn't want to have him get really ill and die on me. (male, less severe)

As in prior research, for the people in this study, sexual desire and activity returned over time for most people.

Current sexual desire and activity varied more by illness group than by relationship status in our sample. Those in the *asymptomatic* group were most typically sexually active, whereas those in the *most severe* group were not; the others were somewhere in between these poles. In sexually active relationships, discussion focussed on condom use. All agreed that combination therapy had not decreased the need for condoms. It appeared clear that attitudes toward condom use had been established at or before diagnosis and did not change as a result of combination therapy.

Several people spoke of their concern about the recklessness that they found in some partners:

He wanted to have sex with me. I remember him saying to me, "You are denying me the opportunity of the experience of having sex with someone who is HIV positive." I said, "What kind of experience could that be? I don't understand where you're coming from," and I still don't. He wasn't able to explain it. It was the thrill or the risk-- I don't know. (male, asymptomatic)

Some addressed the reasons why condoms continued to be important in greater detail:

Some people feel that safe sex is less important if you're taking combination therapy because your viral load goes down. But then there's the cross resistance factor [re-infection with a drug resistant strain of HIV]. If you expose medicated blood to medicated blood, you could do each other more harm than good. So that's why I've said to partners, regardless that we're both positive, I'll still prefer to practice safe sex. (male, less severe)

In most cases, in their own lives, safer sex and condom use are not an issue; they were incorporated in sexual practices with little hesitation:

I think we just left the clinic and you actually leave with condoms there and we left with them. That was it. We didn't have to talk about it, we both knew what needed to be done. (female, asymptomatic)

Prior to me going into the hospital, we never used condoms ... Now I use prophylactic measures [condoms] every time. So that's made it different, but we've adjusted. It's still good. (male, improved)

Use of condoms in long term relationships is not always easy, in which case alternative forms of safer sex may be practised, including forms of sexual pleasuring that do not require condoms.

We don't have anal sex, so we really don't need to. We just put that aside and let's have other ways to thrill ourselves. You do the oral thing and cuddle or whatever when we have sex. (male, less severe)

Or condoms may be used in casual encounters but not in the primary relationship when both partners are HIV-positive. Alternatively condoms are used at the beginning of a relationship, but then stopped:

He found out first, and then we had safe sex, and then I found out and we had safe sex for a bit and then it just dropped off. We were both positive and we had been together for so long. It is hard in a long term relationship. (male, more severe)

Whatever method of safer sex was negotiated, all of the sexually active participants demonstrated concern over the possibility of transmitting HIV to a partner.

A continuing lack of sexual desire or loss of libido was experienced by some people in the *less* and *more severe* symptom groups. Some blamed combination therapies. Others were uncertain whether it was HIV, combination therapies, or 'in their head.' Several had testosterone levels tested and were currently receiving treatment for low testosterone. None reported positive benefits in terms of increased desire as a result of treatment.

No I have none [erections]. It's not "difficulty," it's nonexistent. (less severe)

It took away my libido, my sex drive. I would like to, but there's just nothing there. I've gone for testing. Dr. E has had my testosterone checked and he said the level is right up there. It could be the drug related thing. It could be in my mind (more severe)

The side effects rather than the drugs themselves were seen, at times, as causing low or absent desire:

It's really difficult some times being in a relationship because you think about it but you don't feel like it and you don't have the drive, and if you do then you've got diarrhea or you're not feeling good. Who wants to have sex when you're feeling like that? I've found that sexually I don't even desire sex anymore. (male, more severe)

The lack of desire among *more severe* participants affected the sexual activity of those in the *asymptomatic* and *improved* groups who were in relationships with *more severe* partners. Though the *asymptomatic* and *improved* partners described themselves as desiring sex, this was not acted on since their partners experienced no desire. As the man quoted above observed:

And being in a relationship, it's hard because it's like, "Oh we're not having sex and is this a good thing or a bad thing?" It causes a lot of problems with my relationship. (male, more severe)

For people living with partners who desire sex, realizing that combination therapy could well mean a considerably longer life made them consider the implications of their sexual inactivity for their relationships:

Yeah, it's not if you're going to live, because for me I was so close to death. I know, I think about it now and I think, "Well okay we're going to

have to become more involved sexually because it isn't going to be next year or maybe not even five or ten years away. It could be twenty or thirty years. Who knows?" That is something that I really start to look at again and we have to talk about and change that. (male, improved)

Singles

Not all study participants were in relationships. Some hoped that being single would be a temporary state, though doubts about finding an accepting partner were not uncommon:

I just have to believe that there's someone who will love me in my future. I'm doubtful. Men just can't deal with an HIV-positive woman. But I have to keep believing it. (female, more severe)

Most who were not in an intimate relationship, however, claimed a commitment to being single. In some cases this was because of a preference for casual sexual partnerships rather than a commitment to a long term relationship. Most often, however, the logistics of finding a relationship partner together with concerns around disclosure were the primary explanations for a preference for remaining single.

Negotiating Sexual Activity

Sexually active singles were concentrated in the non-symptomatic groups. Here discussion about sexual activity focussed on disclosure. This respondent projected his own initial feelings towards people who were HIV-positive onto the responses of others toward him:

I automatically think that if I tell somebody that I'm HIV positive then they'll think that I'm a tramp or a slut and I'm not, so I just didn't want to be branded like that, so I think that's part of why I don't go after a relationship because I have to tell them that eventually and they're going to think of me in that manner because I think of myself in that manner. (more severe)

Several provided descriptions of responses to disclosure of HIV status that justified their concerns about how others would respond:

[He] was all freaked out about the whole HIV thing. I honestly thought that if anything that this could be a learning experience for him and I could ease him into the knowledge that there are a lot of people out there like me.... He said it was fine and all okay and it was just something that we would have to work through, and then after about two weeks he said he was trying and that I was a great guy but he just can't do it. (male, asymptomatic)

For many, concerns about the response of others to disclosure were motivations for remaining single, for becoming sexually inactive, or for not becoming sexually active. They described themselves as ‘shying away from’, ‘making themselves socially unavailable’, setting rules for themselves, or telling themselves ‘to just forget it’ when it came to potential sexual liaisons.

