pH positive HEALTH

TREATMENTS • SERVICES • HEALTH

1998 – 1999

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HEALTH STATUS

- The respondents in this sample received their HIV diagnosis fairly evenly across the years of the epidemic, with about half having been diagnosed prior to 1990.
- Most respondents rated their current state of health as being good or excellent, and most often they based this on how they felt.
- Nonetheless, about half the participants had received some sort of medical treatment for their mental health in the previous year, and about half had experienced symptoms of HIV-related illness in the previous month.
- About one-third also reported experiencing symptoms of lipodystrophy in the previous year.
- Two-thirds had been diagnosed with an opportunistic infection and nearly half had such an infection in the previous year; fungal infections were the most common of these.
- Ten percent of respondents had been hospitalised in the previous 12 months due to opportunistic infections.
- Most respondents had adopted a range of strategies to improve their health, most commonly to reduce stress.
- Almost half said they had been diagnosed with hepatitis A and about one third with hepatitis B.
- One in six said they had been diagnosed with hepatitis C.
- About one-third had been diagnosed with depression, half of these in the previous year.

(Please note: Information about CD4 count and viral load appear in the section entitled 'Health Maintenance & Monitoring')

Year of diagnosis

Fifty-two percent of respondents were diagnosed with HIV prior to 1990 and about 13% were diagnosed before 1985. Respondents who were diagnosed after 1995 constituted about 18% of the sample (see Table 1).

Table 1 : Year of HIV diagnosis

	Frequency	Percentage (%)
Before 1985	57	13.4
1985-1989	166	39.0
1990-1994	127	29.9
1995-1999	75	17.6
Total	**425**	**100**

The specific years in which participants of the study were diagnosed with HIV is presented in Figure 1.

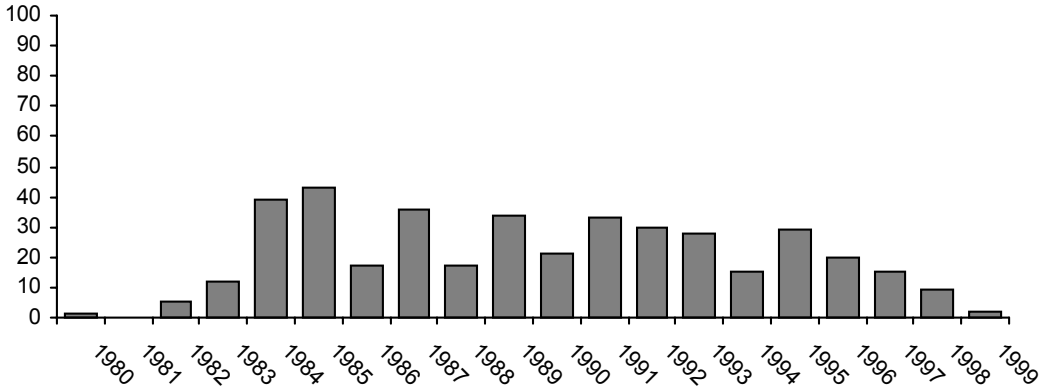

Figure 1 Incidence of diagnosis from 1980 to 1999

Respondents were asked when they thought they had been infected in relation to their diagnosis; 49% believed they were infected within 12 months of their diagnosis (see Table 2).

Table 2 : Time period between perceived infection and actual diagnosis

	Frequency	Percentage (%)
Up to 6 months	165	38.8
7-12 months	44	10.4
1 to 2 years	67	15.8
3 years or more	86	20.2
Unsure/NR	63	14.9
Total	**425**	**100**

General health

Seventy-seven percent of respondents rated their health as good or excellent, 20% described their health as fair, and less than 3% reported being in poor health (see Figure 2).

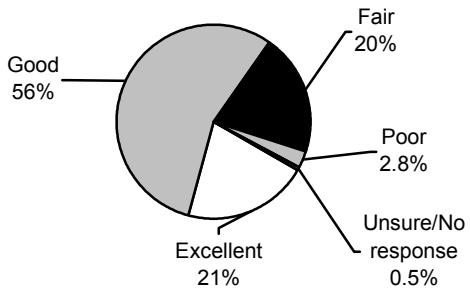

Figure 2 Self-rating of general health

Respondents viewed a range of factors as important in making an assessment of overall health. How the person actually felt was reported as the most important gauge of one's health. Eighty-three percent viewed this as being very important and 15% as somewhat important. About half (50%) considered how they look to be very important and about as many (47%) believed their CD4 count and their viral load (54%) to be very important in making an assessment of overall health. Basing one's overall health on a doctor's opinion was rated least highly among the five response categories, albeit 42% of people rated this as very important (see Figure 3).

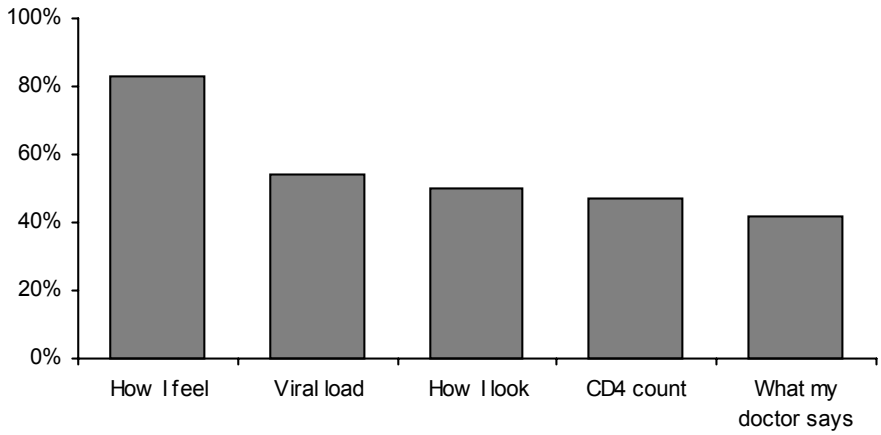

Figure 3 Factors considered 'very important' in assessing health condition

Respondents were also asked to rate how aspects of their health had been in the previous 12 months on a scale from 1 (excellent) to 4 (poor). These included appetite, sleeping patterns, overall stamina, concentration, libido and mood. Sixty-nine percent of respondents rated their appetite as being either good (34%) or excellent (35%), and about 50% rated their stamina, libido and sleeping pattern as being either good or better (see Figure 4). Ratings of 'poor' were highest for stamina (17%), libido (27%) and sleeping patterns (22%).

In relation to the emotional or mental aspects of health, almost two-thirds of the respondents rated their current mood and concentration as being good or excellent and only a few people rated these as being poor (see Figure 4). Forty-seven percent indicated that they had sought medical treatment or counselling for mental health within the previous twelve months. There was a high degree of similarity in participant response to these indicators of health.

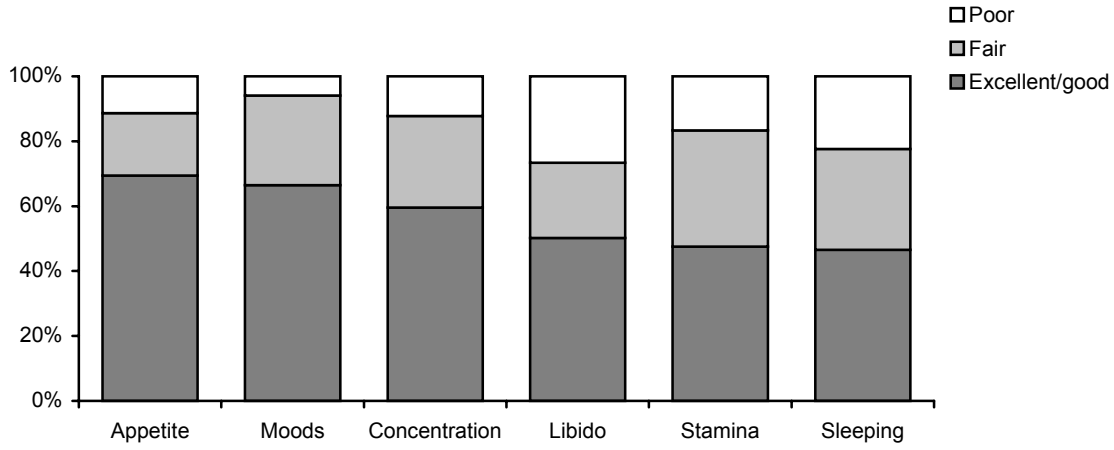

Figure 4 Self-rating of various aspects of health

Most respondents adopted a range of strategies to improve their health (see Figure 5). Of the options offered trying to reduce stress was the most common strategy (79%); others included taking vitamin supplements (58%), improving diet (58%), taking regular exercise (55%), and getting more sleep (47%). About 40% of respondents had stopped or reduced their alcohol consumption and about 25% stopped or reduced tobacco smoking. Some people tried meditation (31%) and one quarter of respondents tried massage.

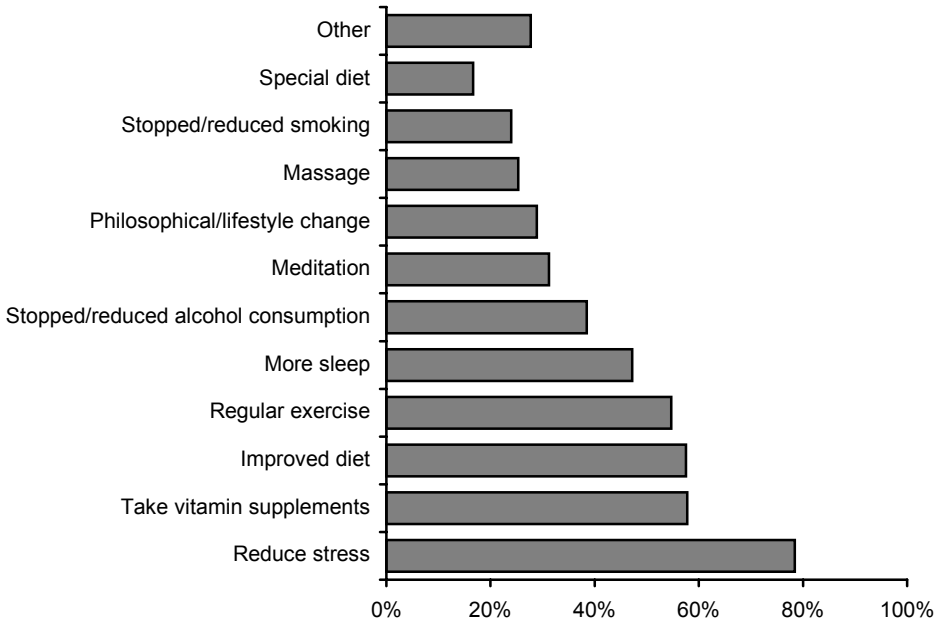

Figure 5 Strategies adopted to improve health

HIV-related symptoms and illness

Respondents were asked to rate the intensity of symptoms they had experienced in the previous 4 weeks, related to HIV or anti-retroviral drugs. The response scale ranged from 1 (not at all) to 4 (severe). Most participants had experienced at least some of the symptoms in the previous 4 weeks and many reported that these symptoms had been severe during that period (see Figure 6). The most common group of symptoms were gastrointestinal, with 88% of respondents reporting the experience of at least one of those listed. The second most common group of symptoms were respiratory, of which 75% of respondents had experienced at least one on the list. Sixty-six percent of respondents had experienced at least one of the mental/psychological difficulties such as insomnia, anxiety, depression or fear.

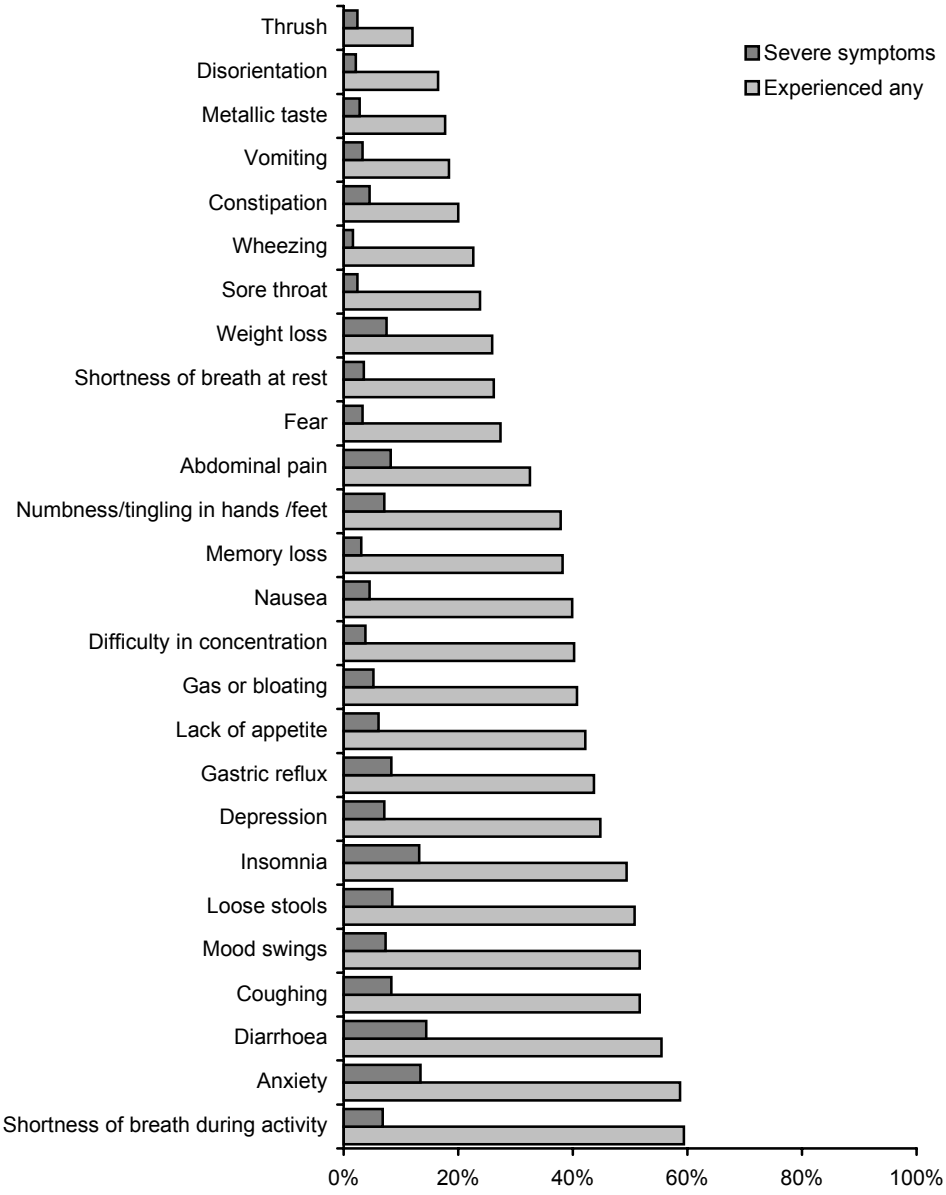

Figure 6 Symptoms experienced in the previous month

The impact these symptoms had on participants' lives was rated from 1 (did not interfere) to 4 (severe) (see Figure 7). Although many respondents said that these symptoms had interfered with their lifestyle, only a minority reported that the impact had been severe. The symptoms most commonly rated as being severe include gastrointestinal (e.g. diarrhoea, loose stools) and emotional/ psychological (e.g. anxiety, insomnia, depression).

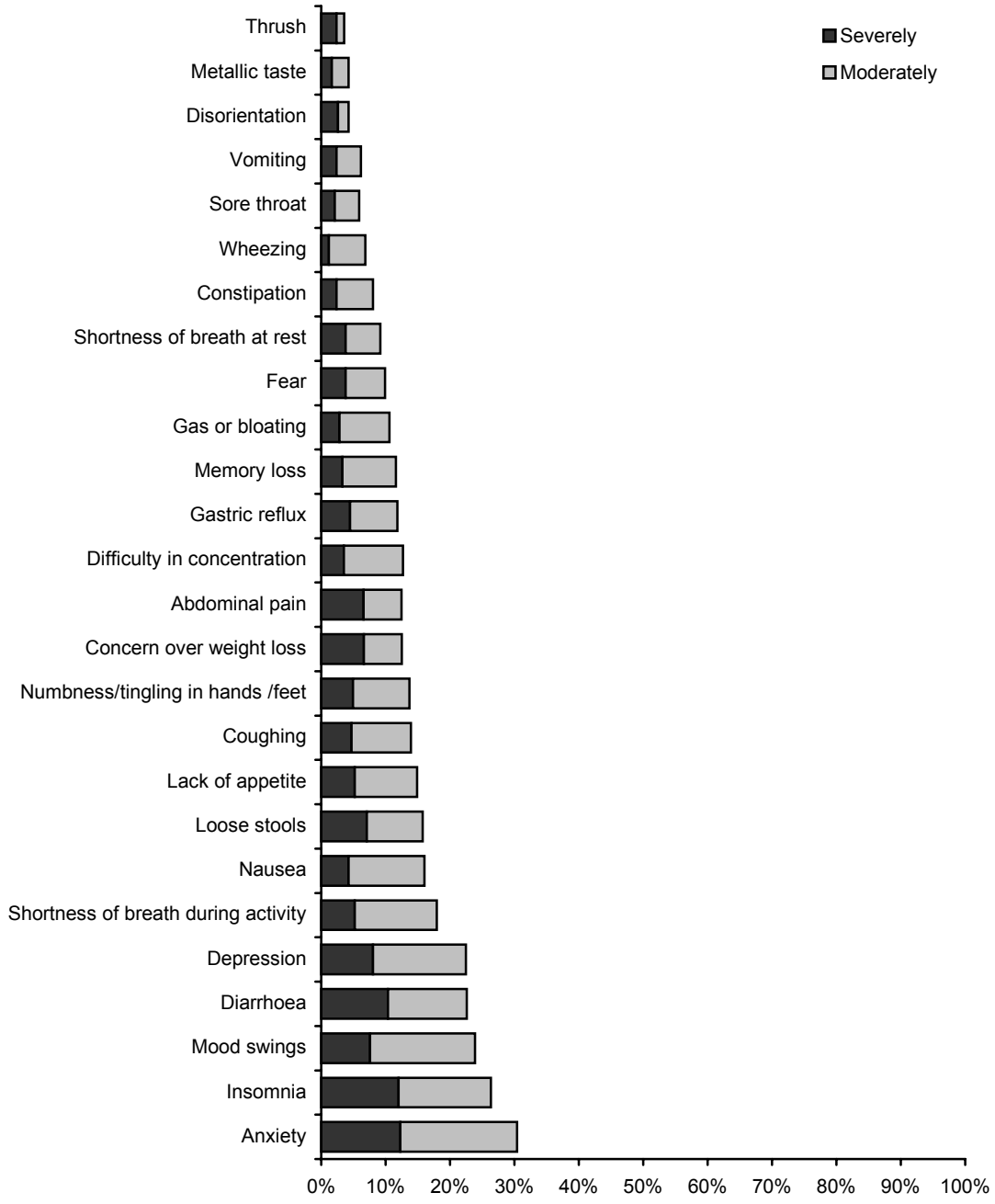

Figure 7 Impact of HIV-related symptoms on lifestyle

Note: Percentages are calculated on the total sample (n=425).

