

What do you need?

*Findings from a national
survey of people living with HIV*

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Original Research Report

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- King's Mill Centre for Healthcare NHS Trust, The King's Mill Centre for Health Care Services GUM Department
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- La Verna Housing
- London Friend
- Lothian University Hospitals NHS Trust, Royal Infirmary of Edinburgh GUM Department
- Mesmac North East
- Mid-Sussex Body Positive (MSBP)
- Morden Citizens Advice Bureau
- Mount Vernon & Watford Hospitals NHS Trust, Watford General Hospital GUM Department
- National AIDS Manual
- National Childrens Bureau
- Navajo Project
- Neath Port Talbot Council Social Services Department
- Newcastle, North Tyneside & Northumberland NHS Trust, Newcastle & North Tyneside Drug & Alcohol Service
- Nottingham City Hospital NHS Trust, Nottingham City Hospital GUM Department
- Norfolk & Norwich Health Care NHS Trust, Norfolk & Norwich Hospital GUM Department
- Northamptonshire Council on Addiction (CAN)
- North Ayrshire Council Vernon Addiction Centre
- North East Wales NHS Trust, Wrexham Maelor Hospital GUM Department
- North Glasgow University Hospital NHS Trust, Brownlee Centre for HIV Counselling, Care and Treatment.
- North Manchester Healthcare NHS Trust, North Manchester General Hospital GUM Department
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- Positive Health Lincolnshire
- Positive Tongue/Tafod Positive
- Positive Transport Scheme (c/o Lighthouse South)
- Positively Women
- POW (Prostitutes Outreach Workers)
- Powys AIDSline Services (PALS)
- Preston Acute Hospitals NHS Trust, Royal Preston Hospital GUM Department
- Queen Elizabeth Hospital NHS Trust, Trafalgar Clinic
- Raft Surrey
- Richmond-Upon-Thames Council Social Services Department
- Royal Berkshire & Battle Hospitals NHS Trust, Royal Berkshire Hospital Florey Unit Clinic for Sexual Health
- Royal United Hospital Bath NHS Trust, Royal United Hospital GUM Department
- Saidso
- Scot-PEP (Scottish Prostitutes Education Project)
- Scunthorpe Body Positive
- Shropshire Buddies & Shropshire Body Positive
- Sheffield Centre for Sexual Health
- Solas
- Somerset County Council Social Services Department
- South Buckinghamshire NHS Trust, Wycombe General Hospital GUM Department
- South Devon Healthcare Trust, Torbay Hospital GUM Department
- South Durham Health Care NHS Trust, Bishop Auckland General Hospital GUM Department
- Southend Borough Council Social Services Department
- Southport & Ormskirk NHS Trust, Southport & Formby District General Hospital GUM Department
- St. Georges Healthcare NHS Trust, Queen Mary's Hospital Roehampton Clinic Department of Sexual Health
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- Staffordshire Body Positive
- Staffordshire Buddies
- Streetwise Youth Project
- Strutton Housing Association
- States of Guernsey Board of Health, Orchard Centre Department of Sexual Health
- Stockport NHS Trust, Stepping Hill Hospital GUM Department
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- Tameside Metropolitan Borough Council Social Services Department
- Taunton & Somerset NHS Trust, Musgrove Park Hospital GUM Department
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1 Introduction

What are the needs of people living with HIV in the UK? This question has never been easy to answer. Over the past twenty years, both the needs of people with HIV and our understanding of them have changed. During this time there have been many assessments of need, usually within specific geographic boundaries (such as health authorities) but no consistent approach to describing needs has been adopted. Most needs assessments have been shaped by a variety of local factors, not least the profile of existing services.

This study provides new insight into the needs of people with HIV, based on a sample of 1,821 people. The approach taken to measuring and describing need offers a fresh perspective on living with HIV in the UK. This approach was shaped by our earlier studies exploring the experience of people with HIV in the era of combination therapy (Anderson & Weatherburn, 1998; Anderson & Weatherburn, 1999; Anderson *et al.*, 2000). These studies have consistently challenged attempts to treat the needs of people with HIV in a simplistic way.

Combination therapy has had a huge impact on people with HIV but this impact has been diverse, individual and unpredictable. The increased possibilities which anti-HIV therapy has offered came with new risks: the risks of side effects and treatment failure; the risks of giving up security and investing in hope when the future remained uncertain. For many people, the problems associated with living with HIV – disability, discrimination, poverty, anxiety, isolation, loss – remained as challenging as ever.

Changes in treatment did not translate into straightforward changes in need. Changes in service use have also been idiosyncratic. The complexity of changes in need has been compounded by the unpredictable relationship between needs and service use. People meet their needs in ways other than through using services, drawing on their internal resources and on the support of partners, family and friends. When they do turn to services, they do not always have a clear idea of the ‘need’ that they are seeking to ‘meet’. Service use is often a process of trial and error, a negotiation in which individuals find their own ways of both understanding and meeting their needs.

This study builds on these findings. The aim of the study was to describe the needs of people with HIV in the UK in such a way that description of need was disentangled, as far as possible, from description of service use. The model of need adopted also reflects a commitment to letting people describe their needs on their own terms.

Changes in service provision over the last five years have been driven as much by political priorities and funding pressures than by an understanding of the changing needs of people with HIV. Such pressures will remain, but a clearer assessment of these needs will hopefully improve our collective capacity to plan and fund appropriate services. This study offers such an assessment. We hope that it captures something of the reality of living with HIV in the UK at the beginning of the 21st century and gives this reality a higher profile in the decision-making of HIV service providers and service commissioners.

1.1 A NEW MODEL OF NEED

1.1.1 *The problematic language of need*

Needs are difficult to pin down. A consistent approach to describing need requires a clear concept – disentangled from the various daily uses of the word.

There are two ways of talking about need that are very different but similar enough to cause confusion. 'Need' can express both a lack of something and the means of overcoming this lack. For example, compare "I need peace of mind" with "I need counselling". The former describes a personal lack, the latter describes one way of addressing this lack. Both are perfectly good ways of using the word.

This dual use of the language creates confusion between needs and services. It is possible to talk about needs entirely in terms of the services that might address personal lacks. But most services have the potential to address more than one lack. Counselling might help to overcome a lack of peace of mind, or self-confidence or self-esteem, *etc.* Describing needs solely in terms of services can therefore be misleading as the underlying problem may remain unexplored.

For the purposes of the model used here, need always refers to a lack, an unwanted deficit, and not to the interventions which might help to overcome such deficits.

If needs are deficits, how are these deficits to be defined and identified? What counts as a needs-defining deficit? There are a number of different ways of answering these questions, all of which have some relevance to the model used in this study:

- Complete accounts of need
- Subjective accounts of need
- Economic accounts of need

1.1.2 Complete accounts of need

In common language, 'needs' are often distinguished from 'wants'. This suggests that needs are somehow more fundamental and so should only relate to the things which people cannot do without. This in turn leads to attempts to describe complete accounts of human need. The most famous is that of Maslow (1954), who defined a hierarchy of needs with basic physiological needs at the bottom and the need for 'self-actualisation' at the top with safety, belongingness and love in between.

Although such models attempt to be descriptive, they always involve judgements about what should (and should not) be a need. For example, in a more recent attempt, Doyal and Gough (1991) insisted that it makes sense to want a cigarette, but not to need one – the need was surely to stop smoking. Yet, for a smoker, cigarettes do meet real needs. Similarly, in our last study, drug use was described both as a cause of need (by creating problems in daily life) and a way of meeting needs (e.g. overcoming the pain of daily life).

There is no complete account of need that everyone will agree with. Needs are determined by individual circumstances, aspirations and priorities. One person's needs may seem irrelevant to someone else with different personal goals.

Unfortunately, however, it is impossible to conduct a needs assessment without some imposition of a framework to understand needs. The framework used in this study is based on the findings of our earlier in-depth qualitative research with people with HIV. It was also informed by discussions with service providers and was necessarily constrained by the limitations of a self-complete questionnaire. It is not a complete account of need, merely an attempt to capture some of the most common needs among people with HIV.

The question of what 'counts' as a need was left to the survey respondents: they were asked if they had experienced any problems in each need area, over the previous 12 months. If, for example, someone reported that they had a problem sleeping, this was taken as one indication of a need for sleep.

Experience of problems is a key indicator of need in this study. However, this indicator does not capture how someone feels about their experience – the subjectivity of their need.

1.1.3 Subjective accounts of need

To address the subjectivity of the experience of need, our model draws on the theory of need proposed by Per-Erik Liss (1993). Liss defines need as the difference between someone's current actual state and their desired goal. This is beguilingly simple. Need is wholly defined by the individual, on their own terms – not by researchers, service-providers or any other 'authority'.

This theory helps to clarify the ways in which needs can change:

- Needs reduce if the actual state improves and moves closer to the desired state;
- Needs increase if the actual state worsens and moves further away from the desired state.

However:

- Needs also reduce if the desired state is lowered and brought nearer to the actual state;
- Needs also increase if the desired state is heightened and taken further away from the actual state.

For example, an improvement in health may reduce need by improving someone's 'actual state' (daily life gets easier to manage) but also increase need by heightening the 'desired state' (a bigger social or working life become possible but obstacles that were irrelevant before now become pressing). Similarly, illness can increase needs by worsening the 'actual state' but decrease needs by lowering the 'desired state'. All of these changes were described in our last study of the impact of combination therapy (Anderson *et al.*, 2000).