What about meeting new people? I think I try to make myself socially unavailable on purpose. I just don’t want to bother. ... You don’t realize what it’s like to meet someone and find them attractive physically and all and then have to one day look at them and say, “By the way, I’m HIV-positive.” It’s a hard thing to do because you don’t know how they’re going to react. So why do I want to put all my energies into something like that when it could just crumble? (male, asymptomatic)

There was a guy at work who I liked. He was just being friendly with me and I was being friendly back, and then finally I thought to myself to just forget it. I’m telling myself that if I started seeing them regularly then I would have to tell them and I work at the same place, and then if we broke up, they could go and tell everybody. Because I’d have to tell him about the HIV and then what if it didn’t work out. How do I know he won’t tell everyone at work? (female, asymptomatic)

You really learn to play the game. I would go out and socialize, and I would flirt. Friends I’ve had now for 17 years crack up at me because they say, “You never go home with anybody. You work them to death and say, ‘Bye, see ya later.’” I would never give my number out, ever. “Do you wanna go out on a date? ‘No.’ Can I get your number? ‘No.’” (male, improved)

Some avoided the need to disclose by always using condoms:

In terms of dating or casual encounters, how do you deal with it? I take precautions, I stock up on condoms.

I: What about telling people?

No. I figure if I use precautions then I don’t have to tell. (male, asymptomatic)

Even among singles, several people rejected sexual activity specifically because they were not prepared to put a partner at risk:

I can never have women in my life anymore, and I’ve always had women in my life. That was the hardest thing to accept. I wouldn’t even consider having sex with a woman because I wouldn’t want to. I got this HIV from having unprotected sex. That’s how I got it and I wouldn’t want to do that to somebody else and go and pass it on. So I haven’t had sex for three years. (male, improved)

What word did you use? ‘Safer?’ You didn’t use the word ‘safe.’ Until you can use the word ‘safe,’ I don’t want to be involved... That’s why I’m single. I was willing to kiss and stuff like that and having an extremely good friend, but not to have any sexual intercourse or relations and that just isn’t good enough. (male, improved)

Similar to those in coupled relationships, lack of desire complicated sexual partnering for singles in both symptomatic groups. Most cited this as the sole reason for not pursuing a relationship.

Family

For those who had gone through lengthy periods of illness, families were especially important. Families that had rallied round during illness were seen as important in maintaining wellness once acute episodes were over. Those in the *more severe* group spoke most of family members as important to their well-being:

In all honesty most importantly is my mom and dad, and without them I wouldn't be here. They have been remarkable. My parents are absolutely unbelievable, strong, strong, strong, strong. You know how mothers have a way of calling and hearing that little tick in your voice and they know something is wrong immediately. Mine can zero in on it in two seconds flat and there's no hiding anything. If I have to hide something and don't call her then she knows something is up. They're

truly
 remarkable,
 my whole
 family is.
 (male, more
 severe)

This was echoed by some in the *improved* group who identified their family as an important influence in their recovery.

There's programs that help me eat, to help me with everything, but if I needed a place to live, if I had no family, I asked the doctor where I would live, and he said in the hospital. ...

Without my family looking out for me when I was so sick, I'd be dead. (male, improved)

For some, an HIV diagnosis eventually led to reconciliation with family members with whom there had been strained relations:

I realize I took a lot out on him [father] now. I realize that now but back then I was thinking, "Just get off my back." I still do that sometimes now but I know now when to stop. I don't do what I did with him before, get all upset with him--I do but I don't take it out on him. I go talk to someone about it. (female, asymptomatic)

The only relationship that's been affected is that it changed the dynamics of the relationship with my brother. We're only eleven months apart, and big brother and little brother, it's like a war zone, and it now isn't anymore. We're like night and day. He'll call and say 'hi' and if you don't pick up the other end of the conversation then it ends with 'hi.' He's just not a talker, but he calls. He will do anything for me. (male, more severe)

For people to whom family involvement was important, it was common for daily activities to be enmeshed in family even when they had partners.

[My partner] comes from a big family too. I think that there's eleven. They're all in this area. I'm lucky because they accept me and treat me just like I hoped they would. I spend most of my time with them. One day with the kids and another day someone will call me over for lunch and on weekends we're always all together. (male, more severe)

Not everyone, however, described consistently good relationships with family. There were those rejected because of HIV or sexual orientation. There were also those who had not disclosed to their family, or to certain members of their family for fear of rejection. Lack of disclosure to family (as well as to employers and friends) was almost uniform among heterosexual participants.

All but one who had disclosed, had done so to only one family member. However, gay and bisexual people at times faced difficulties from family members as well. As one man from a family of twelve children described the response of his in-laws to knowledge of his HIV status:

The in-laws were probably the worst ones.

I: In what way?

Like don't touch my children, or if you get too close then I'll catch it. A lot of fear. (improved)

The 'fear' was not only of HIV, but also a fear of homosexuality:

About a year or so ago, one sister-in-law caught her son doing something with a friend and she said, “What do you want to turn out like, your uncle?” (improved)

Grown children were described as a source of support for some:

I have two grown sons; they’re very supportive. My youngest son lives in Windsor and I see him at least once a week and he calls me and asks if I took my medicine. The one in Toronto will call once a week but he doesn’t call everyday to see if I took my meds. He just calls to see how I’m doing. (more severe)

For participants with young children, spending time with children could represent a ‘shift’ away from a relatively routine, predictable daily life. One man with improved health chose not to return to the labour force but to take primary responsibility for childcare.

It’s a job. We actually have two kids, one is not genetically mine. So it’s a job taking care of two. I clean her [ex-wife’s] house and I do dishes and all those sort of things a mother would. It’s pretty equivalent to having a job really. (improved)

Friends

Earlier research focussed on the importance of friends in providing both emotional and physical support (Weitz 1990; Adam and Sears 1996), particularly during times of illness. Friends appeared to have a less pivotal role and importance in the lives of the people interviewed for this study. When asked about their contact with friends and the role they played in their lives, most described friends primarily in the context of recreational companions.