The percentage of participants who believed that their symptoms were HIV-related is reported in Figure 8. A high percentage of respondents did not necessarily believe these symptoms were the result of their HIV infection. Indeed, other circumstances were often understood to be the likely reason for these symptoms, and there was considerable uncertainty about the causes.

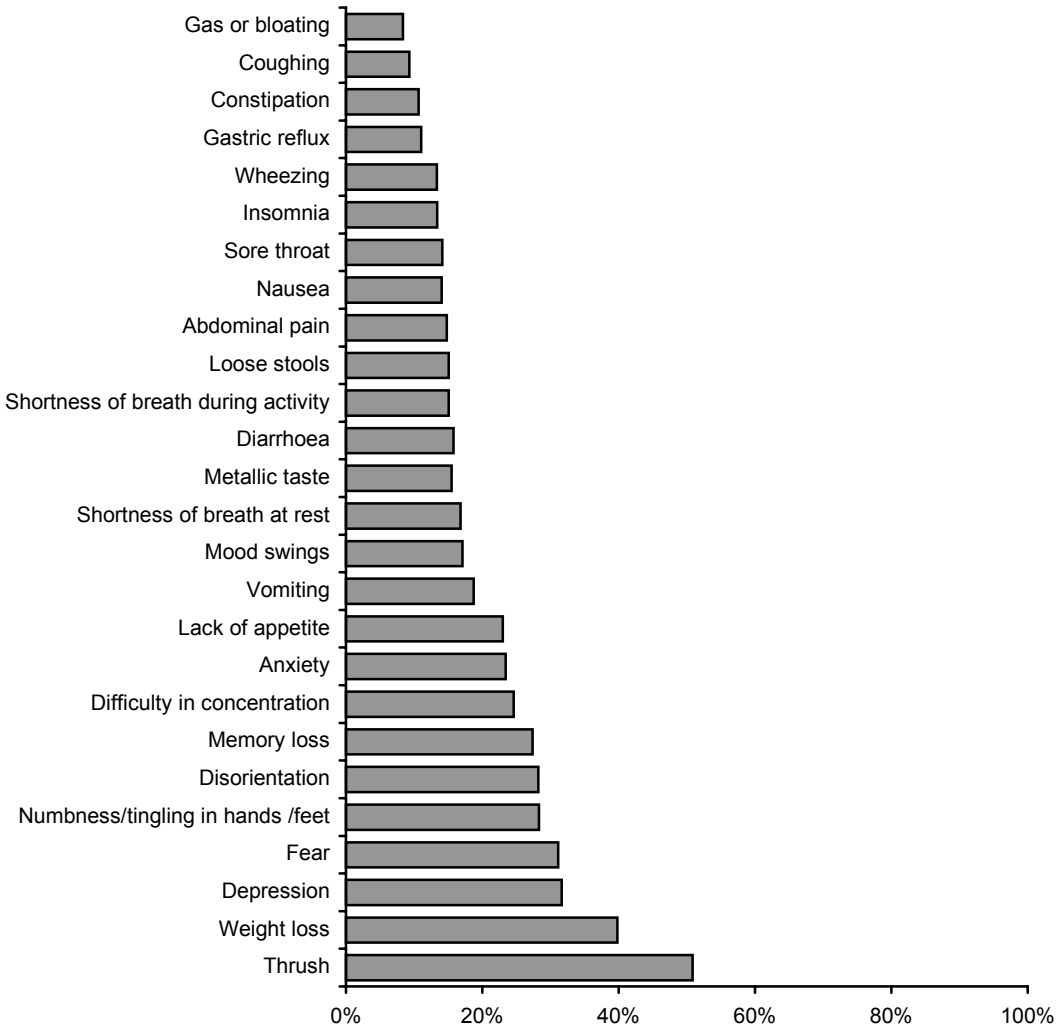

Figure 8 Perceived link between HIV and symptoms

Note: The percentage for each symptom is calculated by including only those people who experienced that symptom.

The percentage of participants who believed that their symptoms are related to taking their HIV treatments is presented in Figure 9. A substantial proportion of respondents did not necessarily believe that their symptoms were the result of HIV treatments. The symptoms that most participants believed to be most related to taking their medication include metallic taste, diarrhoea, loose stools and nausea (see Figure 9).

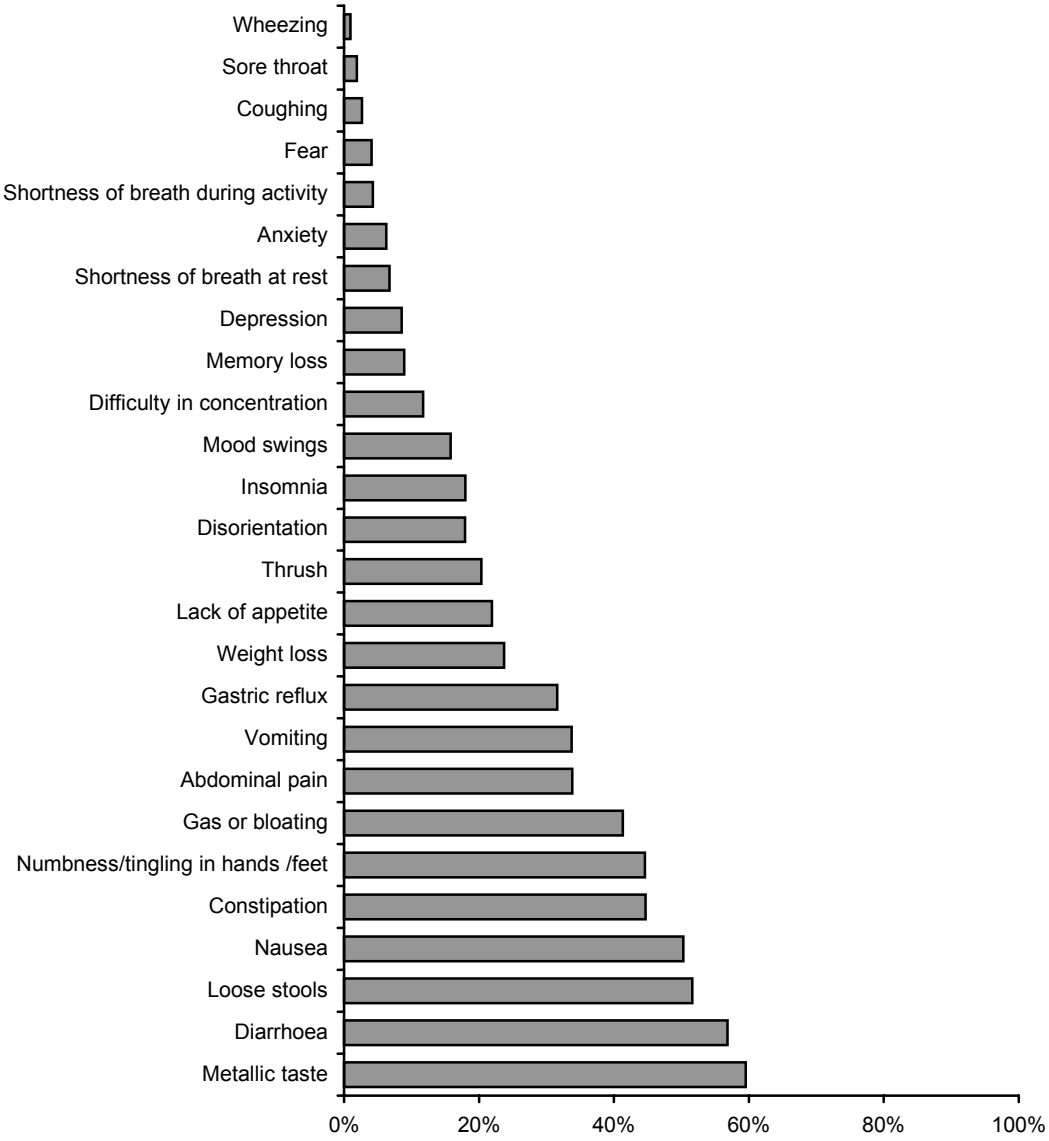

Figure 9 Perceived link between medications and symptoms

Note: The percentage for each symptom is calculated by including only those people who experienced that symptom.

Sixty-one percent of respondents reported experiencing at least one of the three signs of lipodystrophy: sunken cheeks, prominent veins on arms/legs and increasing abdominal girth in the previous year. Of these people, 28% (or 17% of the whole sample) used the word 'severe' to describe at least one of these signs (see Figure 10).

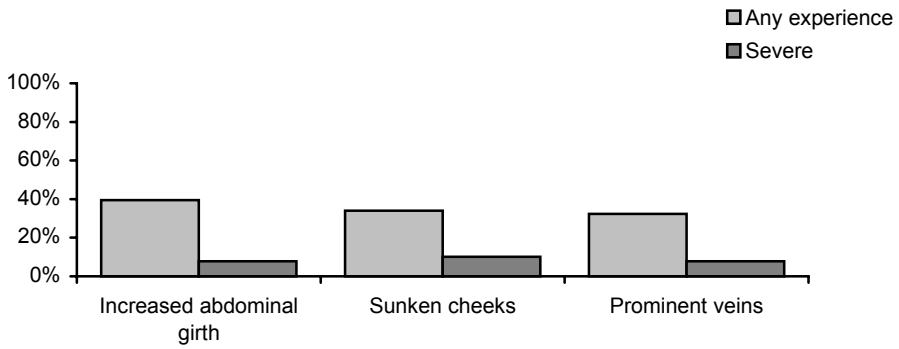

Figure 10 Lipodystrophy symptoms in the previous year

Seventy-one percent of those who experienced any symptoms of lipodystrophy said that it had interfered with their lifestyle, and about 19% said that this had a severe impact on their lifestyle (or, 44% and 11% of the whole sample respectively). A substantial proportion of respondents felt that HIV infection was responsible for sunken cheeks (47%), although fewer attributed the other symptoms of lipodystrophy to HIV infection (see Figure 11).

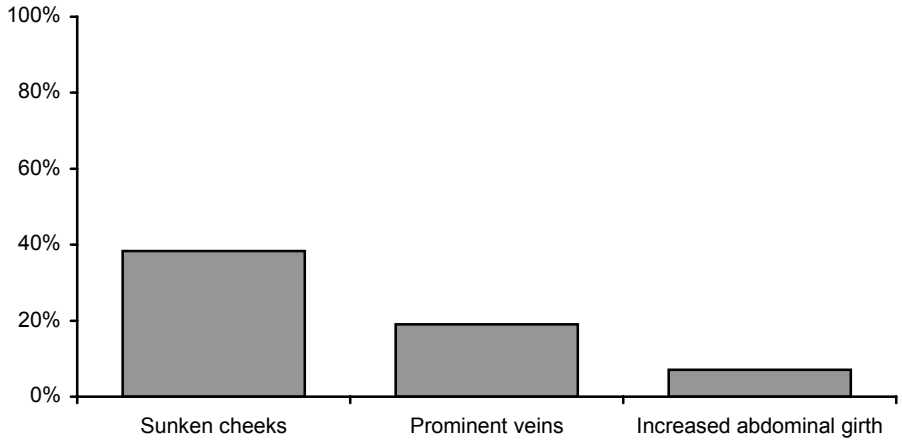

Figure 11 Perceived link between HIV and lipodystrophy

Note: Includes only those respondents who had each of those symptoms of lipodystrophy in previous year.

HIV medications were more commonly felt to be responsible for the symptoms of lipodystrophy, particularly for increases in abdominal girth (see Figure 12).

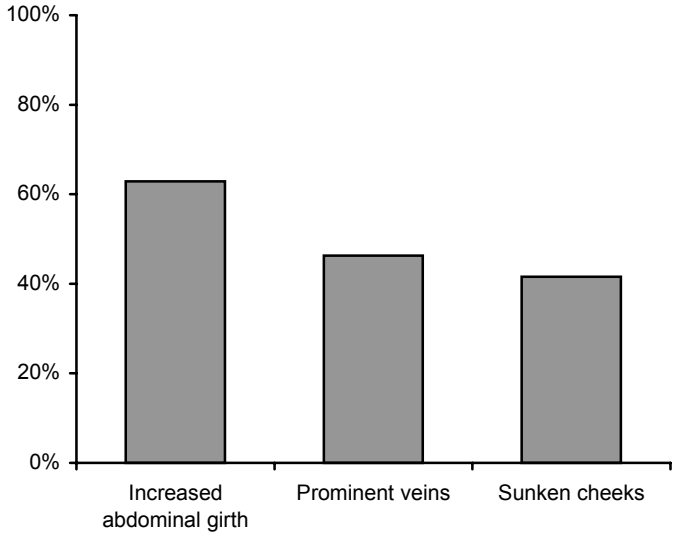

Figure 12 Perceived link between medications and lipodystrophy

Note: Includes only those respondents who had each of these symptoms of lipodystrophy in previous year.

Respondents were asked to indicate whether they had experienced any in a list of commonly experienced opportunistic infections. Sixty-nine percent of the respondents had at some time been diagnosed with at least one of the opportunistic infections in the list (see Figure 13), and 48% of people had experienced such an infection during the previous year. Candida and fungal skin infections were the most commonly reported infections.

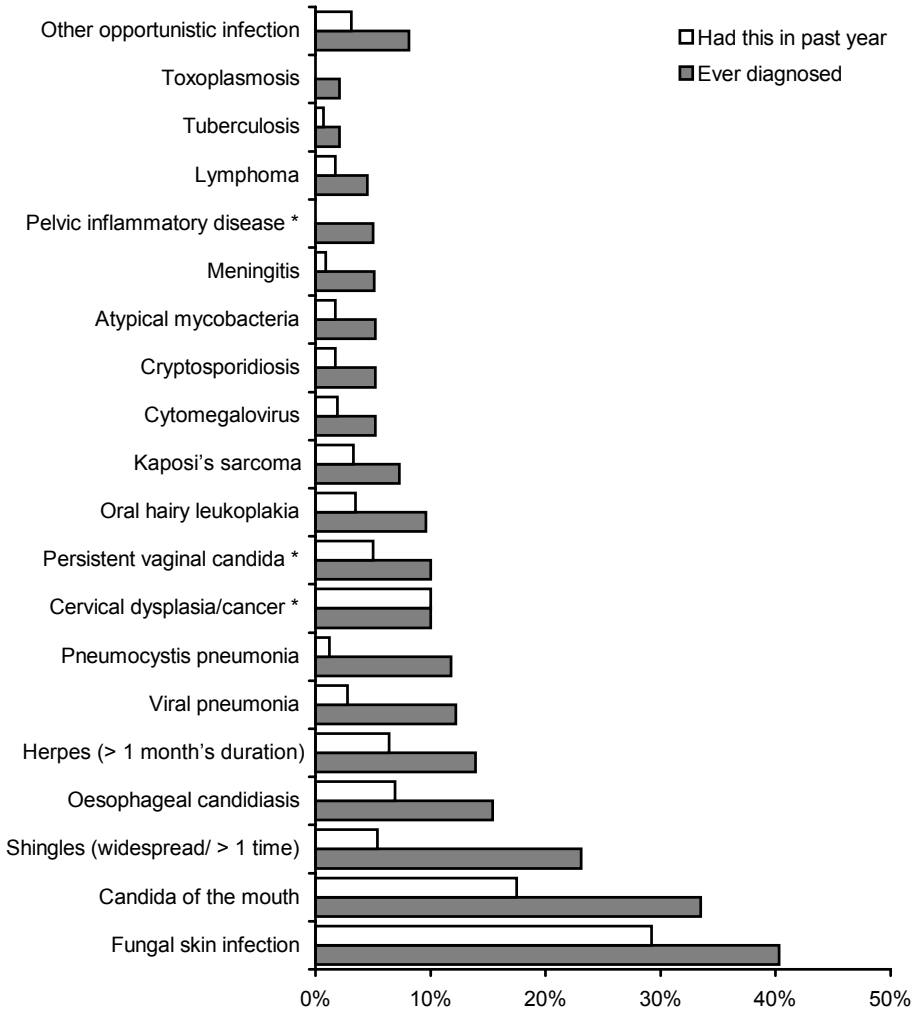

Figure 13 History of opportunistic infections

* Includes only female respondents. There were no cases of cervical cancer.

Participants were asked what they believed were the cause of the various opportunistic infections they had experienced during the previous year. Sixty-nine percent said that stress had been at least one of the causes, 60% cited CD4 count and 48% cited viral load. Half of the participants thought it was due to HIV treatments or non-use of HIV treatments, and 44% reported that diet or exercise was the cause. Eleven percent of respondents reported being hospitalised at some time in the previous 12 months as a consequence of an opportunistic infection due to their HIV infection. A further 22% had been hospitalised more than 12 months prior, for the same reasons.

Other illnesses

The majority of respondents had been tested for each type of hepatitis (A, B and C) at some time in their life. About one third said they had been tested within the previous 12 months for each type of hepatitis (see Figure 14).