The difference between actual and desired states was captured in the model by asking respondents to describe, for each need area, their satisfaction with their current state. Hence, as well as asking respondents whether they had experienced any problems with sleep (for example), the survey also asked them how they felt about their ability to sleep as and when they wanted to.

Crucially, respondents who reported having particular problems were not always dissatisfied with their current state. This reflects either an acceptance of the problem and its impact on life (i.e. a lowering of desired state) and/or ongoing strategies to cope with the problem (i.e. raising actual state through services or other interventions).

Furthermore, in some circumstances respondents who did not report problems were nonetheless unhappy with their current state. This was common for needs with a strong aspirational quality. For example, even if you do not have 'problems' with your current housing, you may feel that your housing is limiting the possibilities of your life, perhaps for independence, family, social contact or quality of life.

1.1.4 Economic accounts of need

Economists like precise, measurable concepts to work with. Consequently they have been among the fiercest critics of the concept of need and have sought to pin the idea down to an unambiguous definition (Culyer, 1995). They argue that, from the perspective of those charged with spending the NHS's money, need is only interesting in as much as it relates to the use of services.

In order that a service cost can be identified for any need, need is defined as an individual's 'capacity to benefit' from health care. Whatever it costs to exhaust this capacity to benefit is the cost of meeting the need.

This definition appears to create the absurd situation where a need is only a need if there is a service available to meet it – if there is nothing to benefit from, there can be no capacity to benefit. In a critique of the economic model, David Seedhouse says:

"It is one thing to say that a person has no need of useless services – but quite another to say that a person cannot need what she cannot have. The idea is nothing less than bizarre. It implies that: if a person has HIV or AIDS then – in 'commonsense' – he has several health care needs. He

may need palliative therapy, he will probably need advice on preventing infection, and he could certainly benefit from a cure. But – in ‘NHSese’ – the AIDS sufferer does not, and by definition cannot, need a cure. He cannot need one because no such thing exists. If a cure were to be available tomorrow, then he would have need of it. But not today.” (Seedhouse, 1994)

In reality, though, the ‘commonsense’ use of need does not extend to things that are completely unattainable. In our last study, when asked ‘What are your needs now?’, a couple of respondents replied: ‘I need a cure’. But these responses were made with laughter or irony – there was an acknowledgement that to talk of a need for something which no-one could give you, was in some sense silly. Their statements were expressions of the general predicament of their lives, not genuine expressions of current need.

Our model includes the idea of ‘capacity to benefit’, but respondents decided for themselves whether they had such a capacity. Furthermore, potential help or support to address any need was not assumed to derive solely from services.

For each need area, respondents were asked to indicate where they had got help from in addressing their problems in the previous 12 months. They were then asked ‘With more help or support, do you think you could reduce, or overcome, these problems?’ Those who answered ‘yes’ or ‘don’t know’ to this question were assumed to have a potential capacity to benefit from further help or support.

Clearly, some respondents who answered ‘no’ to this question might not have been aware of the range of interventions that could address their problems, so it would be wrong to assume that they had no capacity to benefit. Nonetheless, this question provides a useful indicator of need (at least for service providers): the extent of problems among people with HIV for which there is a willingness to seek or accept help or support.

1.2 SUMMARY

This report focuses on 18 need areas, drawn from our previous work on the needs of people with HIV in the era of combination therapy. These need areas are not comprehensive but provide insight across the range of physical, psychological, social and medical needs.

For each need area described in this report there are three key indicators of need:

- Dissatisfaction with current state
- Experience of problems in the last 12 months
- Personal perception of capacity to benefit from further help or support

Each of these indicators has its strengths. In particular:

- The first indicator is true to the subjectivity of people with HIV, taking account of their priorities, aspirations and coping skills as well as their problems.
- The second is a more objective indicator of need – a retrospective description of the actual problems experienced by people with HIV. However, respondents still made their own judgements about which experiences counted as a problem.
- The third indicator provides a measure of the scope for action, through services or informal support, to address the needs of people with HIV.

2 Methods and sample

2.1 METHODS

Priority was given to obtaining a large and geographically diverse sample. This required a questionnaire that was relatively easy to complete and a wide-ranging recruitment strategy.

In order to maximise the speed with which the questionnaire could be completed, most of the questions were closed and only required a tick by the respondent. However, closed questions were not used for any question where the range of answers could not be prejudged. For example, respondents were asked to describe in their own words the problems they had experienced under each need heading.

The questionnaire was published as a 24-page A5 booklet which made clear that all responses would be anonymous. The questionnaire included 17 questions about the demographic characteristics of respondents and another 10 on their personal HIV history. It then asked nine very similar questions about each of 18 need areas. All questionnaires were distributed with a reply-paid envelope.

The questionnaire was piloted with 46 respondents (18 women, 28 men) in two service settings: Positively Women and Terrence Higgins Trust Lighthouse West. All pilot respondents were asked to complete the draft questionnaire and then feedback individually or within a focus group discussion. The discussion focussed on their feelings about the questionnaire including ease of completion and understanding of questions. Pilot participants were paid for their time and effort.

The study received approval from North West Multi-centre Research Ethics Committee (ref: MREC 01/8/60) with confirmation that the research fell within the Department of Health's (November 2000) *Supplementary Operational Guidelines for NHS Research Ethics Committees on Multi-Centre Research in the NHS – the process of ethical review when there is no local researcher*. This national approval ensured that no further approval was necessary from local ethics committees.

As there was no national sampling frame available, recruitment to the survey had to be opportunistic but purposive: i.e. using as many different avenues as possible to reach as many different people with HIV as possible. Distribution began on 8th June 2001 and no further questionnaires were accepted for inclusion after 20th October 2001.

The most straightforward route of distribution was mass mailing via national newsletters and organisational mailing lists. Three major newsletters/magazines included the questionnaire with a mailing: AIDS Treatment Update (6,200 copies), Positive Nation (950 subscribers only) and Vanguard (2,000 copies). The questionnaire was also mailed directly to 1,000 volunteers or members of Gay Men Fighting AIDS; and 420 people with a bleeding disorder and HIV along with about 40 positive partners via the Macfarlane Trust, organised by The Haemophilia Society. This accounts for 10,610 questionnaires distributed directly via the Royal Mail. Of course, not everyone subscribing to AIDS Treatment Update or Vanguard and in contact with GMFA has diagnosed HIV infection but each of these organisations estimates 50-75% of their mailing list has diagnosed HIV. All Positive Nation subscribers and people on the Macfarlane Trust list are assumed to have diagnosed HIV infection. Overall these direct mailings account for 57% of the questionnaires distributed.

The questionnaire also appeared on Sigma's own website and AIDSmap, the website of the National AIDS Manual. The questionnaire could be downloaded (as a PDF) and printed but not submitted on-line.

The remainder of the questionnaires were distributed via local authority service providers, AIDS service organisations and GUM/HIV outpatient clinics throughout the UK. Using NAMbase we wrote to all 740 agencies who were listed in the National AIDS Manual as providing service to people with HIV. About 20 additional invitations were identified by cross-referencing the original mailing list with the membership lists of the National Network of Self-Help HIV and AIDS Groups and the Pan-London HIV and AIDS Providers Consortium.

In total, 198 organisations agreed to distribute the questionnaire directly to their patients, clients and service users with diagnosed HIV (see Acknowledgements). 8,071 booklets were requested by and sent out to 198 agencies. This included 24 local authority/social services agencies, 104 AIDS service organisations and 70 GUM/HIV outpatient clinics. The average (median) number of booklets requested per participating agency was 25 (range 2 to 900). All agencies were invited to mark booklets they distributed with a stamp or mark to indicate its source. All these agencies that recruited more than 20 people with HIV to the final sample have received a targeted data report on the people they recruited.

At the end of the data collection period all agencies were informed that recruitment was closed and asked to count remaining stocks of the questionnaire and let us know how many they had left. Just over half (51%, $n = 101$) of the agencies responded. These agencies report that 30% of the stock of questionnaires they had received remained. This suggests that of the 8,071 booklets distributed from Sigma Research to agencies, 2,421 were not distributed by the agencies receiving them. Hence approximately 5,650 copies of the questionnaires were distributed in addition to the mass mailings above, giving a total of 16,260 questionnaires distributed. Of course some of these would not have gone to people with diagnosed HIV (especially via some of the mass mailings) and some people with HIV probably received multiple copies.

By using as many different avenues as possible, the sampling sought to reduce the biases of opportunistic recruitment to a self-complete questionnaire. However the sample will not include people who do not have contact with services, unless given a questionnaire by friends. It will also be skewed against people who are not literate in English, worried about confidentiality or wary of social research. The sample description below demonstrates that the survey was successful in recruiting a demographically diverse national sample. However, the comparison with national prevalence data on page 10 reveals biases towards respondents who were male, older, White and living outside London.

Overall, we received 1840 completed questionnaires. Nineteen (1.0%) of these were excluded from analysis because less than half the questions were answered; or because they were completed by respondents living outside the UK; or because there was no evidence that the respondent had diagnosed HIV. This leaves a final sample of 1821.

Descriptive statistics were produced using SPSS. Analysis and quantification of respondents' written answers was conducted by identifying categories across a sample of cases followed by iterative checking and development of these categories over the relevant sub-sample.

2.2 SAMPLE DESCRIPTION

There were 1821 respondents in the sample, after exclusions. The following is a description of the characteristics of the whole sample.

Gender

The sample was 85% male ($n=1550$), 15% female ($n=271$).

Age

The age range of the respondents was from 13 to 78 with an average of 40. The majority of respondents were in their 30s or 40s.