I spend a lot of time with my friends, and they’re not necessarily the friends that know that I’m HIV positive. My golf friends. The only golf I play in is really a release as far as being able to not become consumed in the fact that this is happening. I’m just living my daily life as though I’m normal to the extent that I may shy away from relationships but not friendships, not physical friendships, just friendships. I meet a lot of new people everyday and I have a lot of acquaintances and a lot of people I call good friends too. (improved)

I get together with friends two or three times a week. We go drinking. We went out drinking the other Saturday night. We ended up going to the casino and played blackjack. We go to the movies, or go to people’s houses and play euchre. (improved)

Some specifically described ‘removing’ themselves from friendships, either because they were removing themselves from a lifestyle that had led to their infection, or because they didn’t want their friends to go through their struggles with HIV:

The friends that I did have weren’t such great friends. They played games and that’s just too conniving for me so I just said good-bye, so I have no gay friends, but he [my partner] does. (improved)

At one point I guess I had in mind that it would be easier for me to disappear this way than to put anybody through, or remove myself so that if something did happen that it would be easier for them in the long run. And it would be easier for me because I wouldn't have to face people and explain things or cope, so I did pull away a great deal. (more severe)

Or, for others, because they were ashamed of their HIV status and did not want their friends to find out:

‘Cause I’m very ashamed of this disease. So I don’t see people much. I feel really bad about it and I don’t want anybody to know I got it and I’m humiliated by it and the less people that know the better. (improved)

For those who maintained regular contact with friends, there was considerable diversity in whether sero-positivity had been disclosed to friends. Friendships were not all casual and recreational. For some, friends were an important form of support:

I’m lucky, ... I do have a lot of friends and family who are very supportive who don’t mind if I have a bad day or if I’m crying. They listen. I see my friends several times a week. Some time for lunch, some times just to say ‘hello.’ (more severe)

For some, friends were a mainstay during times of illness. Relationships between friends could shift from relationships among peers who shared common experiences and ‘good times’ together to relationships of dependency where friends were relied upon for daily needs. Shifting back later to a relationship between equals could be difficult; friends were not always able to make the transition and continued in caretaking roles and stances. The transition back to ‘just good friends’ could be an uneasy one, and in some cases was not successfully navigated. One person

whose close friend had taken her into her home when she moved to Windsor from across the continent found that as her health improved, her friend could not make the transition from watching over a dying friend, to one who was living a longer life on combination therapies:

She's so busy. The last time she dropped by she said to me, "How come you never call me?" and I said, "I thought you were sick of me. I was waiting for you to miss me." I thought that we would have a lot more time together. I thought we would go to the movies together and go shopping, but that hasn't happened. It's different than what she said would happen when we first planned it out. But I'm grateful for what she did. (more severe)

It was rare for women and straight men to disclose their HIV status to friends. Those who didn't spoke specifically of their fear of stigmatization and their uncertainty of how their friends would react. They typically described withdrawing from former friendships, and a feeling that their friends were 'moving on' and leaving them behind:

How often do you get together with friends? Lately its been pretty bad. My one girlfriend that I used to go out with all the time, I hardly ever go out with her now. I went out with another girlfriend last night. I find I don't really have a lot in common with them really anymore. It's like they're changing. I'm starting to feel as though we're all going in different directions. They're married and have kids and I feel that they have that somebody always there with them. (asymptomatic)

This same woman described her struggle with deciding whether to tell friends about her HIV status feeling that keeping this secret to herself created a wall between herself and her friends, but feeling very uncertain about the consequences of disclosure.

For some who had difficulty connecting with others, the internet provided not only a source of information but also a source of friendship. One heterosexual male participant found a gay community on the internet.

Because I couldn't find people to talk to, I went on the internet and found some gay chat room and started talking to gay people who are more receptive to HIV and more knowledgeable as a rule, and you can actually go and talk to someone on the chat room and say I'm HIV positive and I'm not gay. Well, I got more than information. I got friendship out of it too. I met some very nice people. In fact they have actually flown here to visit me. One from Australia and one from Calgary. (improved)

Or, HIV-positive people provided expertise to others over the internet:

I'm on the internet on an HIV support chat room which is really good. There's none of the trash. I really do find that I help a lot of people on there: how to deal with the feelings, the experiences, the drug reactions. I know people have really appreciated it and I've done surveys that people have come on line to do. One said that my information is in all of the

things that she wrote about in university and she used much of what I said in that and she received high marks for it. It's just things like that, just being there for somebody and talking about it, that the drugs are doing this or that, and letting people know that you may have to take drugs forever but your life can be quite beneficial. (improved)

Support groups

Support groups are a mainstay of AIDS organizations, providing a place where people with HIV can meet others facing similar dilemmas and where they can potentially form friendships or meet eventual significant others. Several participants were actively involved with support groups and the work of AIDS Service Organizations and credited the groups with turning their lives around.

HIV has changed the relationship between me and my friends. A lot of friends now I've met because I'm HIV positive through the volunteering at the AIDS Committee and I know all of the people at the AIDS Committee. I've lost a lot of friends because I'm HIV positive which I think weren't friends to begin with or they would still be by my side. But I've made a lot of new ones. (more severe)

The [support group] meetings are for two hours. Boy, are they a bonus in my life. Just gives us a chance to talk about what's happening to us, like if we are all having trouble with our medications, or are we all having trouble with our local doctors. (more severe)

All of the women we interviewed spoke of wishing there were support groups for women 'like them.' A woman who spent her early years in a city with a considerable number of HIV-positive women and several available support groups had tried to start a group in Windsor, but attributed the difficulty in starting a group to the small numbers of HIV-positive women in the region. Two asymptomatic women who were employed full-time spoke of the difficulty of either getting to support groups after working a full day or of finding a group of women who were employed, as they were.