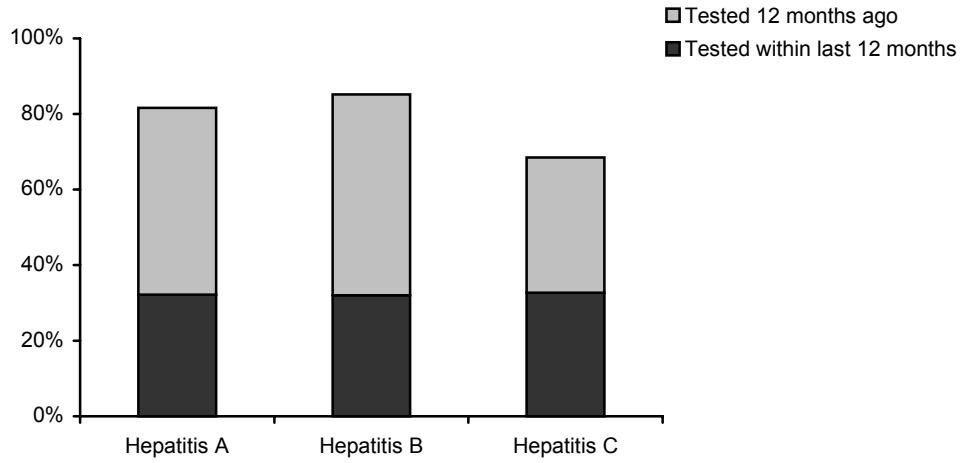

Figure 14 History of testing for Hepatitis A, B and C

There are indications, however, that not all respondents clearly understood the differences between the forms of hepatitis, as evidenced by the fact that 6% of respondents claimed to have been vaccinated for hepatitis C even though such a vaccination does not exist. About one third of the respondents reported being vaccinated against each of hepatitis A (32%) and hepatitis B (39%). Almost half (45%) reported that they had been diagnosed with hepatitis B, and about one-third (34%) with hepatitis A; a smaller percentage (16%) reported being diagnosed with hepatitis C.

Other than the AIDS-defining conditions, the most common illnesses that respondents reported experiencing were gastrointestinal disorders, respiratory disorders, and emotional or psychological difficulties. The majority of those who had experienced such difficulties had done so in the preceding 12 months (see Figure 15).

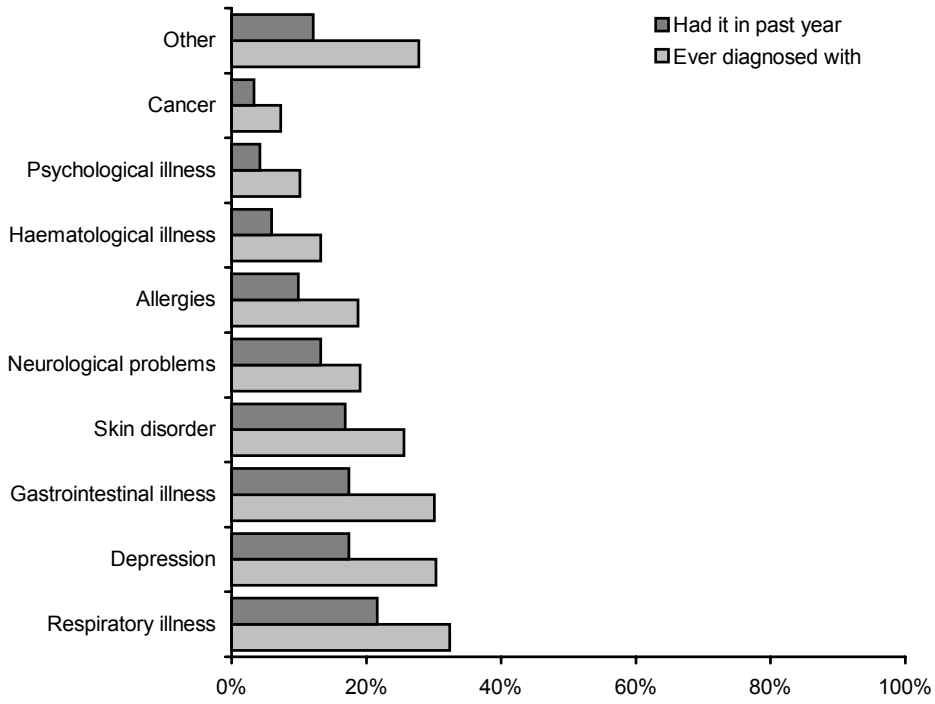

Figure 15 History of non-HIV related illnesses

HEALTH MAINTENANCE AND MONITORING

- Most respondents made a regular occurrence of seeing a doctor about their HIV infection. The type of doctor most commonly seen by respondents was a general practitioner with a high HIV caseload, or a specialist with HIV expertise.
- Few respondents had little or no contact with any health services.
- Gay male doctors were most popular among the majority of participants.
- Although experience with HIV was the most common reason for choosing a particular doctor, other attributes, such as experience in men's health, particularly gay men's health, featured prominently in the choice of doctor for about two-thirds of respondents.
- Most participants reported having a cooperative relationship with their doctor, with joint decision-making being a common aspect of the relationship.
- Most had T-cell and viral load tests at least every three months and had experienced both high and low CD4 counts and viral load results.
- Fifty-one percent of respondents reported an undetectable viral load from their most recent test and 18% reported a CD4 count below 200.

Use of health services

Most respondents consulted a doctor experienced with HIV for the management of their HIV infection (see Table 3). Nearly 75% had a GP with a high HIV caseload, while another 20% consulted a specialist with specific expertise in treating HIV. The same general patterns also applied to the provision of prescriptions for anti-retroviral drugs: almost all respondents (94%) who were taking anti-retrovirals obtained their prescriptions from their key HIV doctor. Forty-three percent had another doctor in addition to their key doctor whom they consulted for non-HIV related issues.

Table 3 : Key doctors for treatment of HIV infection

	Frequency	Percentage (%)
General practitioner	18	4.2
GP with high HIV caseload	303	71.3
Specialist with HIV expertise	93	21.9
Other	7	1.6
No key doctor	4	0.9
Total	**425**	**100**

A broad range of health services were used by the respondents for the management of their HIV infection (see Figure 16). Over half (57%) used services provided by a hospital. Smaller numbers used sexual health centres, community health centres, health centres dedicated for HIV-positive people, and non-hospital based AIDS clinics. One in five respondents (21%) consulted an alternative/natural therapist. A few respondents reported that they did not generally use any health services, preferring instead to manage their HIV infection themselves.

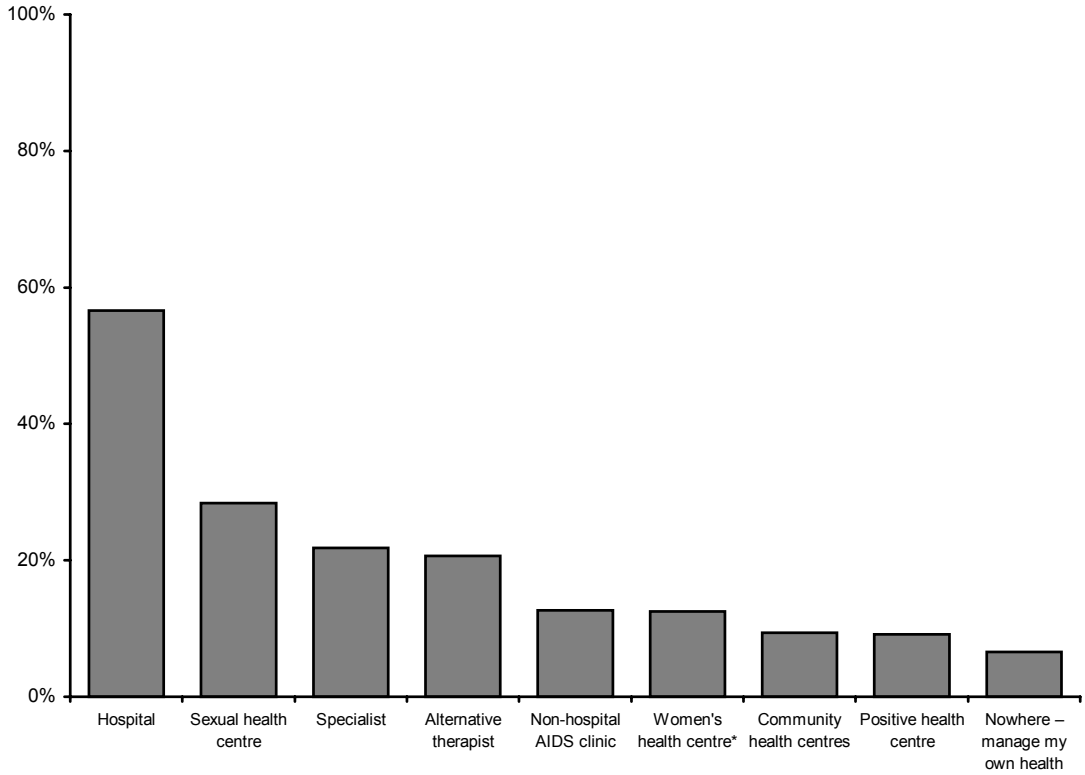

Figure 16 Use of health services

* Includes female respondents only.

The gender and sexual identity of the doctor were important factors in their choice of doctor for many respondents. Forty-five percent of respondents chose their doctor because he was a man, or specifically a gay man (43%), which is a reflection of the percentage of people in the sample (79%) who identified as being gay or homosexual.

Participants responded to a list of possible reasons for choosing their key doctor. Ninety-one percent of respondents chose a doctor with HIV management experience, and over half (56%) reported choosing a doctor considered to be a specialist in HIV-related health (see Figure 17). About two-thirds of participants also specified that their doctor's experience in men's health (66%), and particularly in gay men's health (70%) were reasons for choosing that doctor. About half (52%) said that their doctor's experience with sexual issues was also a factor and 10% reported choosing their doctor at least partly because of the doctor's experience in injecting drugs issues. Among those who reported that they had injected drugs in the previous six months (n=72), 38% said that their

choice of doctor was influenced by the doctor's experience with issues related to injecting drug use. Nine respondents (8 of the 21 women in the sample, and 1 man) cited their doctor's experience with women's health as an influencing factor in their choice.

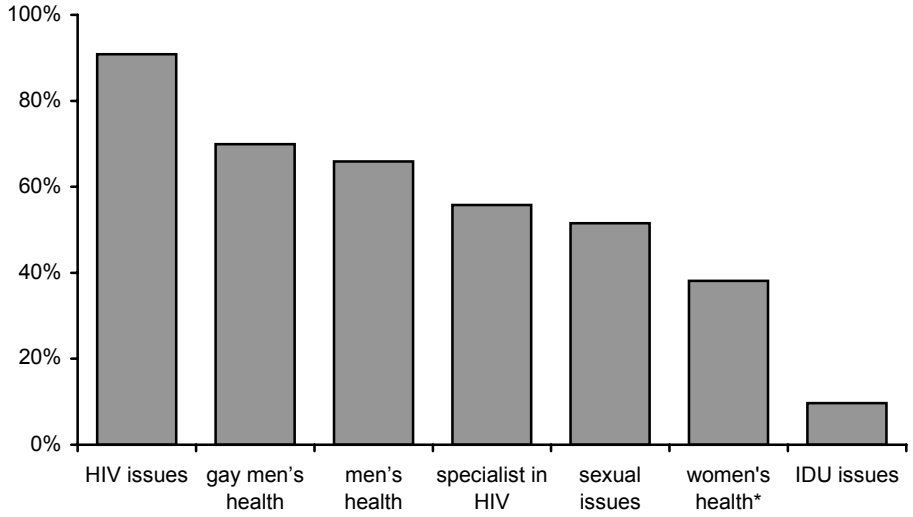

Figure 17 Doctor's area of experience influencing choice of key doctor

*Includes female respondents only.

Half the respondents cited location as a factor in their choice of doctor, with 52% choosing a doctor located close to where they lived. The converse was also true for a small percentage of people (2%) who chose a doctor located at some distance from where they lived. A few respondents (6%) reported that they had no choice in doctor as there were no other doctors available to them.

Ninety percent of respondents visited their doctor at least once every three months and many visited their doctor at least monthly (see Table 4).

Table 4 : Frequency of consultations with key doctor

	Frequency	Percentage (%)
At least monthly	184	43.3
1-3 monthly	198	46.6
3-6 monthly	23	5.4
6-24 monthly	1	0.2
As needed	17	4.0
Never	1	0.2
Total	**424**	**100**

Note: Data on this question was missing for 1 respondent.

In general, most respondents reported having a cooperative relationship with their key doctor. Participants were asked to rate, on a scale ranging from 1 (very much) to 4 (not at all), aspects of the relationship with their doctor, particularly in relation to making decisions about treatment. Many participants reported that they were actively involved in making decisions about treatment with their doctor (see Figure 18). Few respondents indicated that occasionally they felt pressured into accepting whatever their doctor recommended.

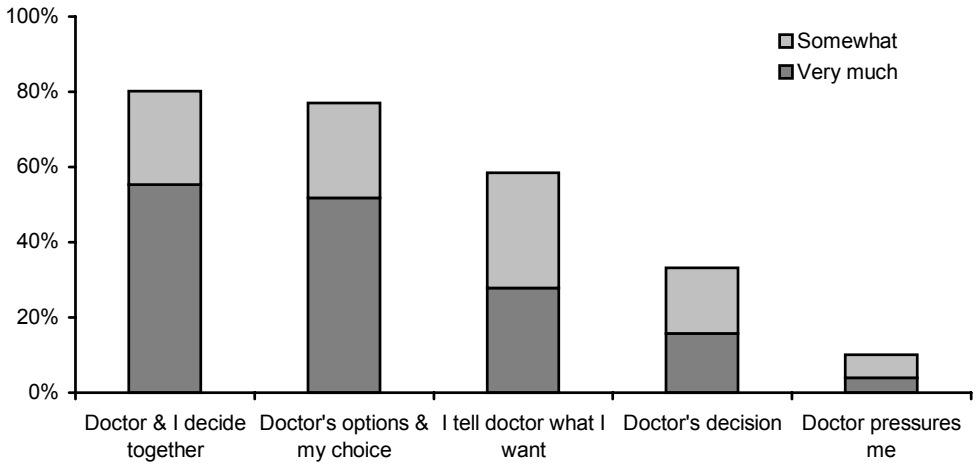

Figure 18 Relationship with key doctor when making decisions about treatment

Blood testing

More than 80% of respondents had T-cell and viral load tests at least every 3 months (see Table 5). It is of note that the frequency of testing reported here is higher than was reported in the recent HIV Futures II study (Grierson et al, 2000: 18).

Table 5 : Frequency of T-cell and viral load testing

	T-cell testing (%)	Viral load testing (%)
At least monthly	16.5	13.6
1-3 monthly	70.6	72.0
4-6 monthly	9.6	9.6
Less than 6 monthly	1.1	1.4
No longer has these tests	0.9	0.9
Unsure/No response	1.1	2.3
Total	**100**	**100**

Thirty-nine percent of respondents reported a stable T-cell (CD4) count, while another 33% indicated a count that had been rising (see Table 6). A smaller percentage (14%) had a CD4 count that was falling.

Table 6 : Trend of T-cell test results

	Frequency	T-cell test trend (%)
Rising	139	32.7
Stable	166	39.1
Falling	60	14.1
Fluctuating	41	9.6
Unsure/No response	16	4.5
Total	**425**	**100**

Half the respondents reported a stable viral load and for another 19% it had been falling (see Table 7). Viral load increases were reported by 16% of respondents.

Table 7 : Trend of viral load test results

	Frequency	Viral load test trends (%)
Falling	80	18.8
Stable	215	50.6
Rising	69	16.2
Fluctuating	32	7.5
Unsure/No response	20	6.6
Total	**425**	**100**

About 40% of respondents had their last CD4 count above 500 while 18% had a count below 200 (see Table 8). These percentages are very similar to those reported in the recent HIV Future II study (Grierson et al., 2000: 19).

Table 8 : Most recent T-cell test results

	Frequency	Percentage (%)
Less than 100	36	8.5
100 to 200	39	9.2
201 to 350	83	19.5
351 to 500	75	17.6
501 to 750	97	22.8
Over 750	75	17.6
Unsure/No response	19	4.7
Total	**424**	**100**

Participants indicated that their CD4 counts had varied considerably over time. Most respondents (84%) had experienced a CD4 count below 500 at some time. Twenty-two percent had experienced a CD4 count below 50 and half (51%) had at some point had a count below 200.

Half the respondents indicated that their last viral load test result was undetectable, with a quarter reporting a viral load of 10,000 or more (moderate to high) (see Table 9).

Table 9 : Most recent viral load test results

	Frequency	Percentage (%)
Undetectable	217	51.2
Low (less than 10000)	81	19.1
Moderate (10,000-50,000)	49	11.6
High (over 50,000)	57	13.4
Unsure/No response/other	20	4.7
Total	**424**	**100**

Respondents indicated that their viral load had also varied considerably over time. While nearly three-quarters (73%) said that their viral load had been undetectable at some time, only 5% reported that it had always been undetectable. Less than half (44%) reported that their viral load had ever risen above 100,000 (high level).

Over one quarter (28%) of respondents reported having both an undetectable viral load and a CD4 count above 500 at their most recent tests (see Table 10). These percentages are very similar to those reported in the recent HIV Futures II study (Grierson et al., 2000: 19).

Table 10 : Relationship between most recent CD4 count and viral load results

	CD 4 count		
	500 +	**200-500**	**<200**
Viral load			
Undetectable (<500)	27.7%	18.9%	6.3%
Low (500 – 10,000)	8.1%	9.3%	2.0%
Moderate (10,000 – 50,000)	4.8%	4.0%	3.3%
High (over 50,000)	1.8%	5.8%	6.8%
Other	0.5%	0.8%	0%

Note: Includes only those people who provided information about their CD4 count and viral load result (n=397).

Please note: The complex relationships between the degree of immune deficiency (as indicated by CD4 count), indices of health, the use of HAART, experience of health, treatments, side effects of medication, and the use of health services, will be addressed in future issues papers.

SERVICES, ACCESS AND SATISFACTION

- Most respondents indicated very few barriers to access to HIV services including doctors or dentists with HIV experience.
- Services such as counsellors, alternative/natural therapists and HIV support groups were well utilised and those not utilising them reported very few barriers to access.
- The most common problem experienced with access to HIV services in general was that the services were too far away.
- Many respondents indicated that cost often limited their capacity to consult dentists and alternative/ natural therapists.
- Most respondents indicated that their doctors and HIV specialists were very good at providing information about treatments and general health, but many said that hospitals and community health centres were less than helpful in this regard.

Access to services

Most respondents (84%) indicated that their access to doctors with experience in HIV management was 'convenient/well-suited' to their needs (see Table 11). A far smaller percentage of people (12%) reported problems with access because of distance from such services. Few reported other difficulties in accessing such doctors.