AGE RANGE	no.	%
<20	6	<1
20s	143	8
30s	781	43
40s	608	34
50s	214	12
60s	44	2
70s	11	<1

Ethnicity

The sample was 89% White, 6% Black African and 5% other non-White ethnicity. The White respondents were 89% male; the Black African respondents were 69% female.

Ethnic group	no.	%
Asian	23	1
Black African	111	6
Black Caribbean	11	<1
Chinese	4	<1
White British	1403	77
White Irish	52	3
White other	155	9
Mixed ethnicity	26	1
Other	22	1

Region of residence

The table below describes the region of residence of the respondents. The regions are the old NHS regions (prior to the April 2002 reorganisation of the NHS).

Region	no.	%
London	786	44
South East	201	11
North West	205	11
Trent	57	3
West Midlands	100	6
Northern & Yorkshire	66	4
Eastern	102	6
South West	107	6
Wales	51	3
Scotland	105	6
Northern Ireland	9	<1
Channel Islands	2	<1

Sexuality

The sample included 1266 gay men (70%), five lesbians (<1%), 220 heterosexual men (12%), 248 heterosexual women (14%), 53 bisexual men (3%) and 9 bisexual women (<1%).

Haemophilia

Eighty men and three women reported having haemophilia (5% of all respondents).

Injecting drug use

Previous experience of injecting drug use was reported by 126 respondents (7%), of whom 31 reported injecting drug use in the previous six months (2% of all respondents).

Immigration problems

Sixty-five respondents described current immigration problems (4% of all respondents).

Most of those who described the nature of their application had made a claim for exceptional leave to remain on compassionate or humanitarian grounds. Others described applications for leave to remain based on UK ancestry or in relation to student or work visas.

The main problem described by respondents was the time taken for applications and appeals to be processed. This could take years, during which respondents could not leave the country. A few respondents said they felt inhibited by requirements to register with either police or the Home Office on a regular basis.

The other main problem was the financial implications of their immigration status. If an application had not been finalised, respondents were not permitted to work, causing financial hardship. In addition, most were not able to apply for welfare benefits.

Partners and children

Half of all respondents (51%, n=920) had a partner, husband or wife at the time of completing the survey. Three quarters of these respondents lived with their partner (39% of all respondents). A fifth (20%, n=362) of respondents had children but only 10% (n=173) were living with children. For some, children had grown up; others were separated from their children.

Educational qualifications

In terms of educational qualifications the sample splits into thirds – one third (33%) had no qualifications, O-levels, GCSEs or equivalent qualifications at school leaving age of 16; slightly less than a third (31%) had A-levels or equivalent vocational qualifications at school leaving age of 18; and just over a third (36%) had a degree or more. These three groups define the 'low, medium and high' education groups used in Table 3.6

EDUCATIONAL QUALIFICATIONS	no.	%
No qualifications	197	11
O-level/ GCSE equivalent (school leaving age 16)	398	22
A-level equivalent (school leaving age 18)	231	13
Other, including vocational/ professional qualifications	333	18
University degree or higher	650	36

Employment

Over a quarter (27%, n=492) of respondents were in full time employment, with very similar numbers working part-time (7%, n=118) or self-employed (7%, n=120). Of the three fifths (60%) who were not in paid employment (n=1082), 178 were unemployed, 713 were signed off long-term sick, 202 were retired and 69 were students.

Living with HIV

The time respondents had lived since HIV diagnosis ranged from 1 month to 18 years, with an average of 7.7 years (median 6.7 years). Sixty-four percent of respondents had been ill because of HIV at some point in their lives (n=1148). Chapter 18 provides a description of the proportion of respondents taking anti-HIV treatments and the problems they experienced.

2.3 COMPARISON WITH NATIONAL SEROPREVALENCE DATA

The difference between the sample and the UK population of people diagnosed with HIV was estimated by comparing sample demographics with the National Survey of Prevalent Diagnosed HIV Infections (SOPHID), conducted annually by the Communicable Diseases Surveillance Centre (www.phls.co.uk). However SOPHID is itself not a perfect measure and SOPHID data was only available for 2000, one year before our survey was undertaken.

This comparison reveals that the sample was disproportionately male, old, White and resident outside London. The biggest divergence from SOPHID was the relatively low proportion of respondents who were Black African. This partly explains the skew away from London, where four-fifths of Black African people with HIV live.

Because of these differences, we urge service providers to consider the pattern of needs within the sub-populations relevant to their area or service (see Chart 3.6) as well as the broad pattern of need across the whole sample.

		sample %	SOPHID %
GENDER	Male	85	77
	Female	15	23
AGE GROUP	15-24	2	4
	25-39	50	60
	40-54	40	30
	55+	8	6
ETHNICITY	White	89	66
	Black African	6	23
	Black Caribbean	<1	3
	Black other	<1	2
	Indian/Pakistani/Bangladeshi	1	1
	Other Asian/Oriental	1	1
	Mixed	1	4
REGION OF RESIDENCE*	London	47	62
	South East	12	10
	North West	12	7
	Trent	3	3
	West Midlands	6	4
	Northern & Yorkshire	4	3
	Eastern	6	4
	South West	6	4
	Wales	3	2
	Northern Ireland	<1	<1

* SOPHID does not cover Scotland or the Channel Isles

3 Eighteen needs: an overview

The eighteen need areas explored in this study are far from comprehensive, but they provide insight into some of the key concerns of people with HIV, encompassing a range of personal, social and medical issues. This chapter summarises the results across need areas and demographic groups.

By quantifying and comparing levels of need, a pattern across the sample can be described. But such comparisons should be made with care, for three key reasons. First, each need area encompassed a range of needs that was quite narrow for some areas but was more open to interpretation for others. The incidence of need is therefore partly an artefact of the scope of meanings that any need could have for respondents. Each need chapter explores these in detail.

Second, the findings below are effectively a picture of 'unmet need'. If service providers are already doing a very good job in meeting a need, the level of need reported ought to be relatively low. Hence the levels of need reported do not necessarily reflect the pattern of service or support required in total to meet these needs.

Third, a picture of need across the population of people with HIV tells us nothing about the needs of any specific individual living with HIV. Patterns of need be different for every individual, and the significance of any single problem will vary. Many respondents expressed the importance to them of being treated as an individual with personal needs and priorities.

Despite these qualifications, the findings should challenge anyone with an interest in the lives of people with HIV to examine their own assumptions about the reality of living with HIV in the UK today.

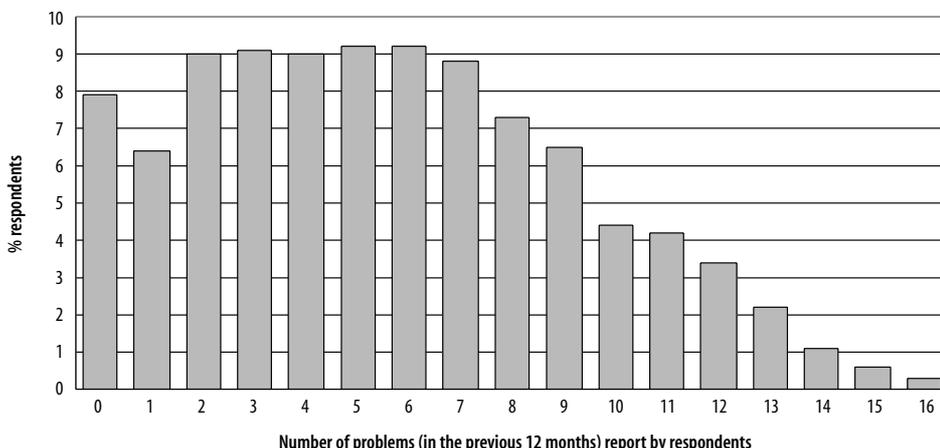
3.1 MULTIPLE NEEDS

Chart 3.1 illustrates the incidence of multiple needs within the sample, using the indicator of experience of problems. Eight per cent of all respondents did not report any problems in the need areas explored in the survey.

Although having seven needs is as common as having only two (or any level of need in between), incidence of multiple needs rapidly declines beyond this level of need.

One third (33%) of respondents identified between zero and three needs (experiences of problems), slightly over a third (37%) identified between four and seven needs and a final 30% identified between eight and sixteen needs.