In the very beginning I felt a very strong need to find support groups. The nurse that worked at the clinic there wanted me to be aware that a lot of the support groups that were out there we weren't going to have a lot in common with a lot of people there. ... I was hoping to find a support group that were people who were professionally educated and employed, but I don't know if you can find a large support group like that. I wanted one that was going to be good for us. (asymptomatic)

Support groups were not a positive experience for all, however. Support groups were described by some as places with 'lots of negative energy' with people sitting around complaining and comparing experiences with medications rather than getting on with their lives:

I used to but I don't like them. When I was living at home and not working I would try to get out and meet people. All I would hear is whine whine, whine, whine, so I said forget it.

I got sick, I got the medicines I needed, I was in clinic the next day, I had nurses coming to my house, all my medicines are paid for. So get over it and stop blaming other people for what's happened to you. (improved)

For most of the people we interviewed, living with HIV has become relatively normalized. They take their medications and go on with their lives. There are no longer the pressing end-of-life and acute illness decisions to be made or searches for therapies to be embarked on that seropositive people faced in earlier years. Many of the participants we interviewed led lives that looked like those of their neighbours, or at least like neighbours who had some form of chronic disorder. As one man commented,

How's it any different from people who have had heart attacks and have to take their medicines? (improved)

TAKING MEDICATIONS

A good deal of the research literature implicitly that there is some thing “wrong” with the patient in understanding adherence, often dividing people living with HIV into two types of persons, “adherers” and “non-adherers.” Evidence from interviews shows the limitations of this model. Barriers to adherence often arise from conflicting demands imposed by work schedules, different medications, food prohibitions, and even outright discrimination as in the case of U.S. immigration policy. Adherence may be the outcome of compromises made in an effort to solve contradictory demands, and may be situational and related to the qualities of particular drugs, as much as to personality traits. Among those compromises are dose adjusting and reworking food rules.

Dose adjusting

The various demands around medication and food timing create incentives to simplify schedules that are at times irreconcilable. Not surprisingly, given the difficulty of the mid-day dose, the most common dosing shift is from a three-times-a-day to twice-a-day pattern, made with or without consultation with a physician, either by changing toward twice-a-day drugs, or by reworking three-times-a-day drugs into a twice-a-day pattern. In some instances, food prohibitions result in movement from a twice-a-day pattern to once-a-day. As this respondent explains:

The hardest thing with the new stuff is the Videx has to be taken on an empty stomach and therefore you can't eat two hours before you take it and an hour after, so you really have to time [it]. I was taking it in the morning when I first got up 'cause I wouldn't have eaten. So it was just easy to take. But now I found that I wasn't eating until later in the day and it was just too hard. I was such a breakfast person. So I switched it around and I'm taking it at night which is actually better because I don't want to eat before bed anyway.

Taking six hours of prescribed time out of each day where nothing can be eaten proved too difficult to schedule for several study participants, who shifted all of their medication into a once-a-day pattern in order adhere to the no-food rule.

Lest these results be read as a less-often-is-better directive, several study participants also reported shifting from a once-a-day pattern to a twice-a-day pattern in order to lessen side effects. Several people taking Sustiva remarked on “weird nightmares” and “wicked dreams” when taking the drug too close to bedtime, and feeling “high” when taken in the morning. Their

apparently successful resolution to this problem was partitioning the medication into two parts taken at different times in the day.

Reworking food rules

Dose adjusting, then, can occur in response to scheduling conflicts, side effects, and food rules. While some drugs require no food intake to assure effectiveness, others are best taken with food to improve gastrointestinal tolerance. In a few instances, scheduling demands were resolved in favor of taking everything on an empty stomach. As one study participant says, "I know some people have a lot of difficulty with the pills. I myself have one of those iron stomachs."

For those without "iron stomachs," limited food intake was relied on to reduce stomach pain, nausea, and diarrhea. For the most part, the attempt was made to adhere to food rules by eating low-fat items, such as fruit or biscuits. In other instances, there was a tendency to "bend" food rules to improve the palatability of the medications.

In addition, one interviewee noted the contradiction between the food rule which forbids eating for at least six hours a day, and the recommendation that nausea and wasting syndrome be addressed by eating many small meals throughout the day.

Experiences with drugs

Once again, it must be stressed that many study participants reported that they were highly adherent despite the side effects they experienced. For others, side effects acted as a powerful disincentive to adherence:

Say you wake up late because you overslept because you're tired or you feel like a dog's dinner and the last thing you want to do is stand there and take a dozen medicines, and some days you just say, "To heck with it," and just don't do it.... You look at it and you know it's going to taste horrible and you know you're going to have heartburn and indigestion and you just say, "I just don't want to do this today." so you skip a dose. It's not right to do but we all do it.

Another respondent agreed:

Why would you want to take something that makes you feel worse than you were? It really gets you depressed. It's very depressing. This is how I've got to live the rest of my life, got to take these crappy drugs, and I feel ready crawl in bed and stay there for the rest of my life. That's how bad it felt.... It's very hard to stay on it when it makes you feel so bad.... It was skip one here, skip one there.

But many persist.

I had a two month period where I was not doing them because I had getting my migraine headaches and I was throwing up all the time so I couldn't take them and that went on for like a good month, but aside from that I have always been on time and have been very good about taking them.

Some study participants express distress over changes to their appearance through lipodystrophy. A few take prescription or unlicensed marijuana to dampen side effects.

Ritonavir appears to pose special problems:

I had not been that compliant with my previous cocktail. I used to look at the Ritonavir jars and think, “you're the enemy because you're making me shit my pants,” but I always managed to choke them down and see what happens.

In other interviews, Ritonavir is referred to as “nasty,” “very bitter,” “awful,” “liquid poison,” and “disgusting and vile.” Some said, “I hate it,” and “Even if I think about it, I start to gag.” Only one respondent remarked that he “didn’t mind” the taste. Some people described attempting to mask it with chocolate milk; another found sucking ice cubes to numb his mouth the only effective way of tolerating Ritonavir. While most reported maintaining adherence in the face of these experiences, these remarks raise the hypothesis that some AIDS-related drugs may have different adherence profiles than others.