Table 11 : Access to doctors with experience in HIV management (n=425)

	Frequency	Percentage (%)
Services well-suited to my needs	358	84.2
I do not use this service	15	3.5
Difficult because of distance	52	12.2
Services not appropriate to my needs	20	4.7
Unsure about confidentiality	11	2.6
Do not know where to find	5	1.2

Note: Items are not mutually exclusive.

Most respondents were generally satisfied with access to anti-retroviral prescribers. Those who were not satisfied most frequently reported difficulties with distance from the prescriber (see Table 12). Thirteen percent of participants indicated that they did not use anti-retroviral prescribers.

Table 12 : Access to anti-retroviral prescribers (n=425)

	Frequency	Percentage (%)
Services well-suited to my needs	321	75.5
I do not use this service	54	12.7
Difficult because of distance	39	9.2
Services not appropriate to my needs	9	2.1
Unsure about confidentiality	7	1.6
Do not know where to find	5	1.2

Note: Items are not mutually exclusive.

Nearly two-thirds of respondents (63.1%) were generally satisfied with their access to dentists with HIV experience (see Table 13). Seventeen percent reported that they did not use dentists. Dissatisfaction with access to dentists was most commonly attributed to difficulty with distance, services not seen as appropriate to needs, and uncertainty about where such services are located, each of which was reported by about 8% of the respondents.

Table 13 : Access to dentists with experience in HIV management (n=425)

	Frequency	Percentage (%)
Services well-suited to my needs	268	63.1
I do not use this service	70	16.5
Difficult because of distance	36	8.5
Services not appropriate to my needs	33	7.8
Unsure about confidentiality	10	2.4
Do not know where to find	35	8.2

Note: Items are not mutually exclusive.

The pattern of accessibility to hospital pharmacies was very similar to that of dentists (see Table 14).

Table 14 : Access to hospital pharmacies (n=425)

	Frequency	Percentage (%)
Services well-suited to my needs	275	64.7
I do not use this service	69	16.2
Difficult because of distance	50	11.8
Services not appropriate to my needs	24	5.6
Unsure about confidentiality	17	4.0
Do not know where to find	3	0.7

Note: Items are not mutually exclusive.

In respect to counselling services and HIV support groups, about one-third of respondents said that they did not use these services (see Tables 15 and 16, respectively). Among those who did use them, there was general satisfaction with the services they received, although distance was still a restricting factor.

Table 15 : Access to counsellors (n=425)

	Frequency	Percentage (%)
Services well-suited to my needs	204	48.0
I do not use this service	168	39.5
Difficult because of distance	26	6.1
Services not appropriate to my needs	22	5.2
Unsure about confidentiality	7	1.6
Do not know where to find	9	2.1

Note: Items are not mutually exclusive.

Table 16 : Access to HIV support groups (n=425)

	Frequency	Percentage (%)
Services well-suited to my needs	227	53.4
I do not use this service	128	30.1
Difficult because of distance	55	12.9
Services not appropriate to my needs	41	9.6
Unsure about confidentiality	22	5.2
Do not know where to find	10	2.4

Note: Items are not mutually exclusive.

Nearly half the sample did not use any alternative/complementary therapy (see Table 17). A small number of people stated that distance (7.5%) and uncertainty with the whereabouts of such services (5.9%) posed problems for them.

Table 17 : Access to alternative/complementary therapists with experience in HIV management (n=425)

	Frequency	Percentage (%)
Services well-suited to my needs	144	33.9
I do not use this service	195	45.9
Difficult because of distance	32	7.5
Services not appropriate to my needs	13	3.1
Unsure about confidentiality	7	1.6
Do not know where to find	25	5.9

Note: Items are not mutually exclusive.

The majority of respondents were not prevented from seeing a **doctor** by cost (see Figure 19) but this was more of an issue for a **specialist**, with 10% reporting that the cost occasionally prevented them from seeing a specialist and a further 5% indicating that cost was *often* a problem. A higher percentage (28%) indicated they were *occasionally* or *often* prevented from seeing a **dentist** due to financial concern. Cost did not restrict most respondents from seeing a **counsellor** or dietician. The service that posed the greatest financial barrier for participants was **alternative/complementary therapy:** 20% reporting that cost *often* prohibited them from using the service, and a further 13% reporting *occasional* financial barriers.

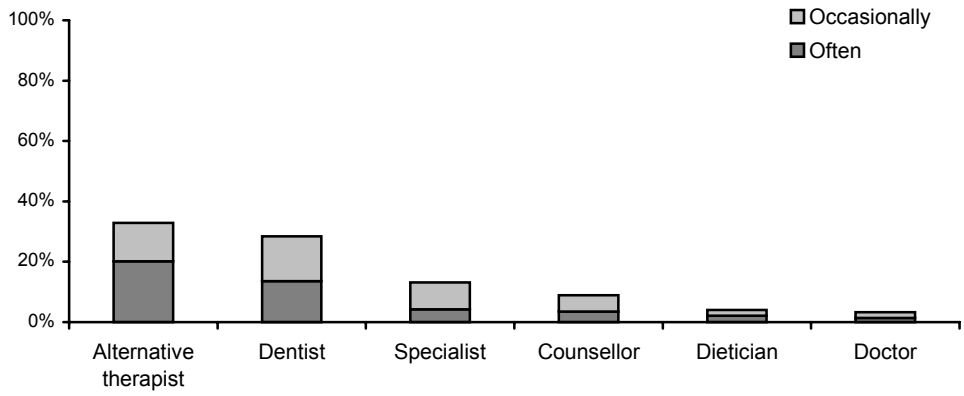

Figure 19 Financial barriers to use of services

Respondents were asked to report the out-of-pocket expenses each month for these health services. Consistent with the results above, the services that cost the most were dental care and alternative/complementary therapy, with 20% and 15% of respondents spending at least $20 per month respectively. About 5% or fewer respondents spent the same amount of money per month on other services mentioned above. About 25% of respondents said they spent at least $20 per month on anti-retroviral drugs, and almost as many spent this amount on other prescribed drugs and vitamins.

Satisfaction with services and information

Respondents were asked how well service providers informed them about a range of HIV treatment options (Note: percentages reported in this section for each service are calculated only on those people who used the particular service. In some instances this is a small number). Most respondents indicated that their key doctor and their HIV specialist were very good at providing information about the range of ***HIV treatment*** options. However, one-third indicated that hospitals

(clinics or outpatient units) and community health centres were generally uninformative or provided poor information about the available options (see Figure 20).

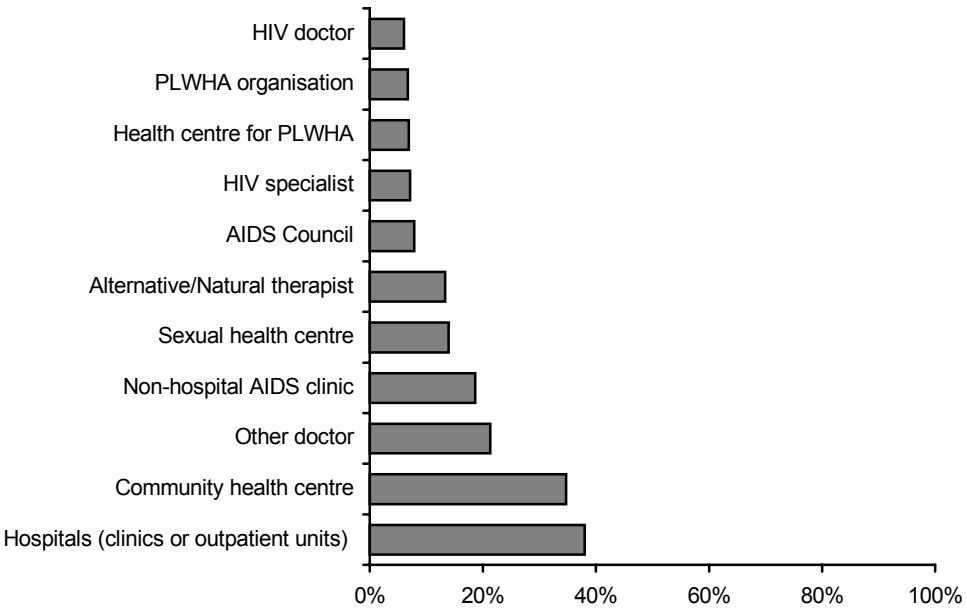

Figure 20 'Poor' or 'uninformative' communication of HIV treatment options by service providers

Note: The percentage for each service is calculated by including only those respondents who indicated they used the particular service.

Over half the respondents indicated that their key doctor and their HIV specialist were very good at providing information about ***general health management*** (see Figure 21)**.** Slightly less than half the participants reported that hospitals (clinics or outpatient units) performed poorly at this task and about 20% thought that community health centres were equally unhelpful.

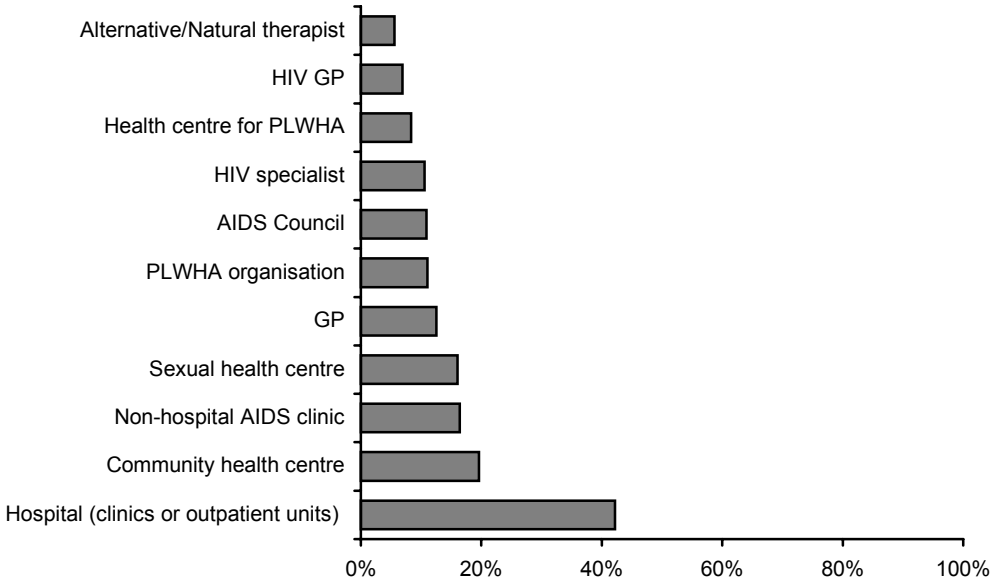

Figure 21 'Poor' or 'uninformative' communication of general health management options by service providers

Note: The percentage for each service is calculated including only those respondents who indicated they used the particular service.

Sixty-two percent of respondents reported that they were always able to find available information they needed about HIV treatments (see Table 18). Over one-third felt the information was always clear, and almost as many believed it was always encouraging. About 20% of people, however, thought that the information was always conflicting.

Table 18 : Attitudes to information about HIV medical treatments (n=425)

	Frequency	Percentage (%)
Always find information I need	262	61.6
Information is always clear	166	39.1
Information is always encouraging	147	34.6
Information is always conflicting	89	20.9
Information is always confusing	46	10.8
Always too little information	29	6.8
Always too little good news	17	4.0

Note: Items are not mutually exclusive.

Most respondents were generally satisfied with the level of emotional and medical support they received (see Figure 22). About one-quarter, however, were dissatisfied with their level of financial support. The majority of participants reported that they did not need any domestic support.

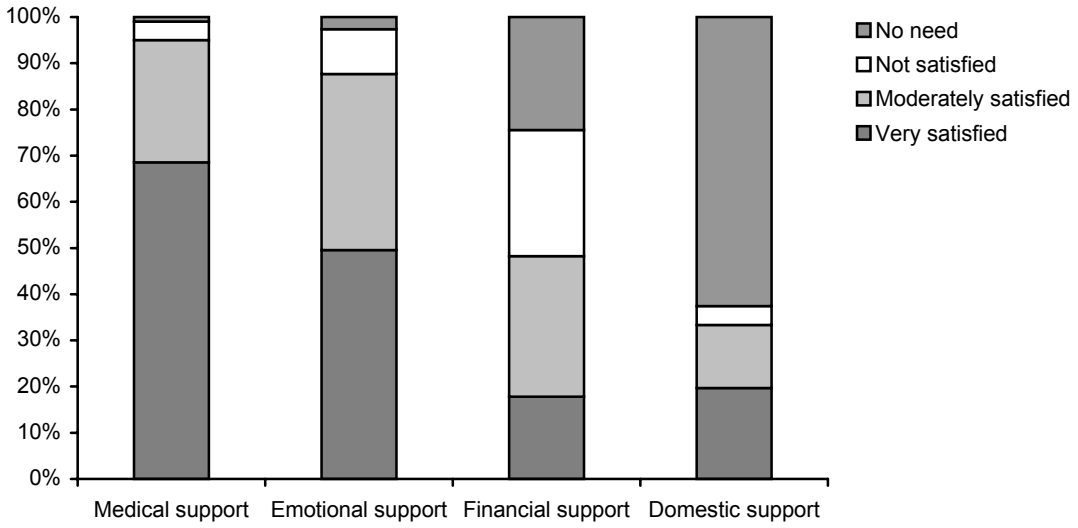

Figure 22 Satisfaction with various forms of support

ANTI-RETROVIRAL TREATMENTS

- Few respondents had never taken anti-retroviral drugs. Fifty percent of respondents had first taken them prior to 1996, including about a third who had commenced them in combination therapy prior to 1996.
- Most respondents were taking at least three anti-retroviral drugs and about 50% were taking more than ten pills per day.
- About 20% of participants were not taking anti-retroviral drugs at the time of interview.
- Although most respondents had taken AZT, less than 20% were doing so at the time of the interview.
- The majority of participants had experienced some side effects from anti-retroviral drugs, and 25% had experienced severe side effects.
- Many had discontinued the use of one or more anti-retroviral drugs in the previous 12 months, most commonly because it had made them sick and/or because they had begun taking a drug in replacement of the one they had stopped taking.

Current use of anti-retrovirals

Seventy-nine percent of respondents were taking at least one anti-retroviral drug at the time of the interview (see Table 19). Of those who were on anti-retroviral treatment, 91% were taking three or more anti-retroviral drugs, 8% were taking two and 1% was taking 1 drug.

Table 19 : Number of anti-retrovirals currently taking

	Frequency	Percentage (%)
None	89	20.9
One	3	0.7
Two	26	6.1
Three	205	48.2
Four or more	102	24.0
Total	**425**	**100**

History of anti-retroviral drug use

Twelve percent of respondents had never taken any anti-retroviral drugs. Of those who had taken anti-retroviral drugs, or were currently taking them, over half (63%) had commenced taking the drugs prior to 1996 (see Table 19).

Fifty percent of the sample commenced anti-retroviral treatment with AZT monotherapy. An additional 34% started anti-retroviral treatment as part of a combination therapy regime, and a small number of people started with monotherapy of other single anti-retrovirals. About 87% of the sample had used a combination regime at some stage (see Table 20).

The largest uptake of anti retroviral treatment occurred in 1996, during which 29% of participants commenced their anti-retroviral treatment.

Table 20 : First anti-retroviral drugs taken

	Frequency	Percentage (%)
Monotherapy - AZT	212	49.9
Combination (more than one drug)	146	34.4
Monotherapy – other drugs	15	3.5
Never taken any/unsure/NR	52	12.2
Total	**425**	**100**

Protease inhibitors had been taken, or were being taken by 72% of respondents at the time of the interview. Of these people, 41% had commenced using protease inhibitors in 1996.

Of those who had used any protease inhibitor, 63% of participants began with Saquinavir as their first protease inhibitor, 28% started with Indinavir and 17% with Ritonavir (see Table 21). (Percentages include some people who commenced their use of protease inhibitors by using more than one.)

Table 21 : First protease inhibitor(s) taken

	Frequency	Percentage (%)
Saquinavir	191	62.8
Indinavir	85	28.0
Ritonavir	52	17.1
Nelfinavir	28	9.2
Other	2	0.7

Note: Includes only those who had taken any protease inhibitor, n=304.

The anti-retroviral drugs most widely used by participants included 3TC, AZT, D4T, Saquinavir and DDI. The majority of respondents who had ever taken AZT, DDI and Saquinavir had stopped doing so (see Figure 23). The most commonly used anti-retroviral drugs at the time of the interview included D4T and 3TC.

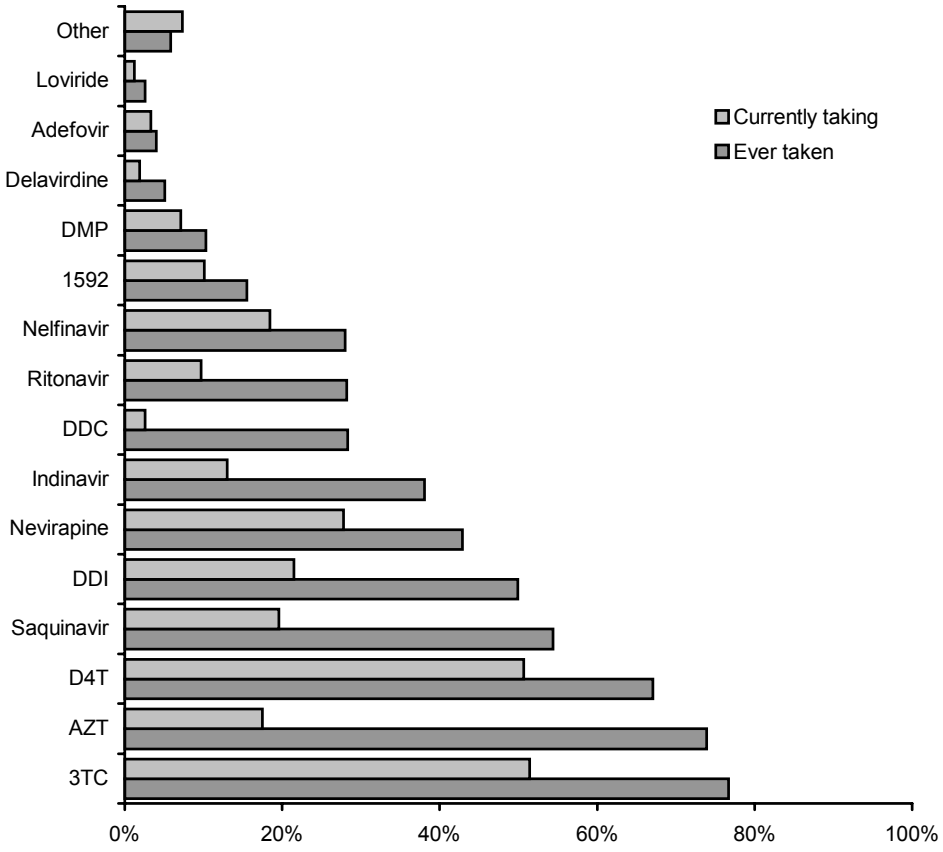

Figure 23 History of anti-retroviral use

The anti-retroviral drugs most commonly used as part of participants' first combination therapy included AZT and 3TC (see Figure 24).