CHART 3.1 Multiple incidence of problems



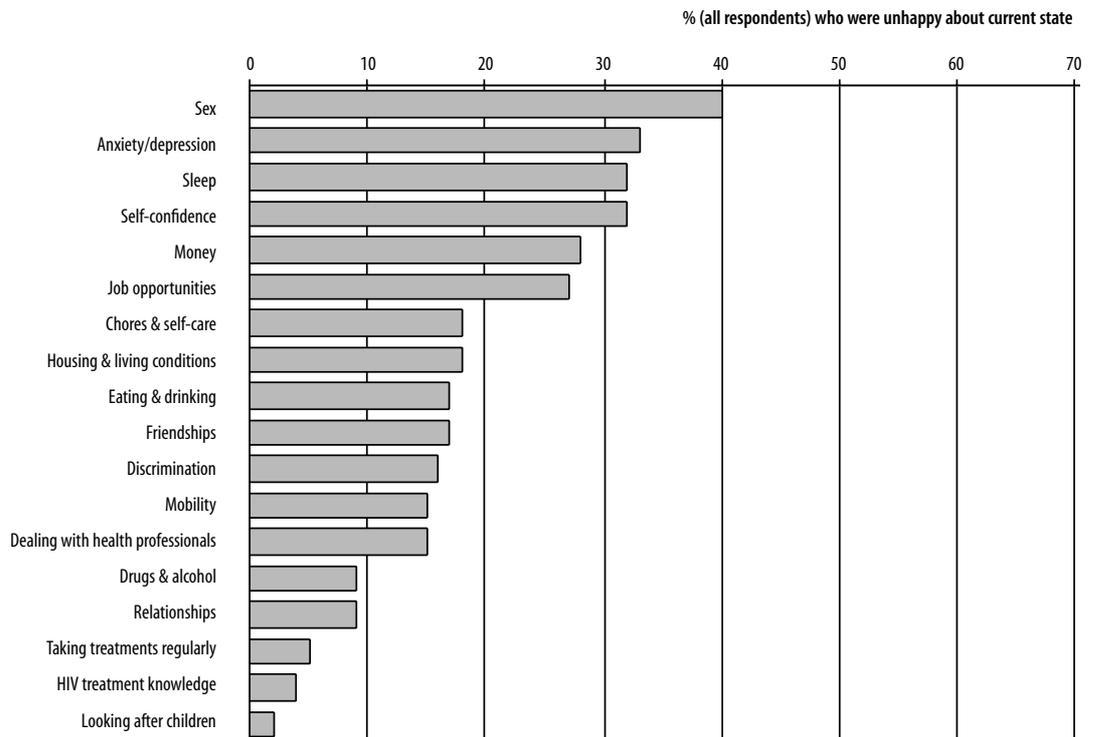
3.2 INCIDENCE OF NEEDS

The three key indicators of need used in the survey are summarised in Charts 3.2 to 3.4:

- Chart 3.2 describes how respondents felt about their current circumstances for each of the need areas. These feelings may reflect many different aspects of life including the experience of specific problems, personal acceptance of problems, the extent of available support and personal aspirations to improve personal circumstances and exploit the possibilities of life. Chart 3.2 provides the best indication of respondents' personal perceptions of need.
- Chart 3.3 describes respondents' experience of problems in each of the need areas over the previous 12 months. This chart and Chart 3.5 omit 'job opportunities' because this need area focussed on respondents' interests, not problems (see Chapter 21). Whereas Chart 3.2 is informed by many different aspects of respondents' attitudes and experience, Chart 3.3 has a single focus: the experience of problems. This focus is the strength of this indicator and makes comparison between the need areas easier.
- Chart 3.4 describes respondents' personal perceptions of their 'capacity to benefit' from further help or support. This is the most important chart for service providers, informal carers and others with an interest in addressing unmet needs.

These charts reveal that although the choice of indicator makes an important difference to the level of reported need, the pattern of needs is broadly the same for each. In particular, the top four needs – related to anxiety, sleep, sex and self-confidence – are the same for each indicator. The charts are dominated by needs that broadly concern respondents' mental health.

CHART 3.2 Feelings about current state



Charts 3.2 to 3.4 illustrate the frequency with which each of the 18 needs was reported among all respondents. However, some of the needs listed are irrelevant to a significant proportion of the sample. Consequently, the experience of those respondents for whom these needs are relevant is under-represented. In particular:

- Among the respondents living with children, 20% were unhappy about their ability to look after their children.
- Among the respondents with a partner, 17% were unhappy about their relationship.
- Among the respondents taking anti-HIV treatments, 7% were unhappy about their ability to take the treatments regularly.

CHART 3.3 Problems

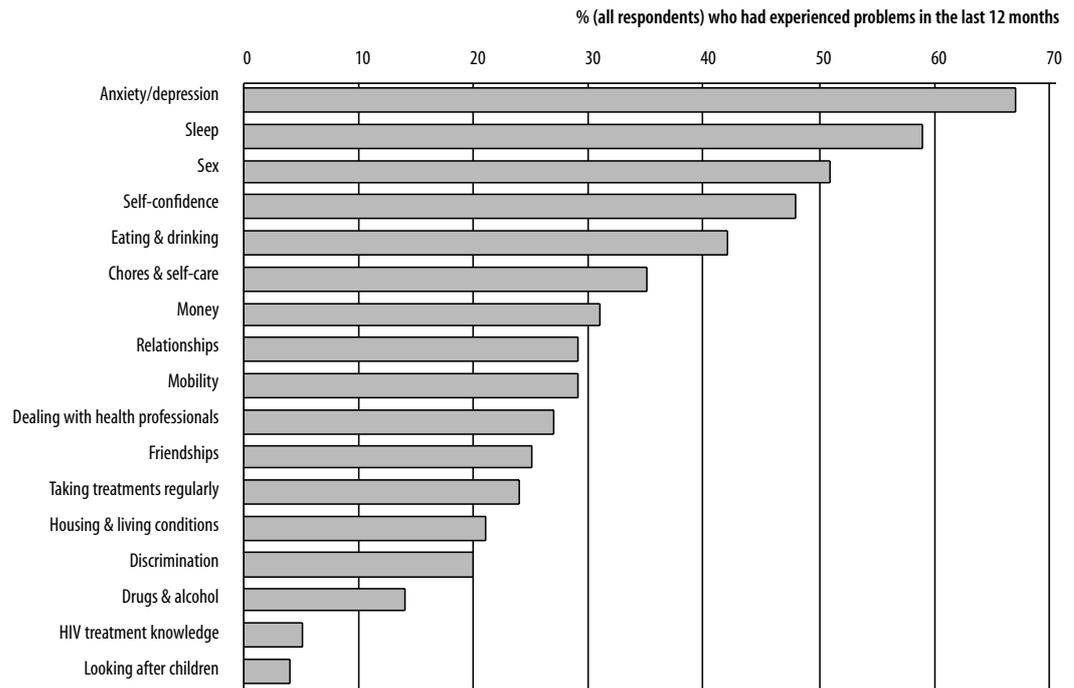
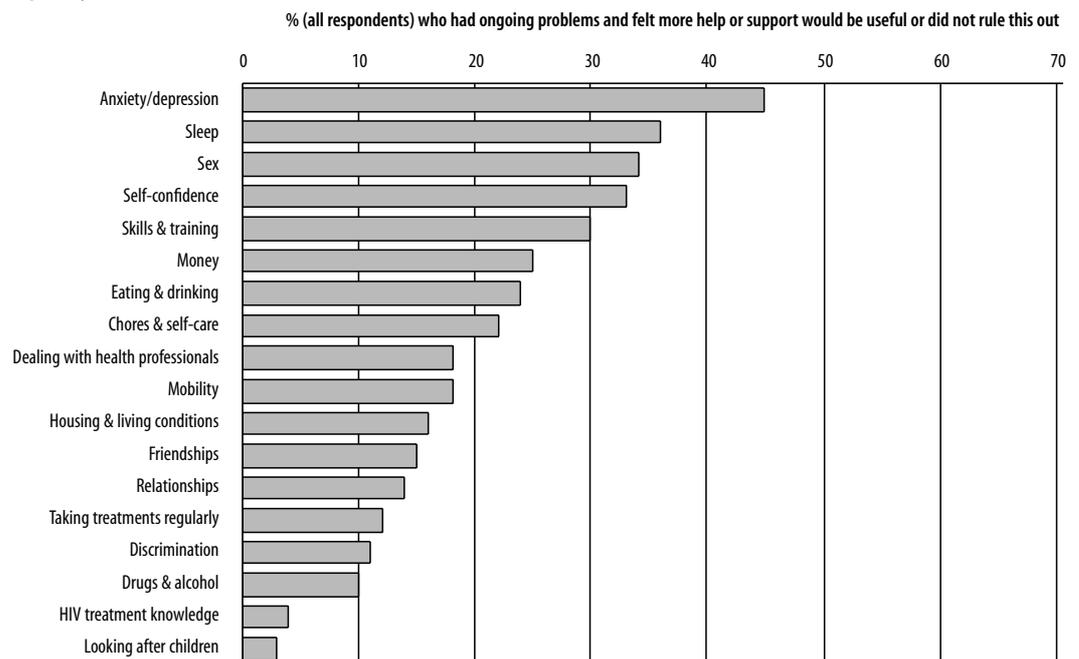


CHART 3.4 Capacity to benefit

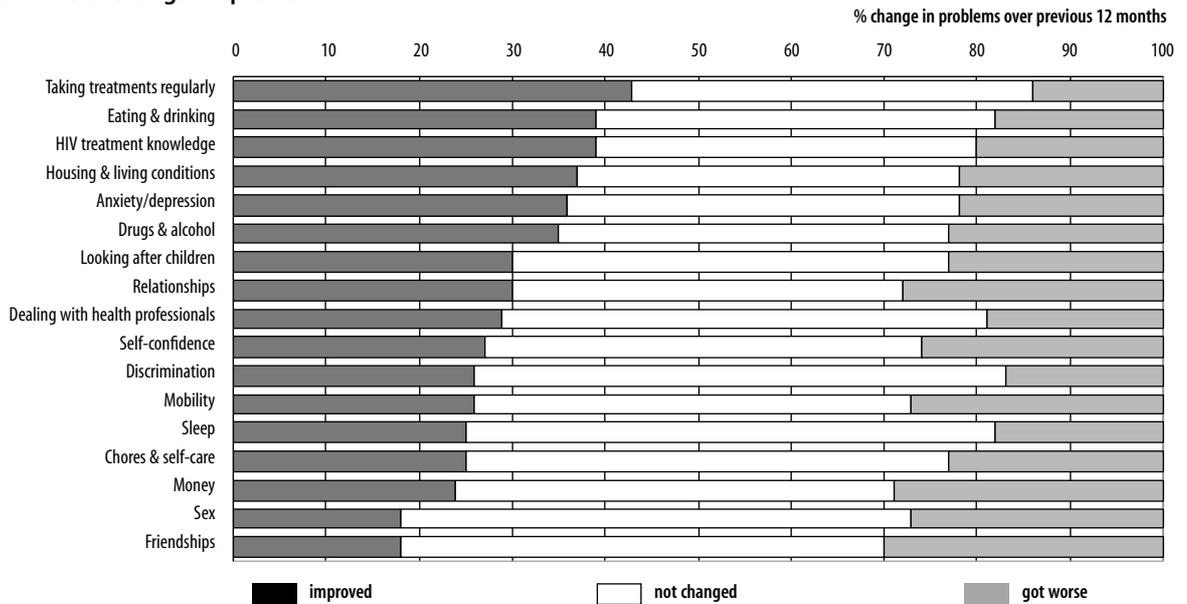


3.3 CHANGES IN NEED

Respondents' retrospective assessments of changes in their needs are summarised in Chart 3.5. The need indicator used is again experience of problems.