At the same time, it is noteworthy that there is no single side effects pattern; in fact there is a great deal of variability in experiencing effects of medications. Six of the 35 participants in this study report having experienced no side effects whatsoever. One remarked,

I just thought it was a big joke, all the side effects. I just flew through everything effortlessly.

Depression

Depression, or “negative mood states,” is a recurring factor associated with adherence in the research literature (Ferrando, Wall, Batki and Sorensen, 1996; Singh, et al., 1996; Gordillo, del Amo, Soriano and González-Lahoz, 1999; Holzemer, et al., 1999; Kalichman, Ramachandran and Catz, 1999; Singh, 1999). Also noteworthy is that it comes up as a factor in research on safe sex practice (Adam, Sears and Schellenberg, 2000). This somewhat opaque category often references existential ruminations about oneself and one’s future. The value of adherence and of safe sex rests on the premise of preserving oneself for a better future, and thus on autobiographical narratives that give coherence and meaning to the self through time. In times or situations where that premise is missing, adherence is not guaranteed to “make sense,” and sometimes even overtly self-punitive behavior may arise. It may be this nexus of meanings that also infuses another finding of adherence research, that “social support” is associated with better adherence and with better survival (Gordillo, et al., 1999). One man expresses the connection between his experience of being rejected by men he desired and adherence:

There's been times that I just thought, “Screw it, I'm not taking them any more.” Yes, maybe I should just leave mother nature take its course. Those times I was feeling very low—unloved. Well you meet somebody, and you tell them, and they don't want to be bothered with you no more. And I mean, I wouldn't mind having relationships at some point in my life. But now I really think that's impossible for me right now. You know, soon as they find out your health status, they don't want to bother with you.

Another expresses the existential dilemmas that influenced his consistency in taking medications:

There were a couple of days when I absolutely forgot to take my drugs. I was so depressed that I have missed doses.... My forgetfulness was a manifestation of a complex number of situations. After I would forget them--one dose-- then I would

have to go, “Well take them while you're making your decision. If you haven't made your decision yet, you still want to keep a best case scenario in case you decide pro, that this is a world worth living in, so you still need to be taking them.”

So I would take them back and a week later I might forget again.... *Interviewer: Are there other things that would make it difficult to stay with the medication and to know whether you've taken it and taken it on time?* Absolutely, the fundamental decision to live or die. I really believe that unless you've made a conscious a decision, sat down, and looked yourself in the mirror and literally said, “I've thought about it, I want to be here, I'm going to live,” and this is what I've got to do. Or looked in the mirror and told your friends, “I'm not taking the drugs, I'm going to die.” Unless you've cognitively, physically, made that choice, you haven't made the commitment to yourself.

These sentiments were echoed in other interviews. Another linked his adherence explicitly to being “happy to be alive.”

Effectiveness

That adherence is influenced by belief in the efficacy of medication is reflected in the existing research (Aversa and Kimberlin, 1996; Smith, Rapkin, Morrison and Kammerman, 1997; Rabkin and Chesney, 1999) and is a primary tenet of the health belief model (Horne and Weinman, 1998; Williams, 1999). There is less in the research literature about how these beliefs come about. A sense of drug effectiveness may change over time depending on subjective experience, medical testing results, media reports, physician remarks, and the views of friends, family, and other people taking the same medications. The reasoning process whereby effectiveness is determined, is perhaps the more interesting part of this process. This respondent remarks on the influence of films, physician, and subjective experience in arriving at a decision about effectiveness, and thus the value of taking medication consistently and on time:

I had seen films on people taking treatments, I had seen people with the AIDS, and I said to myself, “Why do I want to take drugs for to get sick everyday?” So I kind of got turned off that and said, “I won't take that.” Dr. A convinced me that, “If I give a certain medication that won't get you too sick, will you take it?” But I said, “OK, I'll try, but if I get sick I'm going to pass on it.”I had a viral load done just a month after it and it's 90% gone and my CD4 count went up double so these pills are really working great!

For some people, effectiveness is demonstrable and easily believed:

I started them almost probably three years, and turned my life around within six weeks....Within the next blood test my viral load became undetectable and then over three month increments my CD4 count, the first six months didn't go anywhere and then its just been going higher and higher and higher....I looked at them and I thought, “God, you know, these little things are going to do this, or can do this.” And it did it. And you look at that, and that just changed everything....If I have to take them, I will take them on time. Period. I look at it as my fuel, that's

what keeps this going on.

Belief in science and medicine may itself convey the authority that translates into a pragmatic determination to use medications as effectively as possible.

I'm probably one of the best people for this [adherence]. I realize and know wholeheartedly if it were not for the drugs and for the wisdom of the doctor that I would be dead.

And again,

I think taking the pills twice a day is better than sweating to death and dying.

Needless to say, not everyone arrives at a belief in effectiveness. Despite press reports of Lazarus-like recoveries from AIDS through protease inhibitors, the interviews reveal a wide range of responses to combination therapy. While some experience a little or a great deal of improvement, others remain the same or become worse off. Inclusion in this sample of respondents required taking, or having recently taken, combination therapy; those refusing HAART, then, do not appear here. Nevertheless, suspicion was expressed by some currently on combination therapy:

It used to be really bad [at adherence] and it's not as bad anymore. I can constantly taste the pills, and I know the pills are killing me. I tell everybody that I know they are. I know it's bad for your liver and all that other stuff. It's just the tradeoff [that justifies taking them]. I was off the pills for about a week when I went to Cuba.... I stopped for a week and that week felt amazing. I felt amazingly good.

As well, several study participants evaluated HAART in light of previous personal experience on Zidovudine, or observation of friends' experiences of it, or press coverage. Among this group of respondents was a significant portion who had brief or no direct experience with Zidovudine monotherapy, who compared their belief in the ineffectiveness of the latter with a sense of the effectiveness of combination therapy. This again points to the need to conceptualize adherence as neither a global nor a personal attribute, when individual drugs each acquire personal and public reputations, and accompanying beliefs as to their efficacy and value.