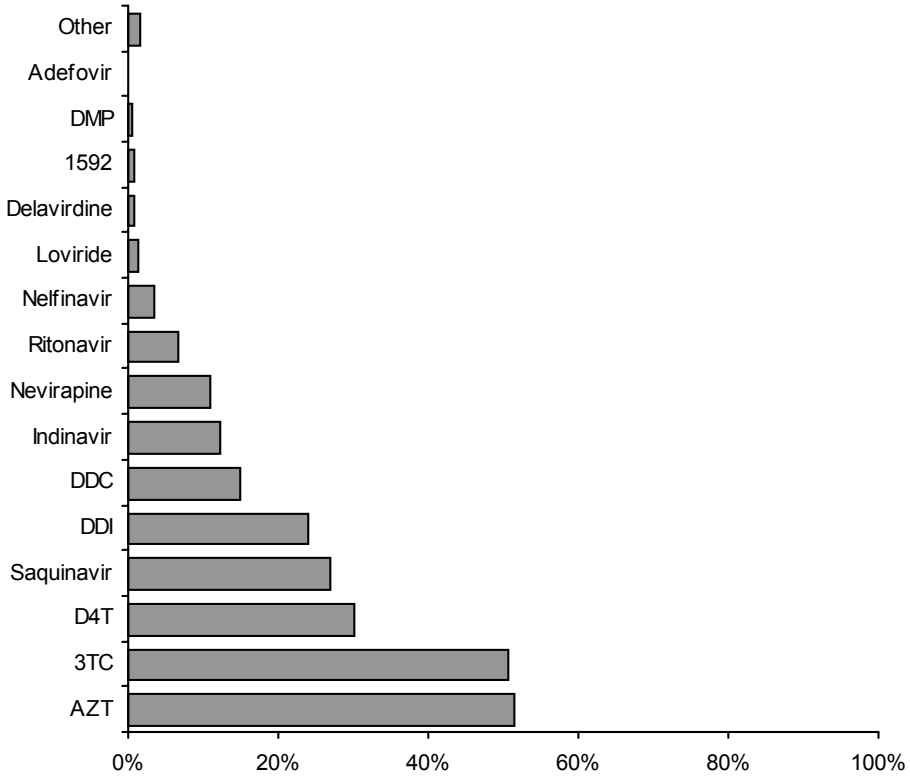

Figure 24 Anti-retrovirals in first combination

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Among those participants who were taking anti-retroviral drugs at the time of their interview, the drugs most commonly taken for a period in excess of 12 months were D4T and 3TC (used by 52% and 49% respectively) (see Figure 25).

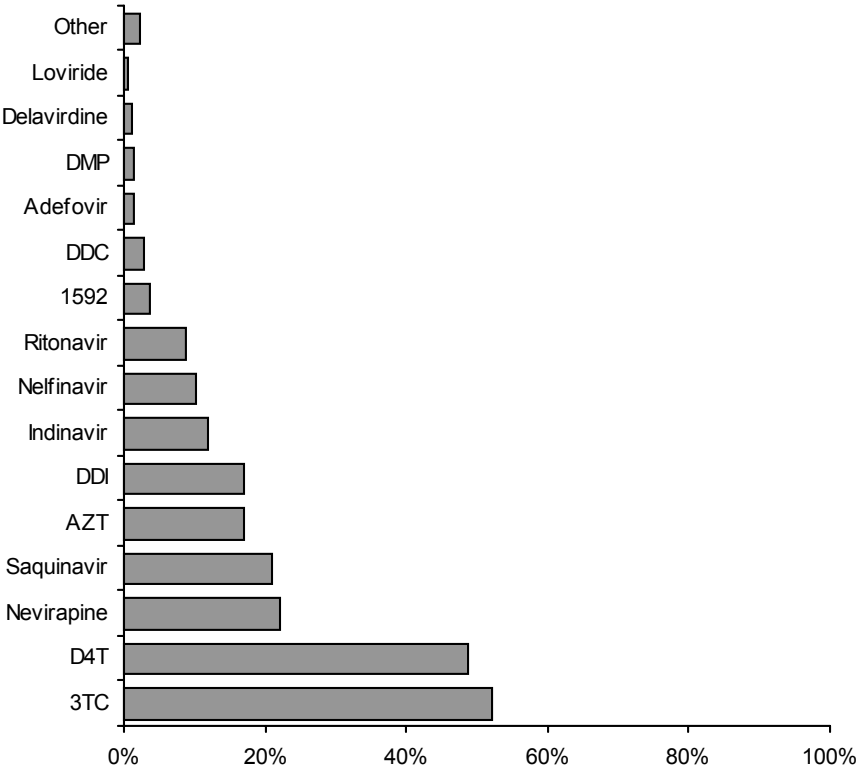

Figure 25 Anti-retrovirals taken for more than twelve months

Of the 88% of respondents, who had taken any anti-retroviral drugs at some time in their life, about 11% of these people had not been informed prior to commencing their treatment of potential side effects from taking the drugs. Forty-two percent of the participants who had taken, or were taking, anti-retroviral drugs reported mild side effects, while a further 32% had experienced severe side effects. One quarter (26%) of the people who had experienced some side effects had not been previously informed of at least some of the side effects that they subsequently experienced. Most (70%) of the people who had experienced any side effects had subsequently discussed these with their doctor.

Seventy-four percent of the respondents who had taken, or were taking anti-retroviral drugs, had at some stage stopped using at least one anti-retroviral drug. About half who had stopped using any anti-retroviral drug did so because they had switched to another anti-retroviral drug, often on their doctor's recommendation. The most common reasons for discontinuing the use of one or more anti-retroviral drugs were that it made the respondents sick, and that the treatment was not working (see

Table 22). Twenty-three percent of people stopped using anti-retroviral drugs because they could not maintain the treatment regimen required.

Table 22 : Reasons discontinuing one or more anti-retroviral drugs

	Frequency	Percentage (%)
I changed to another drug	205	63.6
It made me sick	188	59.2
My doctor advised me to discontinue it	177	55.4
It was not working	122	38.0
The treatment began to fail and I had to switch to another	119	36.7
It was no longer effective	118	36.4
I could not stick to the regimen	74	23.1
I lost faith in its effectiveness	51	15.5
It caused abnormal body fat distribution	45	14.2
My health improved	18	5.7
I could not afford it	2	0.3
Other	96	30.4

Note: n=316 includes only those who had stopped using any anti-retrovirals.
Items are not mutually exclusive.

TREATMENT PRACTICES

- A minority of respondents reported some difficulty with their treatment regimen. Thirty-four percent had problems taking pills on time, and 21% had difficulties with the number of pills they were required to take.
- Twenty-five percent of respondents missed taking pills during the two days prior to their interview, and about 90% had missed taking their pills at some time during the previous 12 months.
- About 20% of people had missed doses every week. Despite this, most considered it very important to take their pills as prescribed, and the majority believed that missing doses was a serious matter that could affect their health.
- Forty-four percent of respondents had been enrolled in a clinical trial at some stage.

Prescribed pills in general

About 50% of the respondents were taking more than ten prescribed pills associated with their HIV infection every day, and 17% were taking more than twenty pills (see Table 23).

Table 23 : Number of prescribed pills taken each day

	Frequency	Percentage (%)
None	67	15.8
1-5	32	7.5
6-10	118	27.8
11 – 15	79	18.6
16 – 20	52	12.2
Over 20	74	17.4
Unsure/ No response	3	0.7
Total	**425**	**100**

Among those people who were taking any prescribed pills, 21% reported that it was *somewhat difficult* or *very difficult* to take the number of pills required. Thirty-four percent found that it was *somewhat difficult* or *very difficult* to take their pills on time.

Anti-retrovirals

The majority of respondents (60%) who had taken any anti-retrovirals 12 months prior to the interview were required to take them twice a day, and for 26% it was three times a day (see Table 24). A smaller proportion (9%) took their pills four or more times a day.

Table 24 : Number of times each day taking anti-retrovirals

	Frequency	Percentage (%)
Once	4	1.1
Twice	213	60.2
Three times	92	26.0
More than three times	30	8.5
Unsure/ No response	15	4.2
Total	**354**	**100**

Note: Includes only those respondents who reported taking any anti-retrovirals in the previous 12 months (n=354).

Thirteen percent of the respondents who were taking anti-retroviral drugs at the time of their interview reported missing at least one dose on the day before the interview and 15% reported missing dose(s) 2 days before the interview (see Table 25). Across those 2 days, 22% of the respondents taking anti-retroviral drugs had missed at least one dose of anti-retrovirals and 5% had missed doses on both days.

Table 25 : Doses of anti-retrovirals missed on days before the interview

	Previous day (%)	Two days prior to interview (%)
None	87.2	85.1
One	8.9	11.0
Two	3.3	3.3
More than two	0.6	0.6
Total	**100**	**100**

Note: Includes only those respondents who reported currently taking any anti-retrovirals (n=336).

Eighty-nine percent of the respondents who had taken any anti-retroviral drugs in the previous year had missed some doses, either accidentally or deliberately, and about 18% had done so at least once per week. People were far more likely to have missed doses accidentally than deliberately in the previous 12 months (80% and 43%, respectively) (see Table 26).

Table 26 : Frequency of missing anti-retroviral doses in previous twelve months

	Accidentally Missed Dose (%)	Deliberately Missed Dose (%)
Once a day or more	1.4	3.1
At least once a fortnight	19.5	8.8
Once a month	11.9	4.8

Once every couple of months	21.5	9.9
Once every six months	26.0	15.8
Never	16.4	54.1
Unsure/ No response	3.4	3.4
Total	**100**	**100**

Note: Includes only those respondents who reported taking any anti-retrovirals in the previous 12 months (n=354).

Among those people who had deliberately missed doses in the previous 12 months, 48% had done so for 24 hours or less while about 27% did so for periods of one week or more (see Table 27).

Table 27 : Longest period of deliberately missed doses of anti-retrovirals in the previous twelve months

	Frequency	Percentage (%)
Up to 24 hours	72	47.7
2-6 days	29	19.2
1-3 weeks	23	15.2
More than 1 months	18	11.9
Unsure/ No response	9	6
Total	**151**	**100**

Note: Includes only those respondents who reported missing any doses during last 12 months deliberately.

The reasons most commonly given for deliberately missing doses of anti-retroviral drugs were being away from home, feeling sick, not wanting to be controlled by the drugs, using recreational drugs, and 'not being bothered' (see Table 28).

Table 28 : Reasons for deliberately missed doses of anti-retrovirals in the previous twelve months

	Frequency	Percentage (%)
I was away from home	53	36.5
They made me feel sick	51	33.7
I did not want to be controlled by them	50	33.1
I could not be bothered	48	31.8
Used recreational drugs	37	24.5
I had a full stomach	23	15.3
I had an empty stomach	22	14.6
I was feeling angry	20	13.2
Did not want people to know I was taking them	14	9.3
I was feeling healthy	6	3.9

Note: n=151, includes only those respondents who reported missing any doses during last 12 months deliberately. Items are not mutually exclusive.

The most common reasons for accidentally missing doses of anti-retrovirals were forgetting, being away from home, having a change in routine, and being too busy (see Table 29).

Table 29 : Reasons for accidentally missed doses of anti-retrovirals in the previous twelve months

	Frequency	Percentage (%)
I forgot	188	65.7
I was away from home	150	52.5
A change in routine	113	39.5
I was too busy	75	26.5
I was asleep	48	16.8
I was sick	43	15.0
I had an empty stomach	30	10.5
I had a full stomach	25	8.7
I was depressed	25	8.7
I could not get used to taking pills	24	8.4
I was feeling angry	12	4.2

Note: n=286, includes only those respondents who reported accidentally missing any doses during the last 12 months. Items are not mutually exclusive.

Respondents were asked to report on the events and times of the day most likely to coincide with missed doses of anti-retroviral drugs (see Figure 26). The most commonly reported time of day for missing anti-retroviral doses was the evening and the event most associated with missing doses was partying.

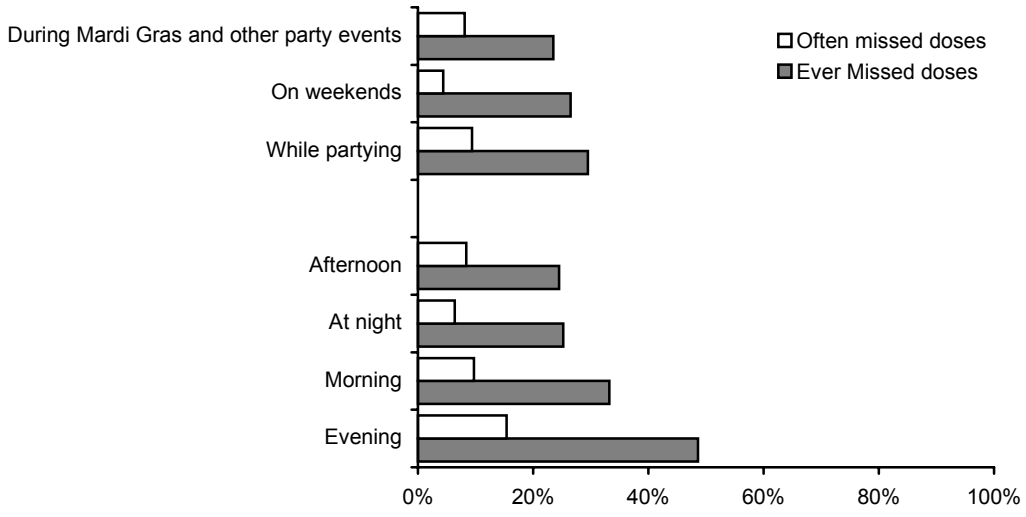

Figure 26 Times most likely to coincide with missing a dose of anti-retroviral

Note: Includes only those respondents who reported having missed any pills in the previous 12 months.

The majority (79.5%) of the respondents who were taking anti-retroviral drugs at the time of their interview believed it was very important to take them according to the prescription (see Table 30).

Table 30 : Importance of taking pills according to prescription

	Frequency	Percentage (%)
Very important	267	79.5
Somewhat important	58	17.3
Not very important	8	2.4
Not important at all	2	0.6
Unsure/ No response	1	0.3
Total	**336**	**100**

Note: Includes only those respondents who reported taking any anti-retrovirals at the time of their interview (n=336).

Forty percent of people taking anti-retroviral drugs did not think that the effects of missing a dose on one's health were serious, whereas the majority held the view that it could seriously jeopardise health (see Table 31).

Table 31 : Beliefs about the effects of missing doses of anti-retrovirals on health

	Frequency	Percentage (%)
Very serious	82	24.4
Somewhat serious	118	35.1
Not very serious	122	36.3
Not serious at all	11	3.3
Unsure/ No response	3	0.9
Total	**336**	**100**

Note: Includes only those respondents who reported taking any anti-retrovirals currently (n=336).

Respondents were asked a series of questions related to how their anti-retroviral regimen impacted on their daily life. Seventy-eight percent of people using anti-retroviral drugs at the time of their interview planned their days in advance to enable them to take their pills (see Table 32). A slightly lower percentage of people (65.5%) reported that they did not let their anti-retroviral regimen restrict their activities. Fifty percent of people indicated that they sometimes forgot if they had taken their pills and 37% reported being helped to remember by their partner or friends. For 25% of anti-retroviral users, their day's activities were planned around taking their pills.

Table 32 : How daily life is affected by anti-retroviral regimen

	Frequency	Percentage (%)
I plan the day in advance	263	78.3
I do not let it restrict my activities	220	65.5
I sometimes forget if I have taken them	165	49.1
My partner/friends help me to remember to take them	123	36.6
I plan my day around the pills	89	26.5
I use an alarm	39	11.6

Note: Items are not mutually exclusive. Includes only those respondents who reported taking any anti-retrovirals currently (n=336).

Certain daily activities were identified by respondents as being associated with pill taking. The most common were eating meals, specific times of day (eg. 7am and 7pm), waking up, going to bed, and getting ready for a meal (see Figure 27).

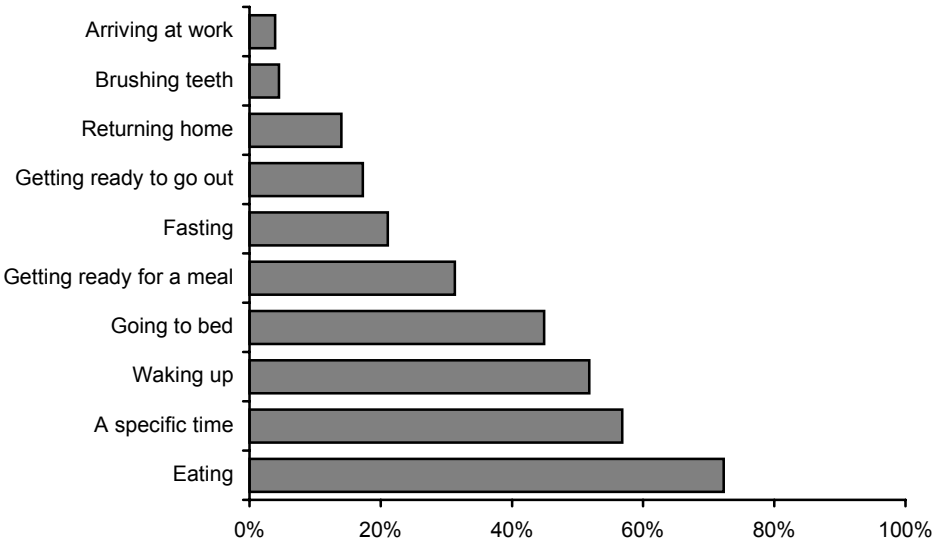

Figure 27 Activities and factors associated with taking anti-retrovirals

Note: Includes only those respondents who reported taking any anti-retroviral drugs at the time of their interview

Participants were asked where they kept their pills. The most common location for storage of anti-retroviral drugs was in the kitchen at home (see Figure 28). Seventy-one percent of respondents reported that they carried a pill container with them.