For each need area, there were always many respondents who had seen their problems get worse. Nonetheless, the general pattern is optimistic: improvement was more common than deterioration. For 13 need areas, problems had got better more often than they had got worse. For four needs, this pattern was reversed, i.e. problems had got worse more often than better: these needs related to friendships, sex, money and mobility.

CHART 3.5 Changes in problems



3.4 SOCIO-DEMOGRAPHIC BREAKDOWN OF NEEDS

There were considerable differences in the patterns of need between different socio-demographic groups in the sample. Table 3.6 provides a detailed account of these patterns using the indicator of experience of problems (or interest in skills and training).

Table 3.6 is designed primarily to give service providers who are working with specific target groups a clear indication of the pattern of need within those subgroups. Although it can also be used to identify differences across subgroups for any need, statistically significant differences have not been indicated. This is because a) the chart emphasises the need patterns within subgroups not across them, b) such differences are difficult to identify and interpret for multi-category variables such as location and ethnicity, and c) the chart is complicated enough already.

TABLE 3.6 Needs by demographic groups

% subsample who experienced problem in previous 12 months

	no. of respondents in subsample	anxiety/depression	sleep	sex	self-confidence	eating & drinking	(interest in) skills & training	chores/self care	money	relationships	mobility	health professionals	friendships	taking treatments regularly	housing	discrimination	drugs & alcohol	HIV treatment knowledge	looking after children
Whole sample	1821	67	59	51	48	42	39	35	31	29	29	27	25	24	21	20	14	5	4
GENDER, SEXUALITY																			
women	271	72	60	40	52	46	51	45	40	29	33	32	22	26	27	23	9	7	17
men	1550	66	59	53	47	41	37	34	30	29	28	26	25	24	20	20	15	5	1
heterosexual men	220	59	46	43	34	38	39	33	35	25	31	21	19	24	26	17	13	8	8
gay/bisexual men	1319	67	61	54	49	41	36	33	29	30	28	27	26	24	19	20	15	4	<1
LOCATION																			
London	786	68	60	55	51	41	47	35	31	31	29	26	28	24	24	20	15	5	3
South East	201	62	59	44	46	38	30	32	26	22	27	29	21	21	18	16	10	4	4
North West	205	66	60	51	44	39	37	34	32	32	29	27	20	26	16	20	15	3	3
Trent	57	71	58	45	37	50	28	39	28	30	33	22	19	40	14	19	11	4	4
West Midlands	100	67	63	43	37	38	32	45	40	26	25	29	27	17	22	23	14	7	4
Northern & Yorkshire	66	71	71	47	55	62	34	45	29	33	35	26	26	32	24	26	22	6	3
Eastern	102	63	53	56	45	41	35	29	34	28	26	25	20	22	16	26	14	4	7
South West	107	68	55	57	54	41	32	36	28	26	26	29	28	22	18	19	8	6	6
Wales	51	66	59	53	49	43	29	39	37	22	29	32	20	20	14	14	10	6	6
Scotland	105	62	56	42	43	45	29	30	31	32	33	27	18	26	21	20	15	5	4
ETHNICITY																			
Black African	113	69	56	32	43	43	73	43	60	31	35	23	21	31	50	27	6	13	26
Black Other	43	63	49	36	37	37	45	33	29	21	21	14	24	12	18	15	16	5	12
White British	1403	66	60	52	48	42	34	35	29	29	29	27	24	24	18	19	15	4	2
White Irish	52	77	58	64	73	40	56	44	35	38	27	40	30	25	25	27	25	10	2
White Other	154	67	56	55	48	37	51	31	34	31	30	32	34	26	26	22	12	5	2
Mixed race	26	76	73	58	58	48	50	31	40	23	23	31	38	27	24	27	16	0	0
SPECIAL CIRCUMSTANCES																			
Immigration probs.	65	79	65	42	59	48	79	41	72	42	48	27	33	28	62	21	11	10	18
History of IDU	126	74	73	49	53	52	50	50	40	27	48	35	30	24	33	27	38	2	6
Haemophilic	83	62	53	44	33	37	29	45	30	29	40	24	17	29	22	15	12	12	8
Living with children	173	68	51	38	46	42	47	42	40	31	34	23	11	24	26	21	8	7	40
EMPLOYMENT																			
full-time	493	59	48	49	43	29	30	18	16	31	10	27	20	20	10	17	11	5	1
part-time/self-emp.	236	64	54	45	44	32	42	20	32	29	15	26	19	19	19	19	9	3	8
not in paid emp.	1073	71	66	54	51	50	42	47	38	28	40	28	28	27	26	22	17	6	4
EDUCATIONAL QUALIFICATIONS																			
low	595	65	60	48	46	44	32	37	32	25	30	23	22	23	22	17	15	6	3
medium	564	68	62	51	49	44	43	39	34	31	31	27	25	26	23	21	14	5	4
high	650	67	57	55	49	38	41	31	29	31	26	31	27	24	19	22	13	4	3
RELATIONSHIPS																			
Does not have partner	898	69	64	54	53	45	39	39	32	21	33	28	31	26	24	21	18	6	3
Has partner	920	64	55	49	44	39	38	32	31	37	26	27	19	23	18	19	11	4	4

4 Housing and living conditions

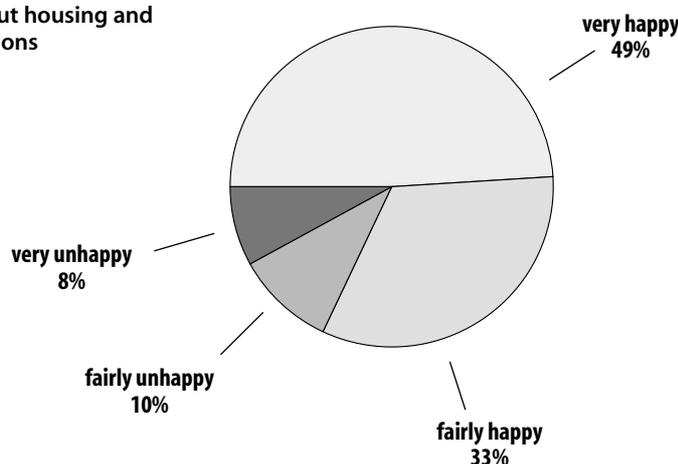
Housing is a basic need. Without shelter, both quality of life and life itself can be hard to sustain. Poor housing and living conditions are likely to increase many of the other needs of daily life. Housing need is also aspirational. Current living conditions may be enough for current life, but they may be a constraint on future possibilities, perhaps for greater independence, well-being, prosperity, social contact or family life. A need for better living conditions may reflect a desire to achieve such possibilities.

4.1 FEELINGS

Respondents were asked how they felt about their housing and living conditions. Overall, 82% felt very or fairly happy (Chart 4.1).

18% of all respondents felt unhappy about their housing or living conditions (n=319)

CHART 4.1 Feelings about housing and living conditions



4.2 PROBLEMS

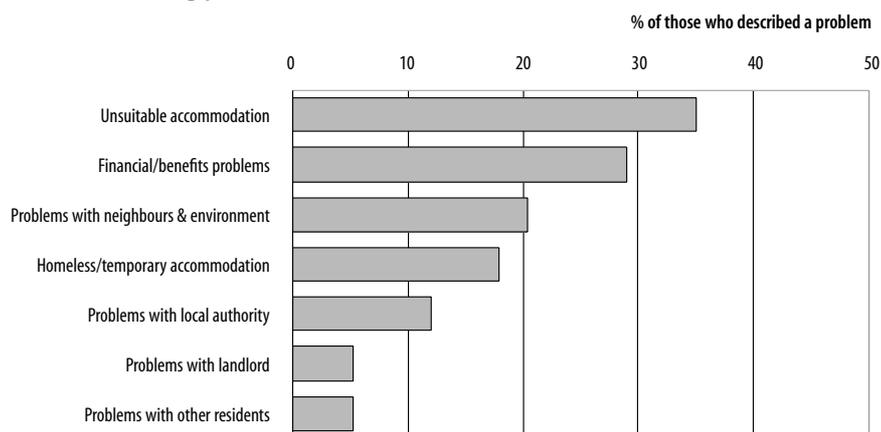
21% of all respondents had experienced housing problems in the previous 12 months (n=378)

Chart 4.2 illustrates the problems that respondents described. Sixty-four respondents (3.5% of all respondents) had experienced homelessness, which could have a profound effect on all their other needs. Homelessness usually occurred with some other form of attendant problem- insecurity, evictions, temporary accommodation, relationship break-ups, abuse or refusal of refugee status.