Memory aids

Many study participants discussed methods that worked successfully to support remembering dosing schedules. Some stored their medication in visible places, such as the kitchen table, or with breakfast cereal and coffee. A few used beepers or watch alarms, but more had tried them out and then abandoned them, finding them too intrusive and too likely to go off at awkward times.

In some instances, household members helped keep track of medication, as in the case of the wife calling at work noted above. But household members can pose adherence problems as well, especially when a partner has a conflicting medication schedule. This study participant adjusted his drug combination to accommodate the eating requirements of his partner:

He's diabetic and he has to eat in a certain amount of time and those two were really conflicting: eating really late is bad for him and me not eating too early is

bad for me so now that I'm on this drug it makes everything easier.

U.S. border crossing

Most Canadians live within eighty kilometres of the U.S. border. The United States maintains an overtly discriminatory policy regarding the entry of seropositive people. Since U.S. border guards are unable to discern who is seropositive, the policy is enforced against those who carry medication for HIV disease. The policy works, then, not as a barrier against the virus, but as a barrier to treatment. Those for whom going home or to work requires crossing into the United States may compromise adherence schedules to avoid border inspection. Others take treatment interruptions and risk the development of resistance in order to travel into the United States for shorter periods.

The exclusionary policies of the U.S. government with respect to cross-border travel for HIV-positive people and, until very recently of both countries toward recognizing same-sex couples for purposes of immigration, served to either keep partners apart, to force them to reside illegally in one country or the other, or to make travel between Canada and the United States whether for jobs, medical care, or family reasons, fraught with difficulty and anxiety. Each partner ran the risk of 'getting tagged' whenever he or she crossed the border. Immigration of either partner was further complicated by their HIV status, necessitating regular cross-border travel to maintain job and relationship, despite the risks. One asymptomatic man left his job and went on government disability, reducing his trips to Canada from his 'illegal' home with his partner in the United States to primarily those for medical care. Another asymptomatic woman who worked in Canada and had a partner in the United States, lived with a sister in Canada several days a week to decrease the number of border-crossings each week. With the increasing practical and legal recognition of same-sex relationships, some could now contemplate a resolution to border crossing problems through immigration to Canada.

ADHERENCE AND ILLNESS EXPERIENCE

Those in the *asymptomatic* and *symptomatic (less severe)* categories typically reported adherence practices more influenced by the structure of their everyday lives than by illness experiences. Doses associated with regular daily life events, especially preparing for bed and getting up, are most consistently taken; doses that must be taken at work, on the road, or outside daily routines are more often lost. Barriers to adherence often arise from conflicting demands imposed by work schedules, different medications, food prohibitions, and even outright discrimination as in the case of crossing the border from Canada into the United States. Depression and existential rumination also play a role in non-adherence.

While most study participants reported extraordinary measures in rearranging their lives to meet dosing guidelines, those in the *improved* and *symptomatic (more severe)* more often reported adherence problems related to illness experience. Those in the *improved* category more often linked their adherence to improved medical markers and subjective experience, while those in the *symptomatic (more severe)* category more often reported adherence problems and interruptions associated with drug side effects and feeling unwell.

Improved

Some study participants reported such significant improvement with protease inhibitors, that their earlier skepticism concerning drug therapy in general was alleviated:

I stopped the drugs. I had reduced my dosage and then stopped the drugs because, friends of mine were sick and enough of them had died and I was a firm believer that AZT was killing them.... Then I had become ill and Dr B had suggested that I go on the combination therapy. It was wonderful because I think within six months, six or seven months, I know it was less than nine months, I had my viral load done again and it was 500. It was right around there, a borderline I recall. It's been undetectable, or less than 50 copies when that new test came out, ever since.

And another interviewee experienced the revitalization that has become the best known aspect of the "protease moment."

It was a fear thing because everybody was saying that AZT was killing them more than curing them. So then of course it changed very quickly and I started them [combination therapy] almost probably three years, and turned my life around within six weeks....At that time I was reluctant...compromising good health for drugs. I finally said to him [doctor], I realize the results are too good to ignore so give me ten days and I'll be off of it [combination therapy], thinking that I would experience all sorts of side effects and discomfort. Well, to my amazement, nothing, NOTHING, other than some sort of adjustment period with your stomach and so on.

But for many others, mixed outcomes were associated with ambivalence about therapy. While this study participant believes, "People who don't take them end up sick," his experience of fatigue and weight loss along with pill burden, despite undetectable viral loads, is reflected in adherence practices.

I was getting to the point that I was just sick of taking them so it came time and I thought I'd just take them a little later and then a little later, then "oh well, it's too late now I guess. I'll have to miss that one." For the three years I'd been on them I was doing excellent—three times a day—and my blood work showed that. Then I was just fatigued with having to take twenty-six pills a day....It's up to you whether you take them or not. People who don't take them end up sick. Similarly side effects or related subjective factors can impact attitude toward adherence even in the context of much improved medical indicators.

I: Do any of those symptoms effect your ability to take your prescribed medication regularly?

Yeah I would say so. When you wake up in the morning, say you wake up late because you overslept because you're tired or you feel like a dog's dinner and the last thing you want to do is stand there and take a dozen medicines and some days you just say to heck with it and just don't do it. ...You look at it and you know it's going to taste horrible and you know you're going to have heartburn and indigestion and you just say I just don't want to do this today so you skip a dose. It's not right to do but we all do it.

Symptomatic (more severe)

For those who have felt unwell both before and after the introduction of combination therapies, medication in general, and adherence in particular, may involve lengthy periods of wrestling with side effects along with significant ambivalence or skepticism.

I started taking them and they made me kind of queezy and I didn't look forward to taking them, and I was a little worried, and so two weeks into it I woke up one morning and I had red spots all over me. Thank God I knew what it was because I've had that reaction to an ear infection and they put me on some antibiotic and I turned red from that, so I knew that it was just a drug reaction, and I thought "Good, I can't take the drugs." So I called up the doctors and said that I can't take the drugs because I'm allergic, I got a pretty clear sign from my body that it doesn't like these drugs, and they said, "Please come in. We think that we can get you through the rash," and I thought, "I don't want you to get me through the rash because this is a clear message to me that it's not good for me."