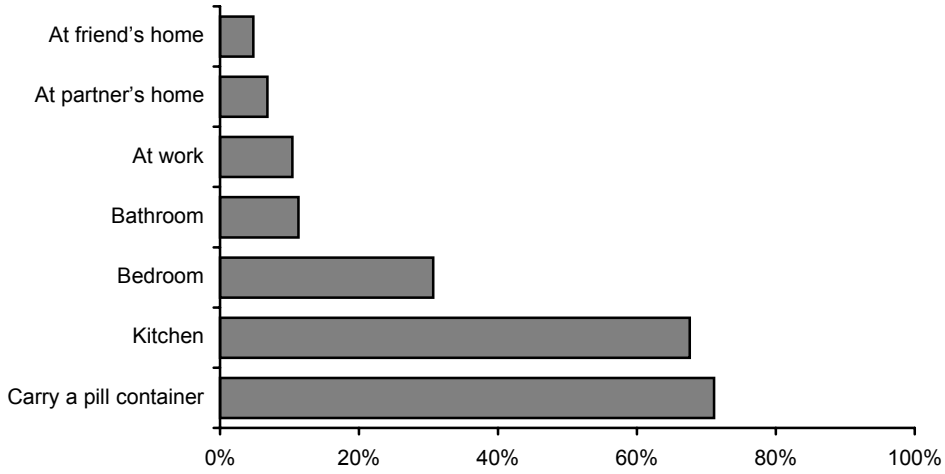

Figure 28 Places where anti-retrovirals are kept

Note: Includes only those respondents who reported taking any anti-retroviral drugs at the time of their interview

The place where most participants reported frequently taking their pills was at home (98%). Other locations or situations in which more than 25% of respondents frequently took their pills included at work and in private (see Figure 29).

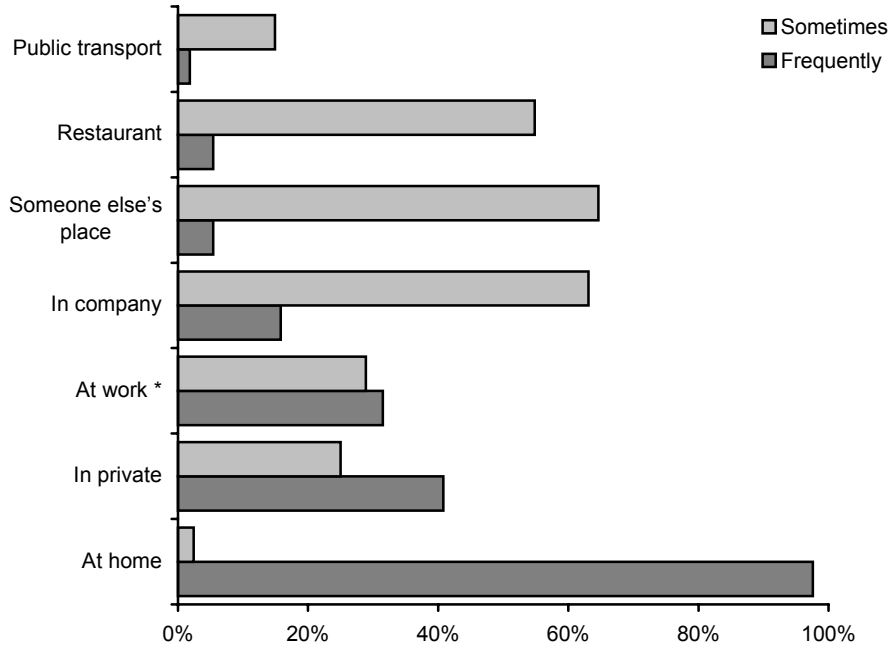

Figure 29 Places where anti-retrovirals were taken

Note: Includes only those respondents who reported currently taking any anti-retrovirals pills.
*Includes only those respondents who were currently employed.

Clinical trials

About 64% of participants had previously been invited to participate in a trial of HIV-related drugs and 44% had enrolled in one (see Table 33). Twenty-five percent of people had decided against participating in a trial, and about 10% had been refused entry into one. Most participants (72%) indicated that they would consider participating in a clinical trial in the future, and 16% were dissatisfied with their level of access to information about such trials. At the time of the interview 9% of respondents were participating in a trial, and a similar percentage had withdrawn from a trial before its completion.

Table 33 : Participation in clinical trials (n=425)

	Frequency	Percentage (%)
Would consider participating in future trial	305	71.8
Ever invited to participate in trial	269	63.3
Ever enrolled in trial	187	44.0
Ever completed a trial	110	26.1
Ever decided against participating in trial	106	25.0
Dissatisfied with access to trials information	68	16.0
Ever refused entry into trial	45	10.6
Currently in a trial	37	8.8
Ever withdrew from trial before completion	36	8.5
Ever been removed from trial	5	1.2

Note: Items are not mutually exclusive.

OTHER TREATMENTS

- Fifty-three percent of respondents had taken PCP treatment or prophylaxis and 29% were taking such treatment at the time of their interview.
- Fifty-five percent of respondents had been treated for herpes, and a similar number had been treated for anti-fungal infection.
- Thirty percent of participants were using Acyclovir to treat herpes and 20% were using an anti-fungal agent to treat a fungal infection during the period of the interview.
- Few respondents had used immune stimulants and treatment for KS. Twenty-three percent had used anabolic steroids, although few were doing so at the time of the interview.
- Most respondents (70%) had used alternative/complementary therapies in the previous 12 months, the most common of which was anti-oxidants.
- A minority had consulted an alternative/complementary therapist in the previous 12 months.
- Nearly 80% believed that marijuana helped to reduce stress and 29% had used marijuana for therapeutic purposes, most commonly to relieve stress.

Use of PCP treatment/prophylaxis

More than half the respondents (53%) had used medication to treat or prevent pneumocystis carinii pneumonia (PCP), and 29% were doing so at the time of the interview. Bactrim was the most commonly used medication (see Figure 30).

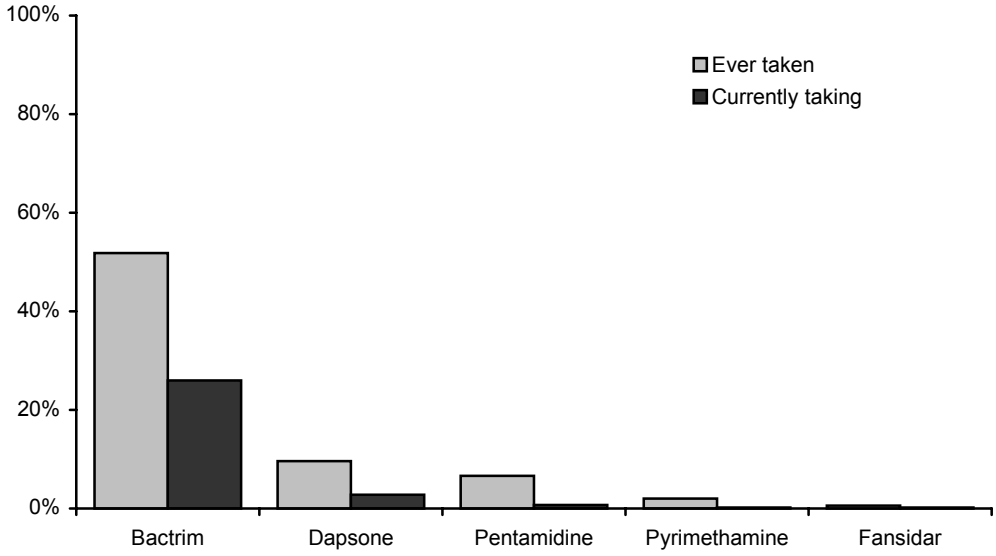

Figure 30 PCP treatment/prophylaxis

Prior to taking PCP treatment/prophylaxis, 50% of the people who took such medication had been informed about the potential side effects (see Table 34). Of those who had taken PCP treatment/prophylaxis during the previous 12 months, 23% had experienced side effects and about 11% had experienced severe side effects. Respondents who had experienced side effects were asked if they had been informed about all of the side effects they had experienced. Forty-eight percent of these people indicated that there were some side effects about which they had not been forewarned.

Table 34 : Side effects of PCP treatment/prophylaxis

	Frequency	Percentage (%)
Informed of side effects before PCP treatment/ prophylaxis commenced *	118	52.2
Experienced any side effects in past 12 months**	52	23.0
Experienced severe side effects in past 12 months**	24	10.6
Not informed of all side effects ***experienced****	25	48

Note: Items are not mutually exclusive.

* n=226 (ever taken any PCP treatment/prophylaxis)

** n=167 (took any PCP treatment/prophylaxis during the previous 12 month)

*** n=52 (experienced any side effects from PCP treatment/prophylaxis during the last 12 months)

There were various reasons given for discontinuing PCP treatment/prophylaxis. The most common were advice from a doctor and improvement in health (see Table 35).

Table 35 : Reason for discontinuing PCP treatment/prophylaxis in the previous twelve months

	Frequency	Percentage (%)
My doctor advised me to discontinue it	22	44.9
My health improved	16	32.7
It made me sick	13	26.5
I changed to another drug	10	20.4
I could not stick to the regimen	3	6.1
I lost faith in its effectiveness	2	4.1
It was no longer effective	1	2.0
I could not afford it	0	0
Other	21	42.9

Note: Includes only those respondents who had stopped any PCP treatment/prophylaxis in the previous 12 months (n=49). Items are not mutually exclusive.

Treatments of other HIV-related conditions

Sixty-two percent of the sample had undergone treatment for HIV related medical conditions other than PCP, (e.g. herpes and fungal infection — see Figure 31 for the full list). Fifty-five percent (55%) of respondents had taken Acyclovir to treat herpes and 30% were doing so at the time of the interview. Fifty percent had taken treatments for fungal infection and 20% were still doing so. Twenty-three percent of respondents had taken anabolic steroids and 6% were still using them; 9% had been treated for CMV and 5% were under treatment at the time of the interview. Fewer people had been treated by immune simulants or were still being treated, or had received chemotherapy or other medications for Kaposi's Sarcoma (KS).

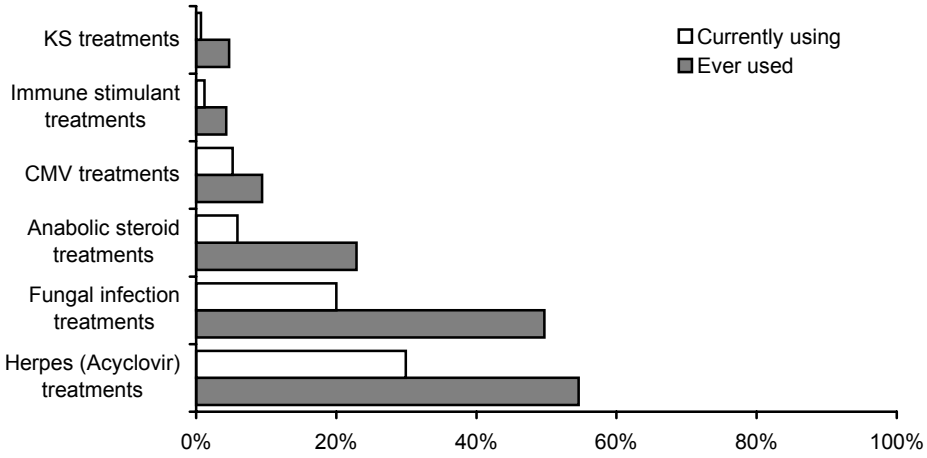

Figure 31 Use of other treatments

Prior to using the treatments reported in Figure 31, 60% of respondents who had used these medications/treatments in the previous 12 months were informed of the potential side effects (see Table 36). Side effects were experienced by 25% of those who used these treatments, and about 30% of these people reported experiencing side effects about which they had not been forewarned.

Table 36 : Side effects of treatments for some other HIV related medical conditions (not including PCP)

	Frequency	Percentage (%)
Informed of side effects before taking*	157	59.7
Side effects experienced*	68	23.2
Not informed of ***all*** side effects experienced**	19	31.2

Note: Items are not mutually exclusive.

* n=263 includes only respondents who had taken any of above treatments.

** n=61 includes only respondents who had experienced at least one side effect.

The two treatments for other HIV-related medical conditions that were most associated with any side effects were immune stimulants and chemotherapy to treat KS (see Table 37). Severe side effects were reported by 80% of those who had been treated by an immune stimulant.

Table 37 : Side effects experienced from treatments for HIV related medical conditions (not including PCP)

	N*	Any side effects (%)	Severe side effects (%)
Herpes treatment (Acyclovir or Zovirax)	179	6.1	0
Fungal infection treatment	146	8.9	1.4
Anabolic steroids	61	27.9	8.2
CMV treatment	28	32.1	10.7

Immune stimulants	10	80	80
Other medication to treat KS	6	50	16.7
Chemotherapy to treat KS	3	66.6	33.3

*n = respondents who had taken the particular treatment in the previous 12 months.

Alternative/complementary therapies

Respondents were asked if they had used various alternative/complementary therapies or substances (see Figure 32 for the full list) as part of a response to their HIV infection. The majority (70%) had used at least one of these alternative/complementary therapies in the previous 12 months. Anti-oxidants were the most commonly used (32%), followed by marijuana (29%) and herbal remedies (28%). Fewer people had used Echinacea, homoeopathic remedies, vitamin megadoses, acupuncture, and Reiki therapy. Those people who used alternative/complementary therapies were no more or less likely to be taking anti-retroviral drugs.

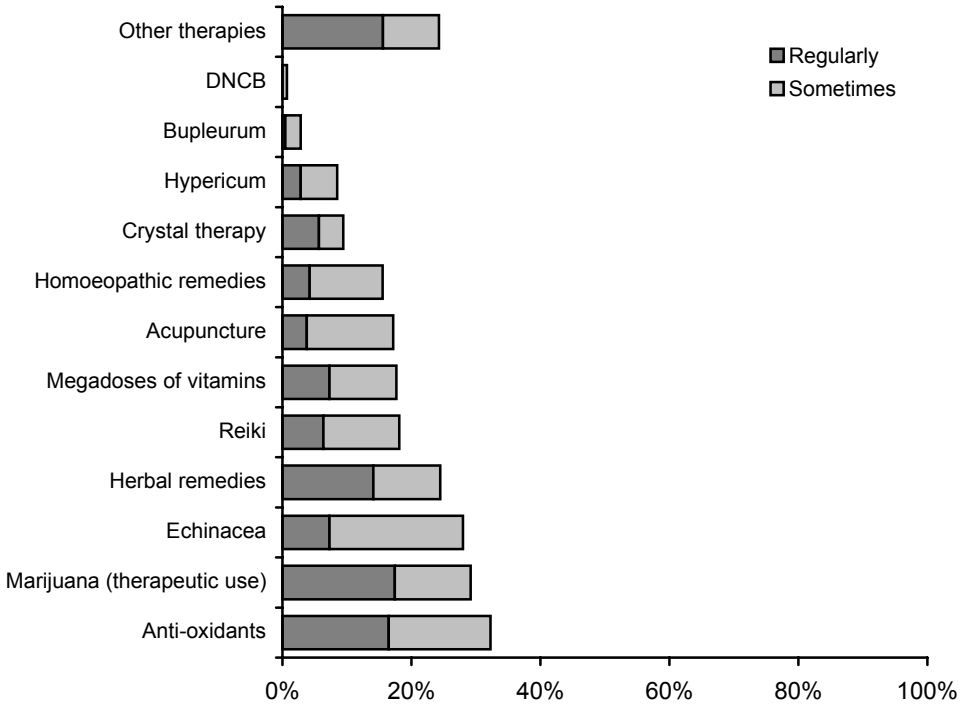

Figure 32 Regular use of alternative/complementary therapies or substances in previous year

Eighteen percent of respondents (18%) had consulted an acupuncturist in the previous twelve months (see Figure 33). Similar numbers of people had consulted a naturopath (17%) or herbalist (15%). A small number had consulted a homoeopath (8%) or kinaesiologist (3%).

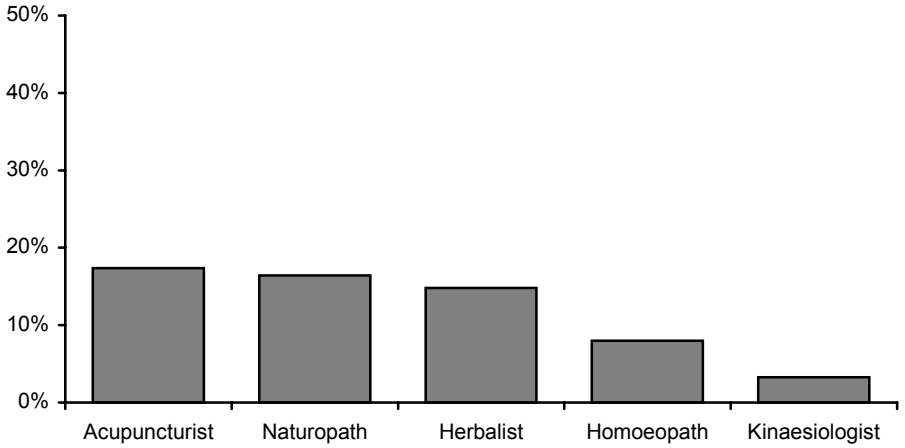

Figure 33 Consulted alternative/complementary therapists in previous year

Most respondents considered therapeutic use of ***marijuana*** to be effective in reducing stress (72%) and promoting weight gain (57%). About 50% believed it was an effective means of reducing pain and 37% thought that it helped counteract nausea (Figure 34).