Accommodation was described as unsuitable because of damp, disrepair, inadequate heating, lack of equipment and problems with access or bath and toilet facilities. The immediate environment could also be debilitating, because of harassment and violence from neighbours or noise or vandalism.

Financial problems mainly concerned difficulties paying rent and mortgages or finding appropriate affordable accommodation. These problems were compounded for many by the failures of the benefits system, ranging from long and exhausting delays to mistakes leading to threats of eviction and the withdrawal of benefits at times of acute need. Beyond the difficulties of claiming benefits, local authorities were also criticized for delays in providing suitable accommodation, refusal of accommodation despite need and the inadequacies of their administration.

CHART 4.2 Housing problems



4.2.1 Changes over 12 months

Thirty-seven percent of those who had experienced problems in the previous 12 months said the problem had improved or been resolved. Most often, this was because of a move to new accommodation. Other respondents had seen changes in their financial circumstances, such as resolution of benefit problems or a return to work; improvements in the repair and condition of housing; better relationships with landlords (public or private); changes in personal relationships and constraints put on trouble-makers.

For 22% of those who had experienced problems, things had got worse. This was often because the people with a responsibility to deal with the problem – the council or landlord – had ignored or exacerbated it. However many respondents also described worsening health, physical or psychological, as a key problem, increasing their need for more suitable accommodation when existing problems remained unresolved.

At the time of the survey, 55% of those who had experienced housing problems felt unhappy with their housing or living conditions (72% of those whose problems had not improved). Among those who did not report any housing problems, 8% were nonetheless unhappy about their housing and living conditions, suggesting a strong aspirational quality to housing need.

4.3 GETTING HELP

Among the respondents who had experienced housing problems in the previous 12 months, 63% had received some form of help to deal with these (Table 4.3). This leaves 37% who had not received any help, or:

7% of all respondents had experienced housing problems in the previous 12 months and had not received any help to address these problems (n=139)

The ‘other’ sources of help included housing associations, solicitors, the police, local councillors and MPs.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or

TABLE 4.3 Sources of help in dealing with housing problems

Source of help	no.	% those with a problem
HIV organisation	114	(30)
council/social services	112	(30)
friends	69	(18)
clinic/hospital	47	(12)
partner	44	(12)
GP	33	(9)
advice or counselling agency	33	(9)
parents	24	(6)
other family	20	(5)
self-help group	14	(4)
telephone helpline	12	(3)
children	3	(<1)
other	45	(12)

overcome their problems. Nine percent did not think that any further help would make any difference. The remainder either felt that more help would make a difference (80%) or did not know what might be gained (12%). Combining these last two groups, we can say that overall:

16% of all respondents had ongoing housing problems and felt that further help or support would be useful, or did not rule this out (n=284)

The most common suggestion was for a permanent solution: re-housing somewhere safe, secure and, for some, with appropriate support to cope with illness and disability. Some respondents wanted statutory authorities to meet their obligations to provide social housing to those in need without excessive delay, while others focussed more on the basics of the service they delivered, seeking a supportive, helpful, non-discriminatory response, sensitive to the needs of people with HIV. They wanted more information and advice, greater transparency and more specialist support. Those for whom the fundamental problem was money typically suggested greater financial assistance. Those who faced insecurity because of their immigration status wanted this resolved, as quickly as possible.

4.4 SUMMARY

Of all the respondents to the survey:

- **18%** felt unhappy about their housing and living conditions
- **21%** had experienced housing problems in the previous 12 months
- **16%** had ongoing housing problems and felt that further help or support would be useful, or did not rule this out

5 Eating and drinking

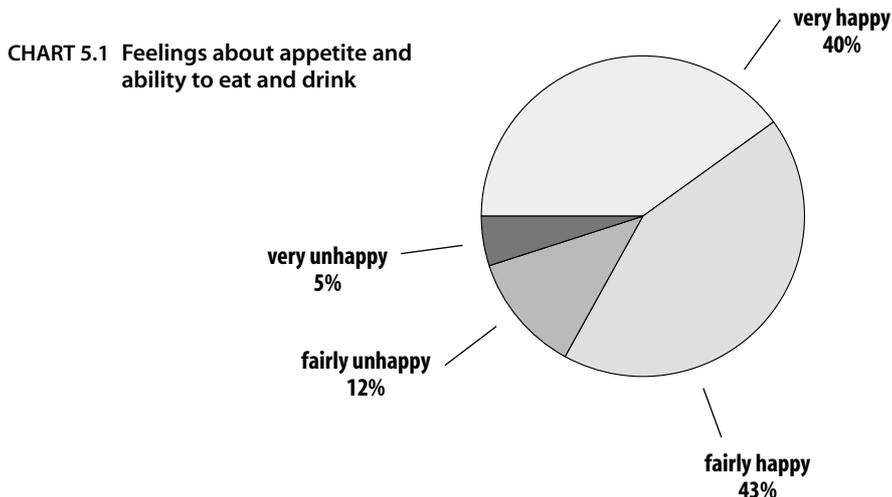
Everyone has a daily need for sustenance, fulfilled through eating and drinking. But if eating or drinking become difficult, because of loss of appetite or physical problems, the need remains. The need may also remain if food is unattainable, though this is a lesser problem in the UK.

Problems with appetite and ability to eat and drink have the potential to be very damaging if they lead to weight loss and vulnerability to illness. This basic need can affect all other needs in daily life including health, mobility and well-being.

5.1 FEELINGS

Respondents were asked how they felt about their appetite and ability to eat and drink. Overall, 83% felt very or fairly happy (Chart 5.1).

17% of all respondents felt unhappy about their appetite and ability to eat and drink (n=308)



5.2 PROBLEMS

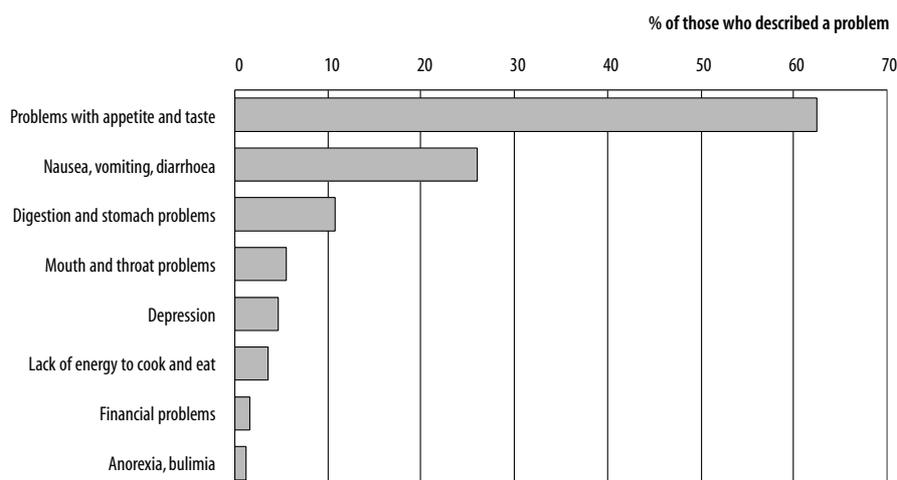
42% of all respondents had experienced problems with their appetite or ability to eat and drink in the previous 12 months (n=756)

Among these respondents, 663 had appetite problems and 220 had physical problems with eating or drinking. Chart 5.2 illustrates the range of problems described. Problems with appetite and taste included problems that arose from taking HIV treatments and problems created by illness or specific conditions. Treatment side effects and associated illnesses are also implicated in many of the other problems described – nausea and vomiting, digestion problems (e.g. reflux, bloating, constipation, ulcers) and mouth and throat problems (e.g. thrush, sore gums, inability to swallow).

Although relatively few respondents specifically mentioned depression, the general loss of appetite reported by many respondents is likely to reflect a range of mental health problems as well as specific physical or pharmacological causes.

Very few respondents mentioned a lack of money as the main reason for their difficulty eating properly though some Africans reported difficulties affording African foods. Insufficient energy needed to shop, cook and eat food was a greater problem.

CHART 5.2 Problems with appetite and ability to eat and drink



5.2.1 Changes over 12 months

Two fifths (39%) of those who had experienced problems in the previous 12 months said the problem had improved or been resolved. For some, changes in lifestyle had helped such as a better diet and eating patterns, better stress management, giving up smoking, taking more exercise or a change in living conditions. Others simply reported better general health. However, for most respondents, improvements were down to treatment, one way or another. Whereas some had seen their health and appetite improve through starting anti-HIV treatments or dealing with specific illnesses, others had gained from changing the anti-HIV treatments they were taking. Medications that addressed the immediate problem, such as anti-nausea pills and thrush treatments, had also helped.

For 18% of those who had experienced problems, things had got worse. Starting or changing medications and coping with side effects was a common reason. However many also described increasing unhappiness or depression as the source of the problem, created by a deterioration in health or by the loss of important people or sources of support. Worsening health could become a vicious circle if it led to loss of appetite and further vulnerability to both physical and emotional stress.

At the time of the survey, 39% of those who had experienced problems were unhappy about their appetite and ability to eat and drink (56% of those whose problems had not improved). Among those who did not report any problems, only 2% were unhappy about their ability to eat or drink.