This person reports overcoming the drug reaction and persisting with combination therapy but also experiencing adherence problems related to sleep induced by other prescribed drugs.

Another study participant reports a similarly checkered history:

I always felt like a guinea pig for every new drug that was coming out because none of them seemed to work for me. I was never able to take one for a long long time, and I'm still in that boat actually.... I tried to take my drugs regularly because they ram that into your head that if you don't you're going to get sick, you're going to get sick, but a few times you miss doses, it's just natural....I've missed doses but I'm not missing them on a regular basis because my viral load went from 200,000 down to 5,000 and back up almost to 200,000 again and I didn't know why.... I had something in my mouth, black dots, and the doctor said, "Get him in here right away." That was a bad time. They didn't bother me, and then I had to go through radiation and then I got really really sick. The radiation made me really sick and it took me a long time to get back on my feet again and get re-energized. I felt like it almost took a year before I thought I have to feel normal again....There's a lot of times when I look in my box of pills that I keep and think, "God, I could just throw them all out right now."

And again, this person living with AIDS shows conflicting discourses around perceptions of effectiveness, subjective experience, and medical authority.

I know the pills are killing me. I tell everybody that I know they are. I know it's bad for your liver and all that other stuff—it's just the tradeoff.... I stopped for a week and that week felt amazing. I felt amazingly good.... Sometimes I find myself keeping busy with my friends and stuff and losing track of time, and thinking, "Well I'm not at home so I'll take them later," but a lot of the times I do take them but a lot of times I don't. The doctor knows about it because it shows up on my labs and stuff, and he just looks at me and gives me a little snarl and says, "Are you taking your meds?" and I feel so guilty because I don't....I usually take them at the times I need to take them, but a lot of times basically when I'm out or busy or I just want to go do something and now I have to take them, so

sometimes I just don't bother.

Adherence may vary by particular drug. At the time of the study, Ritonavir was available only in liquid form.

I had not been that compliant with my previous cocktail. I used to look at the Ritonavir jars and think, "you're the enemy because you're making me shit my pants," but I always managed to choke them down and see what happens.

Others report high levels of adherence despite an adverse response. In this instance, adherence is bolstered by social support and past experience with medications.

I'm pretty good with taking my medication...almost all my life I've been on medication for one thing or another. I'm pretty good at it....Plus friends call me, my mother calls me, and my sister calls me, so even if I would forget, than everybody has my back asking me if I've taken my medication. Then they call me before supper and ask again. So it's kind of hard to forget, which is good because I know there's a lot of people who care about me and make sure.

A personal philosophy linked to belief in medical science enhances adherence practices here:

I'm probably one of the best people for this. I realize and know wholeheartedly if it were not for the drugs and for the wisdom of the doctor that I would be dead. I've skirted it twice. I'm not stupid and I'm not playing games. This is for my life....I know in my heart that they are the reasons that I'm still here. At one point I used to say that I'm living on borrowed time and that this time it's a gift.

These findings raise questions concerning the degree to which non/adherence can be a self-reinforcing condition where belief in effectiveness improves adherence which improves effectiveness, or ineffectiveness generates disbelief which diminishes adherence which accelerates ineffectiveness. They also foreground the importance of illness status and experience in adherence practices.

CONCLUSION

A previous study of the impacts of HIV on personal, family, and work relationships (Adam and Sears 1996) done in the early 1990s included many participants from the same region. This study, completed at the end of the first decade of AIDS and before the introduction of the protease inhibitors, offers a benchmark against which experiences of living with HIV in the era of combination therapies can be compared. Now at the end of the second decade of AIDS, a pattern of both change and stasis emerges.

Compared to the earlier study of a similar sample of people living with HIV in the early 1990s, workplace problems are little changed. Few employers provide flexibility for those suffering symptoms, and adherence to medication regimens often conflicts with workplace demands. In the early 1990s, people living with HIV began to be covered by legislative protections concerning discrimination against persons with disabilities. Despite the law, a great many practical considerations around employer attitudes, fulfilling job requirements while ill, time

inflexibility, trade union policy, and work-related benefits resulted in few people being able to avail themselves of these protections. This continues to be the case a decade later. This apparent relative constancy in the day-to-day work situation must be contrasted, however, with larger changes in the socio-historical environment. The AIDS era is coterminous with the rise of neoconservative agendas in government restructuring. A decade ago, the downsizing of social support programs was immanent; a decade later, the relationship between work and the out-of-work “social safety net” has shifted and people living with HIV must cope with its consequences. (See Policy Implications below for more on this point.)

The other major socio-historical change during this period is in the health of people with HIV in general. As previously noted, this contrast can be over-rated. Even before the introduction of combination therapies, there were a great many seropositive people who remained in the labour force, or who were attempting to establish a foothold in employment and make careers, despite the common presumption at the time that the only trajectory of any importance was *out* of employment. Similarly, today, the health status of HIV-positive people is also more mixed than the vision of HIV disease as “chronic manageable illness” implies. With these caveats in mind, combination therapies have created a class of people with *improved* health status and helped stabilize many others as (relatively) asymptomatic. As a result, workplace problems remain a primary preoccupation as people attempt to move back into the labour force, reconcile treatment demands with workplace requirements, and cope with the stress of employment in industries where downsizing has intensified demands on the workers who remain.