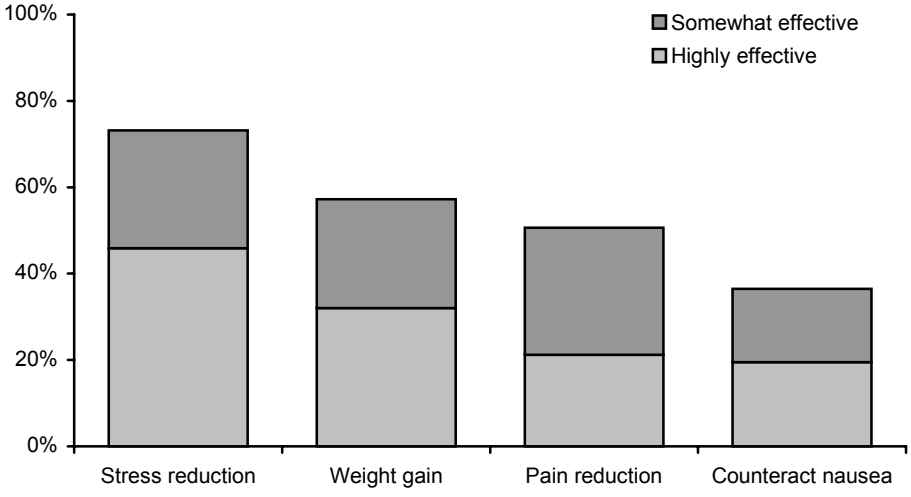

Figure 34 Effectiveness of therapeutic use of marijuana

Nearly one third of the respondents (30%) were of the opinion that using ***recreational drugs*** could assist in relieving stress. Twelve percent of respondents had used at least one other recreational drug, other than marijuana, for therapeutic purposes during the previous year. Among the respondents who had used any recreational drugs ***therapeutically*** in the previous year (35% of the sample), 42% believed the drugs helped to relieve stress while 10% attributed no therapeutic benefits to the drugs.

Respondents were asked whether they believed there were drawbacks to using recreational drugs — 33% thought that the drugs damaged health.

PERSONAL ATTITUDES AND BELIEFS

- The majority of respondents expressed some concern about medicines in general, toxicity, side effects, dependency, and the possibility of jeopardising future treatment options.
- Although being sceptical about the capacity of medicine to cure all illnesses, most respondents did believe that modern medicine could control most illnesses.
- Respondents had concerns about drugs used to treat HIV. Concerns about medicine in general reflected attitudes to HIV medications in particular.
- There was a certain level of scepticism among respondents about the role of drug companies, with most believing there to be more interested in profit than developing safe treatments.
- Despite all these reservations, most respondents felt that medical treatments were very helpful in managing HIV infection, as was attending to one's own well-being.
- Comparatively few respondents, although still the majority, believed that alternative/complementary therapies were helpful in managing HIV infection.
- Most respondents believed that anti-retroviral drugs, particularly combination therapy, provide effective treatments for HIV.
- More respondents thought that the decision to commence HIV treatment should be based on symptoms, CD4 count levels, viral load levels, and doctor's advice rather than infection.
- Although the majority of respondents reported being influenced by various media sources in their decisions about anti-retroviral use, the influence was not seen to be strong.
- Advice from a doctor was more influential in decisions about anti-retroviral use than that from other health services.
- One's own experiences of anti-retroviral treatments and the experiences of other positive people were more influential in decisions about anti-retroviral use than advice from friends or relatives.
- Decisions about the use of alternative/complementary therapies were influenced mainly by personal experience.

Beliefs about medicine and therapies

More than 80% of respondents expressed some concerns about medicines in general. Concerns were focused on toxicity, side effects, dependency, and the possibility of jeopardising their future treatment options (see Figure 35).

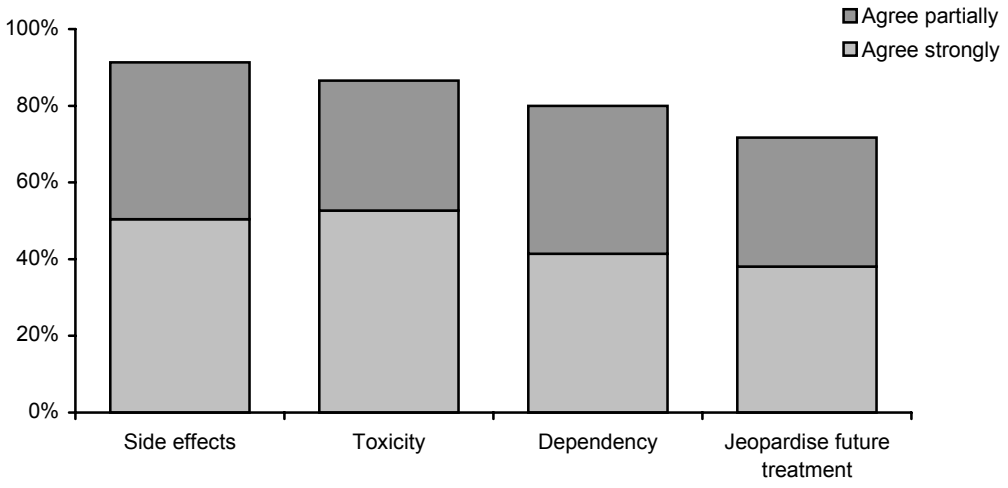

Figure 35 Concerns about medicine in general

More than half (55%) the respondents thought that medicine would not be able to find a cure for all illness, but over 80% did believe that medicine could control most illnesses (see Figure 36).

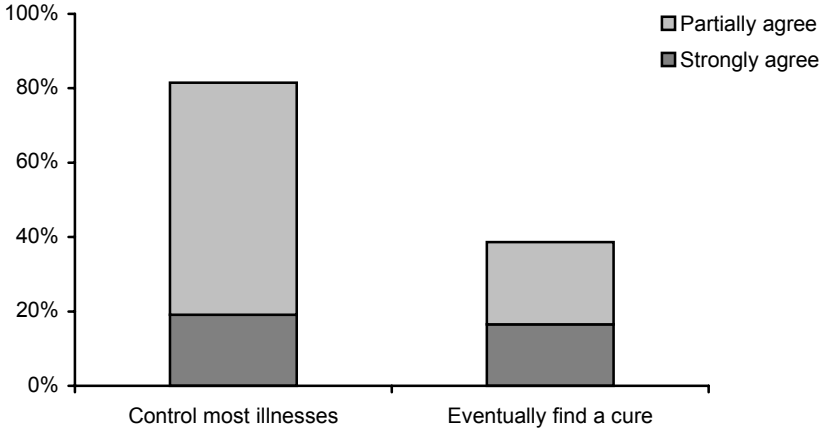

Figure 36 Expectations of medicine in general

Half of the respondents agreed strongly with the statement that drug companies are more concerned with profit than providing safe treatments, while a further 35% indicated partial agreement.

About half the respondents were very concerned about the toxicity of ***HIV treatments*** (57%) and their side effects (53%). Twenty-eight percent agreed strongly that the use of HIV treatments could jeopardise their future use of treatments, and 21% agreed strongly that 'anti-retroviral drugs are still too experimental to be sure of their benefits'. Most respondents did not agree that anti-retroviral therapy could 'upset a natural balance keeping the virus at bay' (see Figure 37).

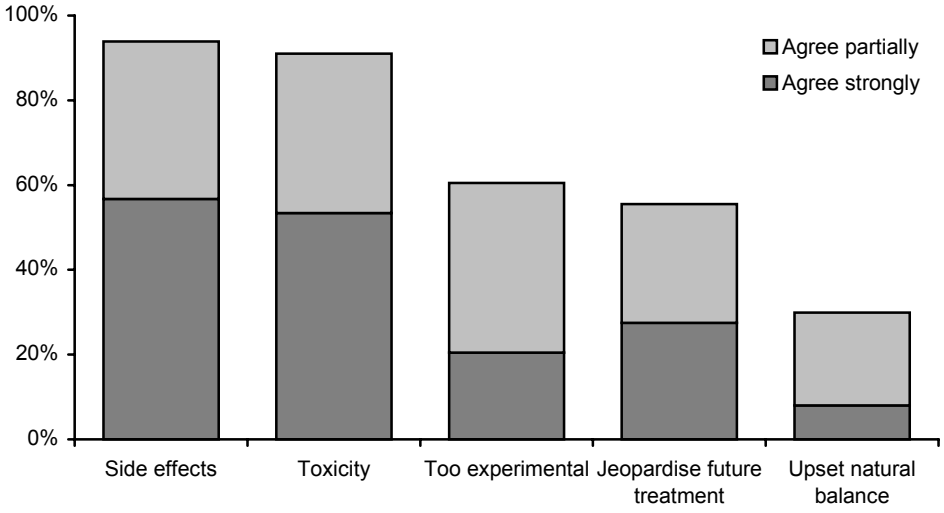

Figure 37 Concerns about drugs used in treating HIV

Most respondents did not believe that antiretroviral therapy represented a cure for HIV, but many did believe that the drugs keep HIV under control and are helpful in improving overall health (see Figure 38).

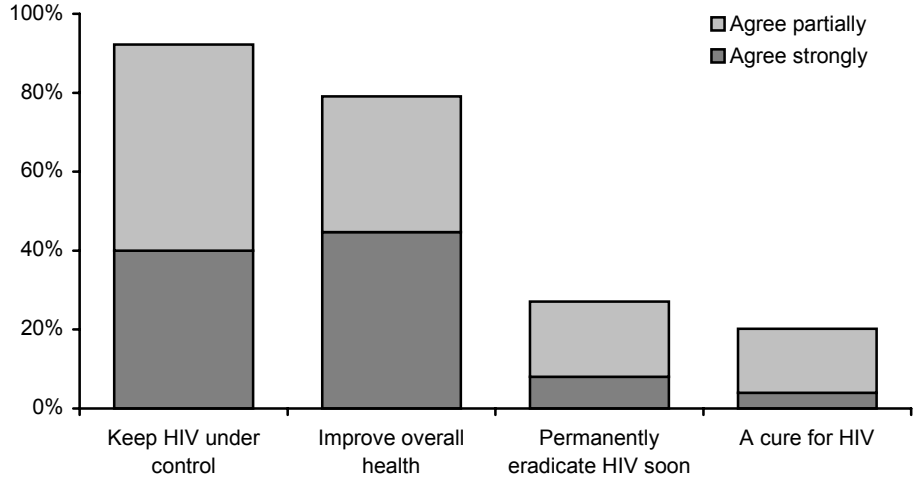

Figure 38 Expectations of drugs used in treating HIV

Combination anti-retroviral therapy was believed to be a highly effective HIV treatment by 62% of respondents. Slightly fewer (40%) held such a firm opinion about the effectiveness of protease inhibitors, and fewer still were as convinced of the effectiveness of AZT in combination with other anti-retrovirals (21%) (see Figure 39). Many people did not consider the use of AZT alone an effective treatment and some (17%) were of the opinion that it could have a counter-productive effect on treating HIV infection. About 52% of people thought that alternative or complementary

therapies had some effect in treating HIV infection, but only 11% thought such treatments were highly effective.

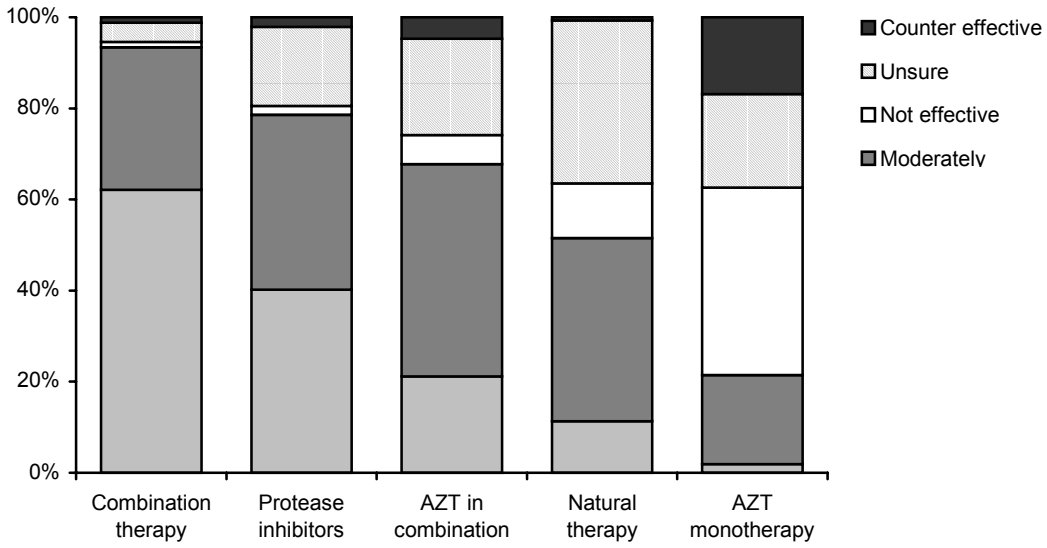

Figure 39 Perceived effectiveness of various HIV treatments

Almost all respondents reported the view that both medical treatments and attending to one's personal well-being were helpful ways to manage HIV infection (see Figure 40). Although less strongly held, the majority also agreed that alternative or complementary therapies were helpful.

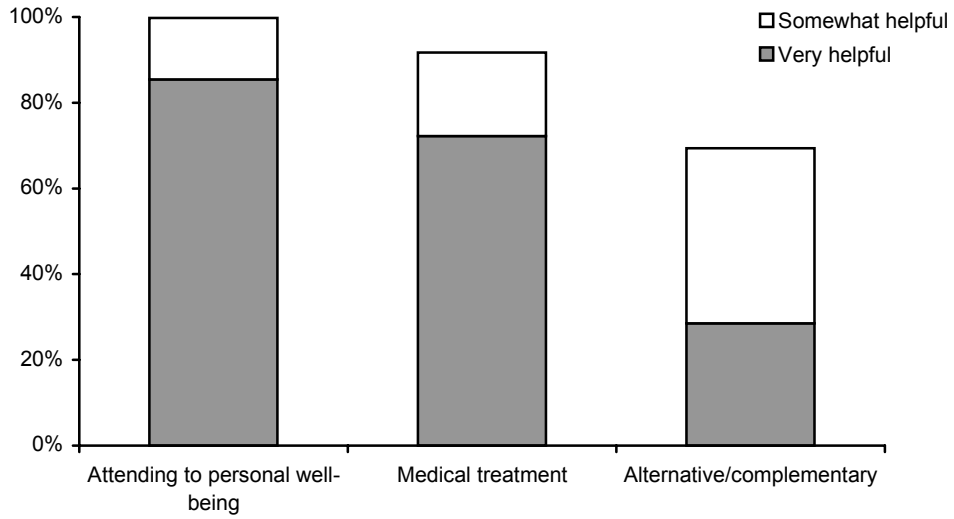

Figure 40 Factors assisting HIV management

Commencement of treatment

Respondents were provided with a list of factors commonly cited as reasons for commencing anti-retroviral therapy and were asked to indicate how important each factor rated in their own decision to commence HAART. A doctor's recommendation to commence antiretroviral treatment was rated by 78% of participants as *somewhat important* or *very important*. Other factors, such as CD4 count, viral load, and the appearance of symptoms were cited by 50% to 60% of participants. Fewer respondents indicated that HAART should commence at the point of becoming infected (see Figure 41).

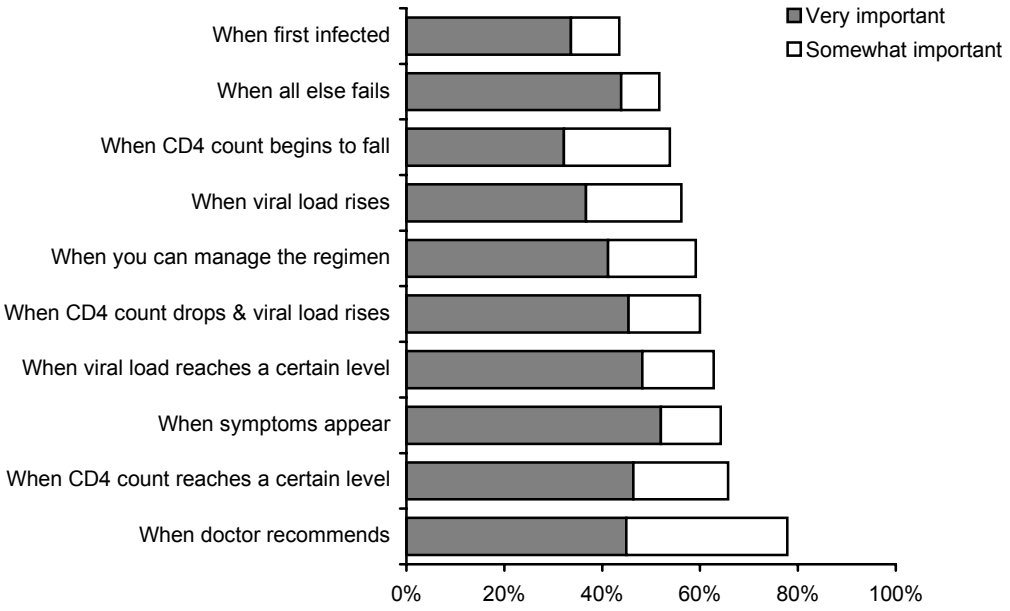

Figure 41 Commencement of anti-retroviral treatments

Those people who nominated CD4 count and viral load levels as indicators of commencement of anti-retroviral treatment, were subsequently asked what levels would precipitate their decision. Fifty-one percent of the respondents who indicated that a CD4 count was an important indicator thought that a CD4 count below 500 would be the point at which treatment should begin (see Table 38). Another 36% indicated that treatment should begin when the CD4 count falls below 200. Twelve percent were unsure of the level at which they would make a decision to begin treatment, although the CD4 count was still seen as a key factor in this decision.

Table 38 : CD4 count and commencement of HIV treatment

	Frequency	Percentage (%)
When CD4 count falls below 500	143	51.3
When CD4 count falls below 200	100	35.8
Unsure what level	34	12.2
NR/DK	2	0.8
Total	**279**	**100**

Note: Includes only those respondents who nominated CD4 count as a reason to commence anti-retroviral treatment.

Among the respondents who reported that viral load is an important factor in making a decision to start treatment, 20% thought that a viral load above 500 would be the point at which they would begin treatment (see Table 39). A higher percentage of these people (33%) indicated that a viral load above 10,000 would be an important factor in commencing treatment, while a similar number (34%) reported that a viral load level above 50,000 would be an indication to start treatment. Twelve percent were unsure what viral load level would precipitate their decision to start treatment.