5.3 GETTING HELP

Among the respondents who had experienced problems with their appetite or ability to eat and drink in the previous 12 months, two thirds (65%) had received some form of help to deal with these problems (Table 5.3). This leaves 35% of those with problems who had not received any help, or:

15% of all respondents had experienced problems with their appetite and ability to eat and drink in the previous 12 months and had not received any help to address these problems (n=267)

The 'other' sources of help included dieticians, dentists, counsellors and a range of complementary therapies (acupuncture/ traditional Chinese medicine, colonic irrigation, homoeopathy, hypotherapy, kinesiology, reflexology) and cannabis.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Thirty percent did not think that any further help would make any difference. The remainder either felt that more help would make a difference (37%) or did not know what might be gained (32%). Combining these last two groups, we can say that overall:

24% of all respondents had ongoing problems with their appetite or ability to eat and drink and felt that further help or support would be useful, or did not rule this out (n=442)

Suggestions for what might help were very diverse. At this point, many more respondents identified financial problems as the limiting factor on the quality of their food intake.

Respondents also wanted a better service from professionals: more personalised care and greater sensitivity to the impact of side effects; better advice on eating and nutrition; and more support in coping with the basic challenges of daily life, including shopping and cooking. Improvements were also sought in living conditions, stress levels, emotional support and exercise. Medications still got their mention – starting anti-HIV treatments, finding treatments with fewer side effects, overcoming specific illnesses, stimulating appetite and energy or getting off treatment altogether.

5.4 SUMMARY

Of all the respondents to the survey:

- 17% felt unhappy about their appetite and ability to eat and drink
- 42% had experienced problems with their appetite or ability to eat and drink in the previous 12 months
- 24% had ongoing problems with their appetite or ability to eat and drink and felt that further help or support would be useful, or did not rule this out.

TABLE 5.3 Sources of help in dealing with appetite and eating/drinking problems

Source of help	no.	% those with a problem
clinic/hospital	338	(45)
partner	139	(18)
GP	132	(17)
friends	116	(15)
HIV organisation	108	(14)
parents	56	(7)
other family	44	(6)
council/social services	37	(5)
advice or counselling agency	29	(4)
self-help group	25	(3)
children	20	(3)
telephone helpline	9	(1)
other	69	(9)

6 Sleep

Sleep is a fundamental human need. Different people may require very different amounts, but everyone needs regular sleep to survive and thrive.

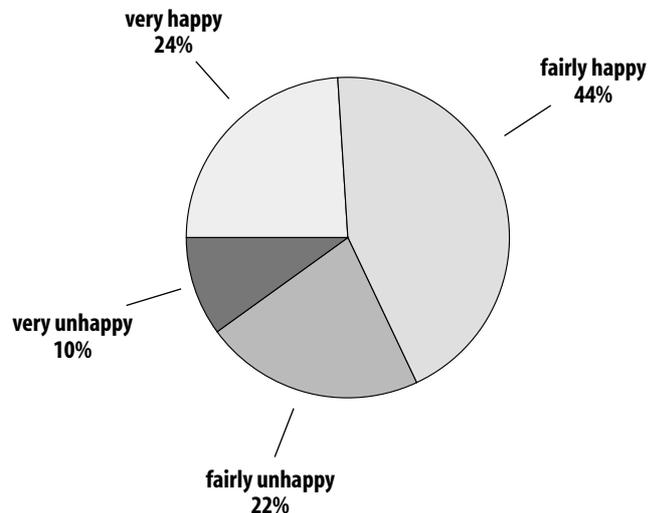
Lots of people who sleep well have aspirations about their sleep – wanting more of it or wishing they could live with less of it. But the need for sleep is most acutely felt by people who do not sleep well, for whom sleep disturbances can seriously undermine quality of life.

6.1 FEELINGS

Respondents were asked how they felt about their ability to sleep as and when they wanted to. Overall, 68% of respondents were very or fairly happy (Chart 6.1).

32% of all respondents were unhappy about their ability to sleep as and when they wanted to (n=570)

CHART 6.1 Feelings about ability to sleep



6.2 PROBLEMS

59% of all respondents had experienced sleep problems in the previous 12 months (n=1072)

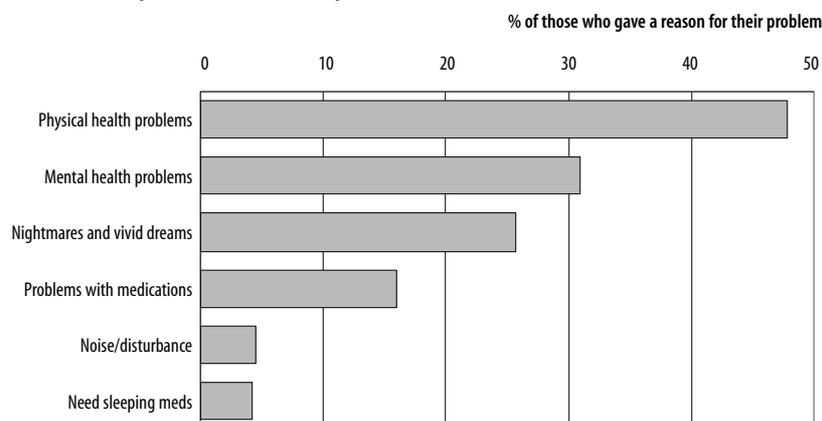
Most problems concerned insomnia of one form or other: restlessness and lack of sleep; intermittent and disturbed sleep; problems going to sleep or waking early; and irregular sleeping patterns. For a few respondents, fatigue and exhaustion led to long periods spent asleep and difficulties staying awake or getting up.

Some respondents also described the reason (or reasons) for their sleeping problems (Chart 6.2). A wide range of physical health problems were described including various forms of pain and soreness (e.g. neuropathy, arthritis, aching bones), nausea and vomiting, skin irritations and regular trips to the toilet. However, fevers and night sweats were much the most common physical cause of sleep disturbance, identified by 8% of all respondents.

Mental health problems included stress, anxiety, inability to relax, panic attacks and depression. Worry generated insomnia but insomnia also created more opportunities to worry. There were plenty of things to worry about in the night, such as health and illness, relationships and children, money and housing conditions and, inevitably, HIV and mortality.

The biggest single mental health problem is described separately in Chart 6.2: nightmares and vivid dreams, mentioned by 7% of all respondents. There is considerable overlap between this category and 'problems with medications' as several respondents specifically identified Efavirenz as the cause of these vivid dreams. The side effects of many other treatments also disturbed sleep, but only a few respondents mentioned the timing requirements of their treatment regimens as a cause of sleep problems.

CHART 6.2 Reasons for problems with sleep



6.2.1 Changes over 12 months

A quarter (25%) of those who had experienced problems with sleep in the previous 12 months said that the problem had improved or been resolved. Many improvements were due to changes in respondents' lives and outlook, such as changing HIV treatments or adapting to treatment regimens; better health and self-confidence; and changes in personal circumstances such as starting work, taking time off work, moving house or separating from a partner. More direct strategies for dealing with sleeping problems included taking sleeping pills or anti-depressants; getting counselling or more social support; and the use of complementary therapies (acupuncture, aromatherapy, massage, yoga, relaxation techniques) and cannabis.

For 18% of those who had experienced problems, things had got worse. The reasons for deterioration included HIV diagnosis, starting or changing treatments, side effects, pain, depression and the many worries of life such as poverty, housing problems, work pressures and the demands of living with others.

At the time of the survey, 53% of those who had experienced problems were unhappy about their ability to sleep (63% of those whose problems had not improved). Among those who did not report any problems, only 1% were unhappy about their ability to sleep.

6.3 GETTING HELP

Among the respondents who had experienced sleep problems in the previous 12 months, 57% had received some form of help to address these problems (see Table 6.3). This leaves 43% who had not received any help, or:

25% of all respondents had experienced sleep problems in the previous 12 months and had not received any help to address these problems (n=458)

The 'other' sources of help included sleeping pills, psychiatry, counselling and complementary therapies (acupuncture/traditional Chinese medicine, homoeopathy, herbal medicine, kinesiology, relaxation techniques, hypnotherapy) and cannabis.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Thirty-one percent did not think that any further help would reduce or overcome their problems. The other two thirds either felt that more help would reduce their problems (35%) or did not know what might be gained (34%). Combining these last two groups, we can say that overall:

36% of all respondents had ongoing sleep problems and felt that further help or support would be useful, or did not rule this out (n=658)

Suggestions of what might help were similar to the reasons for actual improvements described above. Some felt that changes in their lives were needed, such as changes in treatment, employment, housing, income, debt, relationships and social support. Others focussed more on interventions that might reduce the immediate problem: sleeping pills, counselling, relaxation techniques and various complementary therapies.

TABLE 6.3 Sources of help in dealing with problems sleeping

Source of help	no.	% those with a problem
clinic/hospital	358	(33)
GP	222	(21)
partner	89	(8)
HIV organisation	86	(8)
friends	76	(7)
advice or counselling agency	41	(4)
parents	33	(3)
council/social services	30	(3)
other family	28	(3)
self-help group	17	(2)
children	8	(<1)
telephone helpline	7	(<1)
other	85	(8)

6.4 SUMMARY

Of all the respondents to the survey:

- **32%** were unhappy about their ability to sleep as and when they wanted to
- **59%** had experienced sleep problems in the previous 12 months
- **36%** had ongoing sleep problems and felt that further help or support would be useful, or did not rule this out.