For those who have left the labour force, returning requires considerable determination, dedication, effort, and often a willingness to search out new forms of employment and to leave behind previous training, accumulated experience, seniority, and skill. Government and workplace insurance, disability, and drug plans impose barriers to returning to work which considerable numbers are unable to overcome. Recent cuts to a wide variety of social programs and adjustments to eligibility criteria discourage those who are currently benefiting from these programs from taking a chance on returning to work. They fear being found ineligible for social assistance if work is too difficult for them or if they are laid off or fired from their job. Those in the improved group have often experienced life threatening conditions and many have divested themselves of possessions and moved to be closer to family in anticipation of declining health. For some, returning to work is an essential part of ‘being well again.’ They embark on lengthy periods of training and accreditation in order to return to full-time employment and/or advance in their chosen area. Others change fields and ‘started again’ to build up seniority, skills, and credentials. Jobs provided structure, social contacts, and purpose for them and almost any job, even if it is at a skill, responsibility and pay level below what they had before, is important.

Compared to a decade ago, family and personal relationships also show considerable continuity. The most noteworthy change is the more consistently supportive reaction of families to HIV-positive family members today. At the end of the second decade of AIDS, the public hysteria that characterized the first decade has diminished. People living with HIV now rarely report family members imposing a virtual quarantine upon them as some did a decade ago. Satisfaction with ongoing relationships with partners is much the same, as is trepidation in

initiating relationships among single people.

Also similar to a decade ago is the relative secrecy practised by heterosexuals. With the partial exception of African Americans interviewed a decade ago in Detroit, many of whom lived in communities hard hit by the HIV epidemic, heterosexual people then and now anticipate little understanding and support from people around them and therefore disclose their sero-status to few, if any, trusted individuals whom they know. Despite steadily climbing rates of HIV infection among heterosexual women, and men as well, the overall incidence is such that most heterosexual people continue to believe that HIV is not part of their social reality. Gay men, by contrast, whose communities have confronted HIV for many years, feel able to disclose their sero-status more widely, expect their friends and social networks to respond well, and thus are better able to draw on the social support they can provide. Still, even this comparison must be qualified by experiences of gay men who, nevertheless, face rejection from their fellows, especially in dating situations.

Two decades of AIDS and the widespread use of combination therapies have resulted in a greater sense of “routine” around AIDS, less public panic or even comment, and an apparent normalization of HIV disease insofar as it has become viewed as a primarily medical issue. With this evolution in public discourse has come a shift in the way that people living with HIV themselves think about their relation to the disease. Whereas significant numbers in the first decade took on AIDS as an identity, HIV is now more often relegated to a more secondary aspect in many people's lives. In the hostile social climate of the first decade, many people with HIV, especially those in gay and lesbian communities, mobilized themselves into community organizations, advocacy groups, support groups, and social networks (Adam 1997). In contrast, in the interviews reported in this study, participants often reported not knowing anyone else who is HIV-positive, less sense of identification with other sero-positive people, and apparently less need to identify themselves to AIDS service organizations or to seek out support groups

For those with many years of living with HIV, this can feel like a lack of acknowledgement of the multiple losses they have experienced through the course of the epidemic which may include losses of: partners, friends, employment, a sense of direction in life, sexual confidence, family and community support. Depression continues to appear in this and other studies as a factor in adherence (and in safer sex practice). Much depression arises from the “usual” sources, such as stressful events like job loss, relationship problems, health crises, and so on, but HIV remains a contributing factor as well.

POLICY IMPLICATIONS

Workplace and social benefits

- Concerns about potential discrimination, loss of employment, stigmatization, and breaches of confidentiality continue to pose difficulties in the workplace. Small firms which administer their own supplemental health benefits plans raise the risk of exposure of sero-status to employers. More (not less) extensive coverage by provincial single-payer medical plans would provide better confidentiality of medical status as billing records would then need not be seen by managers.

- Contemporary trends among neoconservative governments in “tightening up” welfare eligibility may have the contrary-to-intended effect of increasing incentives for people to hang on more tenaciously to the programs in which they are enrolled. Heightened barriers to disability, employment insurance, and drug benefits programs reduce the ease of transition *off* programs as well as *on*. Several study participants spoke of feeling ‘trapped’ on disability programs because of the fear that similar coverage would not be available if they were working. Programs guaranteeing drug coverage only for the poor create strong disincentives to return to work since coverage may be lost in resuming work. Given the extraordinary cost of HIV medications, people with HIV who are currently on transfer payments face a high-stakes gamble in attempting to resume employment: the potential for employment income must be weighed against the risk of losing access to medications and consequently the risk of seriously jeopardizing health which in turn could lead to job loss again.
- Counselling services and support programs could also help make the transition back to work.
- The overtly discriminatory border crossing policy enforced by the United States constitutes a barrier to adherence to medication, to support networks, and to the ability to earn a living. With no demonstrable effect in controlling HIV transmission, this policy has little more than a punitive function imposing an unnecessary disability on people living with HIV. During the study period, the Canadian Ministry of Health tentatively proposed the adoption of the same exclusionary policy in Canada (since rescinded).

Adherence issues

- Adherence may be the outcome of compromises made in an effort to solve contradictory demands, and may be situational and related to the qualities of particular drugs, as much as to personality traits. Autobiographical narratives that give order to one’s sense of self provide foundations upon which adherence decision making occurs. Adherence rests on the premise that (long) life is inherently valuable, and personal assessments of that value are made through a conjunction of autobiographical narratives around personal, work, and family relations, and with experiences of medications. Public messages concerning the (lack of) value in aging may also have an impact on this assessment, perhaps especially for women and gay men. People may be more likely to adhere well to medications that they believe are making them better, whether measured subjectively or through medical testing, but these beliefs may change when these indicators point to a worsening condition. Both of these can be self-reinforcing conditions where belief improves adherence which improves effectiveness, or ineffectiveness generates disbelief which diminishes adherence which accelerates ineffectiveness.
- Adherence to medications is best improved, then, when dosing can be tailored to the structures of everyday life and integrated and “anchored” in daily, routine events. Since there is no single structure that applies universally, medication decisions need to be made recognizing individual variations. Successful adherence also presumes a sense of self

value founded on social support, active coping orientation, personal stability, and perceptions of aging--all large issues not easily addressed through outside intervention. And finally adherence is also related to perceived efficacy: subjective sense of illness, medical indicators, and/or side effects can all create (dis)incentives for continuation of medication.

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