Table 39 : Viral Load and commencement of HIV treatment

	Frequency	Percentage (%)
When viral load rises above 500	52	19.5
When viral load rises above 10,000	88	33.1
When viral load rises above 50,000	90	33.8
Unsure what level	32	12.0
NR/DK	4	1.5
Total	**266**	**100**

Note: Includes only those respondents who nominated viral load level as an indicator of anti-retroviral treatment.

Influences on the use of anti-retroviral treatment

MEDIA AND CAMPAIGNS

HIV magazine articles and treatment information campaigns influenced the treatment decisions of 53% and 52% or respondents, respectively (see Figure 42). Forty-five percent reported being influenced to some extent by the gay press and 33% by articles in medical journals. For the most part, however, not many respondents were 'very much' influenced by these various media sources.

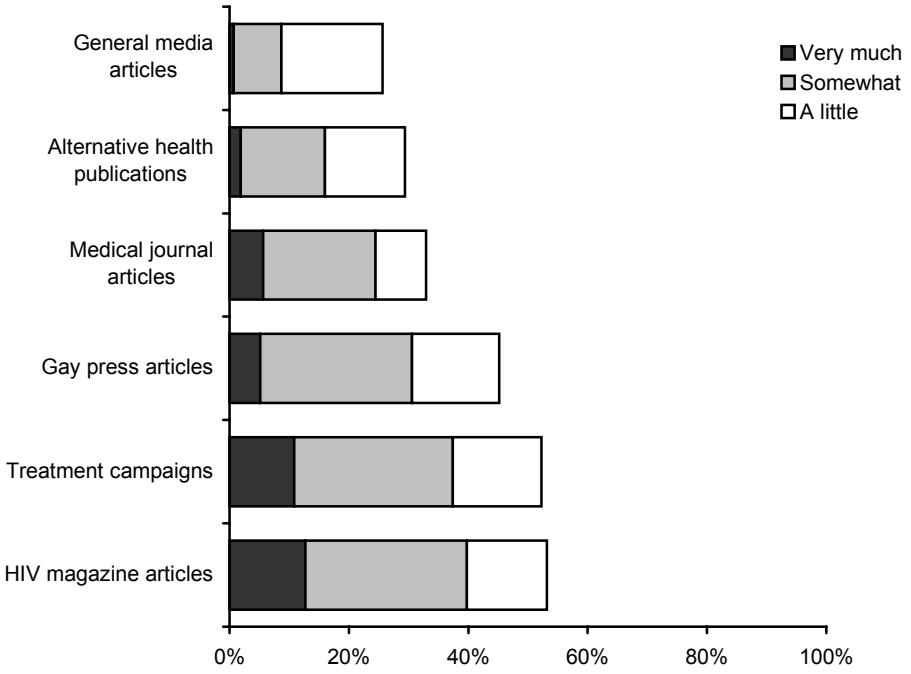

Figure 42 Influence of media on decision to take anti-retroviral treatments

HEALTH SERVICES

Advice from a doctor was rated by most respondents (92%) as having an influence on their decisions about anti-retroviral treatment (Figure 43). Thirty-two percent were influenced to some extent by advice from AIDS Councils, 38% by advice from PLWHA organisations, and 23% by advice from alternative health practitioners. Since most rated advice from a doctor as the most influential (70%), other sources of advice were only 'somewhat' or 'a little' influential.

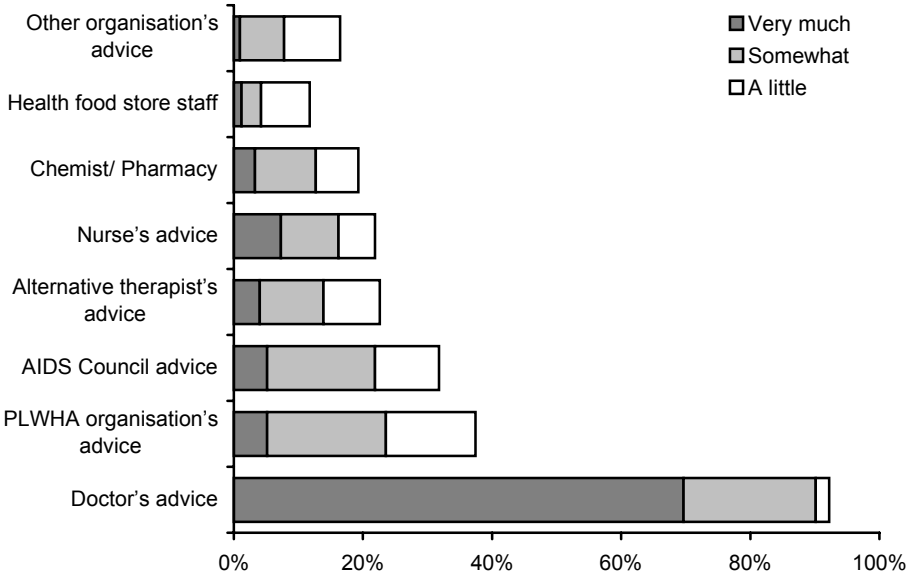

Figure 43 Influence of services on decision to take anti-retroviral treatments

PERSONAL CONTACT AND EXPERIENCES

One's own experiences with anti-retroviral treatment therapies and the experiences of other positive people were more influential in making decisions about anti-retroviral treatment than receiving advice from other friends and relatives (see Figure 44). Forty percent of the respondents reported being influenced 'very much' by their own experiences, and 25% reported the same experiences of other positive people.

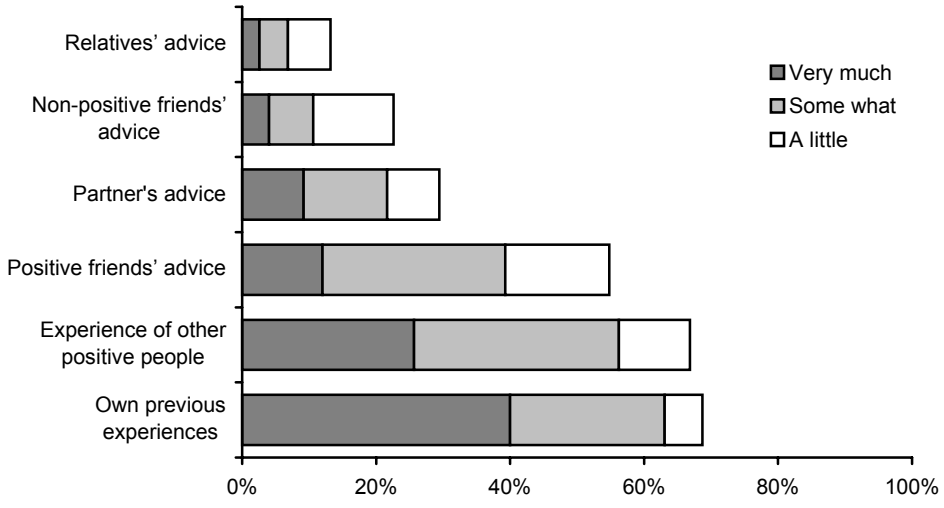

Figure 44 Influence of personal contact and experience on decision to take anti-retroviral treatments

Influences on the use of alternative/complementary therapies

Influences on the decision to use alternative or complementary therapies were similar to that of anti-retroviral use, except that the level of influence from all sources was less pronounced.

MEDIA AND CAMPAIGNS

Between 30% and 40% of respondents were influenced to some extent by HIV magazine articles, treatment information campaigns, the gay press and alternative health publications, although fewer than 5% were 'very much' influenced by these media (see Figure 45).

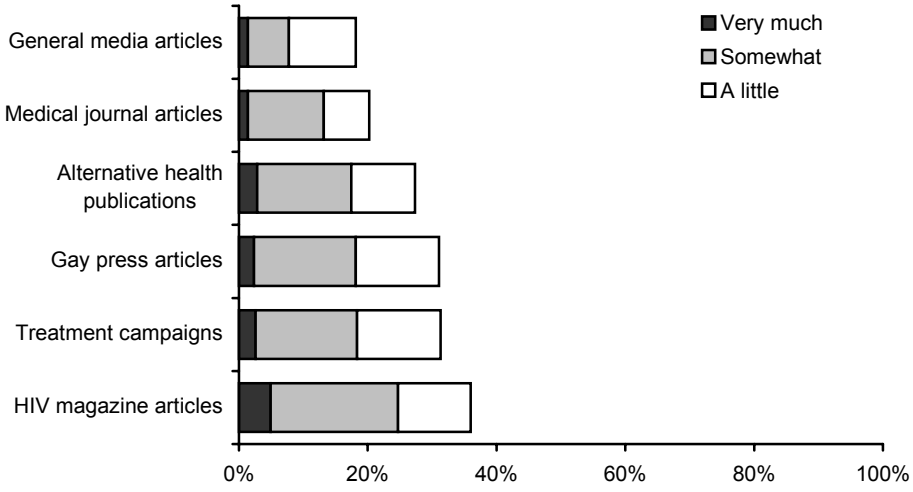

Figure 45 Influence of media on decision to use alternative/complementary therapies

HEALTH SERVICES

The respondents' doctor influenced the decision to use alternative/complementary therapies for 40% of participants (see Figure 46). Other health services were less influential in decisions about use and very few people were influenced 'very much' by any of the services, with the exception of advice from doctor (17%).

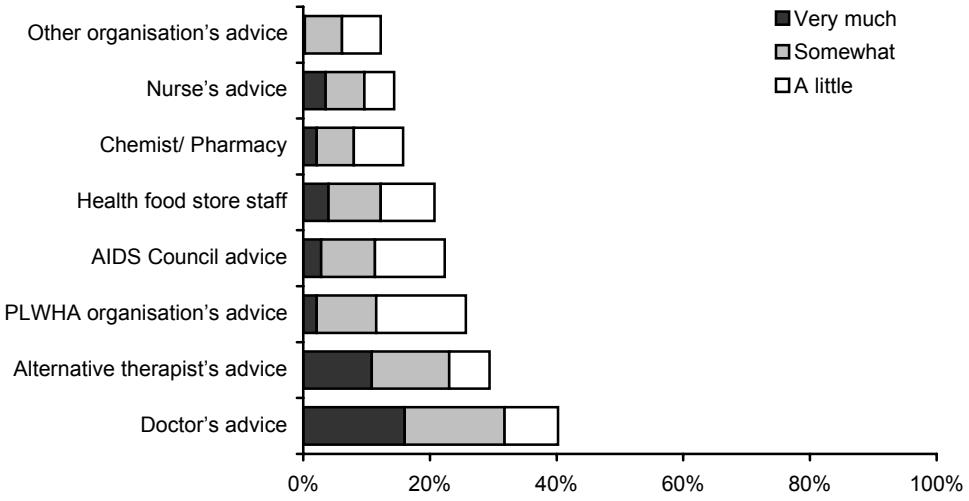

Figure 46 Influence of services on decision to use alternative/complementary therapies

One's own experiences with alternative/complementary therapies, the experiences of other positive people, and advice from positive friends influenced over 40% of participants (see Figure 47). Advice from relatives, partner, and non-positive friends influenced fewer people.

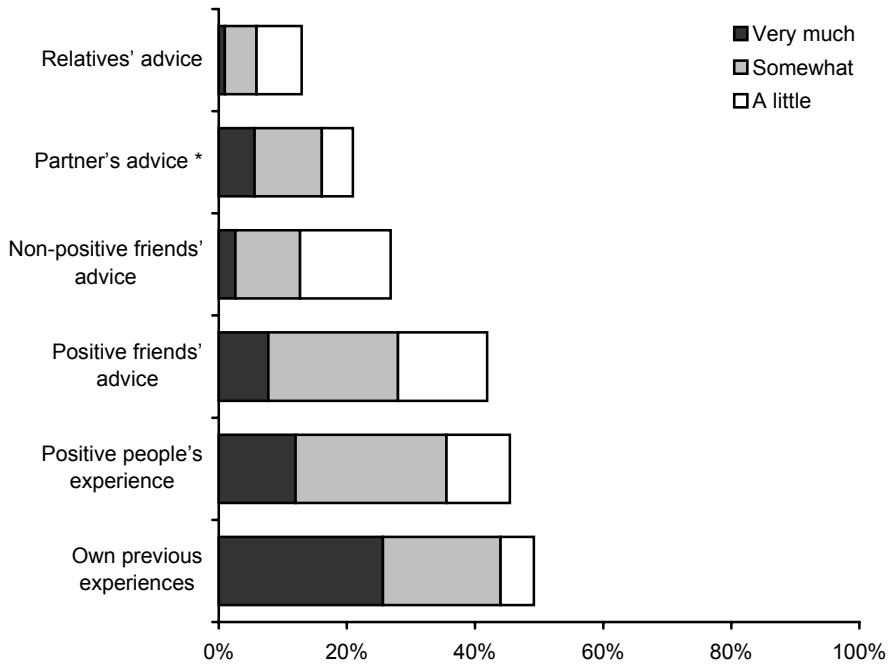

Figure 47 Personal influence on decision to use alternative/complementary therapies

DISCUSSION

Most respondents made a regular occurrence of seeing a doctor about their HIV infection. The type of doctor most commonly seen by respondents was a general practitioner with a high HIV caseload, or a specialist with HIV expertise. Few respondents had little or no contact with any health services. Gay male doctors were most popular among the majority of participants. Although experience with HIV was the most common reason for choosing a particular doctor, other attributes, such as experience in men's health, particularly gay men's health, featured prominently in the choice of doctor for about two thirds of respondents. Most participants reported having a cooperative relationship with their doctor, with joint decision-making being a common aspect of the relationship.

Instances of HIV diagnosis among respondents in the sample were fairly evenly spread across the years of the epidemic, with about half the sample diagnosed prior to 1990. Most had T-cell and viral load tests at least every three months and had experienced both high and low CD4 counts and viral load results. Even so, results from respondents most recent viral load and CD4 count test results showed that about 50% had an undetectable viral load level and 18% had a CD4 count below 200. Most respondents rated their current state of health as being good or excellent, and this assessment was often based on how they felt. Symptoms of HIV related illness had been experienced by about 50% of respondents in the previous month, while signs of lipodystrophy had been experienced by 61% in the previous year. Being diagnosed with an opportunistic infection had occurred for nearly 50% of the sample in the previous 12 months; fungal infections were the most commonly experienced of these infections. Ten percent of respondents had been hospitalised in the previous 12 months due to opportunistic infections.

Hepatitis A had been diagnosed in almost 50% of respondents and hepatitis B in about 30%. Slightly fewer people (18%) had been diagnosed with hepatitis C.

Most respondents had adopted a range of strategies to improve their health in general, with the most common strategy being to reduce stress. Many respondents had experienced depression; about 30% had ever been diagnosed with depression, half of these in the previous year. Furthermore, about 50% of respondents had received some sort of medical treatment or counselling for their mental health in the previous year.

Few respondents had never taken anti-retroviral drugs; about 50% had first taken them prior to 1996, including about 30% who had commenced combination therapy prior to that time. Most respondents were taking at least three anti-retroviral drugs at the time of the interview, and about 50% were taking more than ten pills a day. There were some people (20%) who at the time of the interview were not taking any anti-retroviral drugs. Although most respondents had at some stage taken AZT, less than 20% were doing so at the time of the interview.

A majority of the people taking anti-retroviral drugs had experienced side effects; for 25% of respondents the side effects were rated as severe. Many in the sample had, during the year, discontinued the use of one or more anti-retroviral drugs. The most common reasons for

discontinuation were that it made them sick or that they had switched to using another drug recommended by their doctor.

Many respondents, although a minority, had some difficulty with their treatment regimen. Taking pills on time was more of a problem than was the number of pills that needed to be taken. Twenty-five percent of respondents missed taking pills during the two days prior to their interview, and about 90% had missed taking their pills at some time during the previous year. Eighteen percent had missed doses each week over a 12-month period. Although missing doses of anti-retroviral drugs was quite prevalent, most respondents considered it very important that they take their pills as prescribed and the majority believed that missing doses could have serious implications for their health.

Various media sources had an influence on respondents' decisions about anti-retroviral use, albeit the influence was not rated as being strong. Health services also had an influence on respondents' decisions about anti-retroviral use, although only doctors were rated as having a strong influence. One's own experiences with anti-retroviral use and the experiences of other positive people were other important influences on decisions about anti-retroviral use.

Many participants had taken treatment/prophylaxis for PCP and about 30% were doing so at the time of the interview. About 50% had taken acyclovir to treat herpes, and just as many had taken anti-fungal treatments. At the time of the interview about 30% were using acyclovir and 20% were using an anti-fungal agent. Few respondents had used an immune stimulant or treatment for KS, and although 25% had ever used anabolic steroids, few were doing so at the time of the interview. Most respondents had used an alternative/complementary therapy, the most common of which were anti-oxidants. A smaller number had consulted an alternative/complementary therapist in the previous year. Nearly 30% of respondents had used marijuana for therapeutic purposes, most commonly to relieve stress. Decisions about using alternative/complementary therapies were influenced predominantly by personal experience, advice from doctors, and alternative/complementary therapists.

There were few barriers to access HIV services. Most respondents had little difficulty accessing services provided by a doctor or dentist with HIV experience. Although large minorities indicated they rarely used services provided by counsellors, alternative/natural therapists, and HIV support groups, when these people did access such services they usually did so with little difficulty. Services that were deemed to have access difficulties were usually attributed to the distant proximity of such services. Another commonly expressed reason for finding difficulty in accessing services were the costs associated with the services, particularly those offered by dentists and alternative/complementary therapists. Information about treatments and general health was accessed easily from doctors and HIV specialists, however many respondents indicated that hospitals and community health centres were not as helpful in providing such information.

The majority of respondents expressed some concern about medicines in general: toxicity, side effects, dependency, and the possibility of jeopardising their future treatment options. Although generally sceptical about the capacity of medicine to cure most illnesses, respondents tended to think that medicine could control and manage most illnesses, at least to some extent. The same concerns respondents had about medicine in general were also true of their attitudes to HIV

medications in particular. Respondents were also sceptical about the role of drug companies, with most believing these to be more interested in profit than with developing safe treatments. Despite these reservations, most respondents thought that medical treatments were very helpful in managing HIV infection, and even more believed in tending to one's own well-being. Fewer respondents, although still the majority, thought that alternative/complementary therapies were helpful in managing HIV infection. Most respondents agreed that anti-retroviral drugs, particularly combination therapy, were effective treatments for HIV. Respondents were more likely to believe it was best to commence treatment for HIV when symptoms first appeared or when CD4 count or viral load levels reached certain levels than at the point when a person first became infected.

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