7 Household chores and self-care

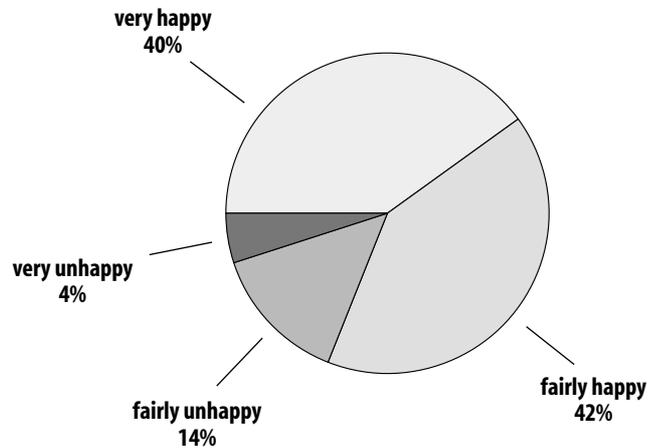
To get through the day, we all have to manage a steady succession of tasks from washing and dressing to shopping, cooking and cleaning. Some of the tasks can be put off (at least until tomorrow) whereas others, particularly those relating to self-care, are more critical to maintaining independence and quality of life.

7.1 FEELINGS

Respondents were asked how they felt about their ability to do household chores and look after themselves (with any help they were getting). Overall, 82% felt very or fairly happy (see Chart 7.1).

18% of all respondents felt unhappy about their ability to do household chores or look after themselves (n=327)

CHART 7.1 Feelings about ability to do chores and self-care

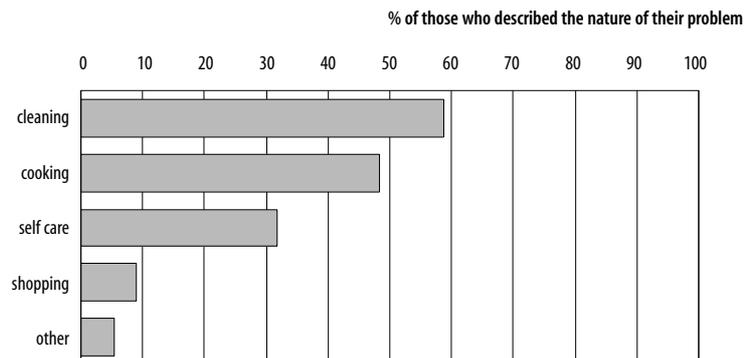


7.2 PROBLEMS

35% of all respondents had experienced problems doing household chores or looking after themselves in the previous 12 months (n=639)

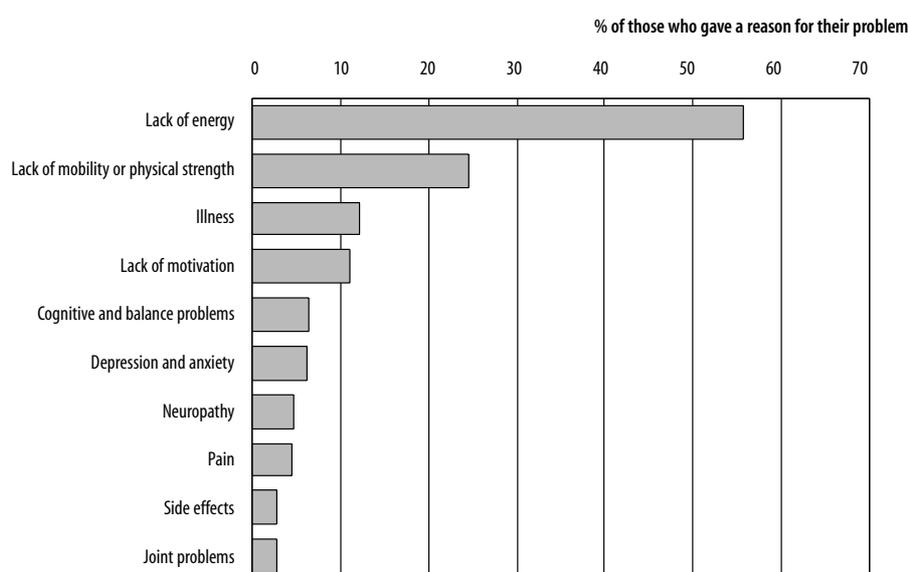
Problems with household cleaning and cooking were most common, followed by problems related to self-care including difficulties dressing, bathing and washing (Chart 7.2).

CHART 7.2 Problems with household chores and self-care



Many respondents also identified the reasons for these problems (Chart 7.3). The main reason was fatigue and lack of energy, often closely linked to loss of mobility and physical strength, illness, or lack of motivation. Debilitating illnesses included opportunistic infections of HIV disease and the demands of other chronic illnesses such as haemophilia (also reflected in the joint problems), asthma and arthritis. However, most illness was described in more general terms: fevers, nausea and feeling unwell. The impact of illness, pain, neuropathy and side effects is clear not only in the extent of reported fatigue but, more profoundly, in the losses of strength and mobility.

CHART 7.3 Reasons for problems with household chores and self-care



7.2.1 Changes over 12 months

A quarter (25%) of those who had experienced problems in the previous 12 months said that their problems had improved or been resolved. This was usually because of better health and/or mobility, which for many reflected the success of treatment or a change in treatment. Improvements had also been achieved through getting domestic help from the council, voluntary services or friends and family. Stress reduction, greater personal motivation and better housing were also mentioned.

For 23% of those who had experienced problems, things had got worse. The reasons mirror those just described: deteriorating health, mobility and energy; loss of domestic support services; more frequent depression; and poor living conditions.

At the time of the survey, half (49%) of those who had experienced problems felt unhappy about their ability to do household chores and look after themselves (61% of those whose problems had not improved). Among those who did not report any problems, only 2% were unhappy about their ability to do household chores or look after themselves.

7.3 GETTING HELP

Among the respondents who had experienced problems in the previous 12 months, three fifths (60%) had received some form of help to deal with these problems (see Table 7.4). This leaves 40% of those with problems who had not received any help, or:

14% of all respondents had experienced problems doing household chores or looking after themselves in the previous 12 months and had not received any help to address these problems (n=253)

The 'other' sources of help were mostly commercial cleaners or home-care agencies.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Twenty-nine percent did not think that any further help would make any difference. The remainder either felt that more help would make a difference (46%) or did not know what might be gained (25%). Combining these last two groups, we can say that overall:

22% of all respondents had ongoing problems doing household chores or looking after themselves and felt that further help or support would be useful, or did not rule this out (n=395)

TABLE 7.4 Sources of help with household chores and self-care

Source of help	no.	% those with a problem
partner	150	(23)
council/social services	116	(18)
friends	115	(18)
clinic/hospital	74	(12)
HIV organisation	67	(10)
parents	49	(8)
other family	42	(7)
GP	40	(6)
children	25	(4)
advice or counselling agency	18	(3)
self-help group	12	(2)
telephone helpline	3	(<1)
other	50	(8)

Respondents' suggestions of what might help mostly reflected an acceptance of current health and mobility problems and a desire to cope as best as possible with these, though some respondents wanted better treatment or access to physiotherapy or complementary therapies.

Home help of all kinds was suggested – including cleaning, laundry, cooking, shopping, childcare, gardening and odd jobs. Many respondents who were getting nothing felt that even a relatively small amount of regular help would ease the pressure on them. The obstacles to getting a service included lack of local information and unmanageable costs. Some of those who were already getting help wanted a better quality of service: home carers who actually cared and showed understanding of personal needs.

Improvements in housing and living conditions were also suggested, including both rehousing and enhancements to the suitability of existing facilities – showers, washing machines, etc. However it was changes in lifestyle and social relations that others wanted: getting a partner, a job or a better social network were perceived to be routes to increasing personal motivation and control over daily life.

7.4 SUMMARY

Of all the respondents to the survey:

- 18% felt unhappy about their ability to do household chores or look after themselves
- 35% had experienced problems doing household chores or looking after themselves in the previous 12 months
- 22% had ongoing problems doing household chores or looking after themselves and felt that further help or support would be useful, or did not rule this out.

8 Mobility

Mobility is integral to a variety of needs: sustaining an active life, obtaining the necessities of life on a regular basis, accessing services and maintaining friendships and relationships. The extent to which these various needs can be met following loss of mobility, and the importance that different people attach to these needs, will reflect the overall need for mobility.

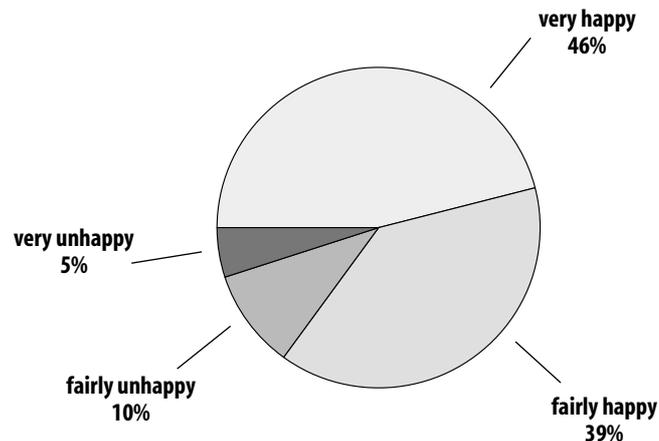
Although loss of mobility can be a serious problem for someone within their own home, the survey took a broader perspective, asking respondents about their ability to get around locally – to hospital, the shops, services and to see friends.

8.1 FEELINGS

Respondents were asked how they felt about their ability to get around locally. Overall, 85% felt either very or fairly happy (Chart 8.1)

15% of all respondents felt unhappy about their ability to get around locally (n=270)

CHART 8.1 Feelings about ability to get around locally



8.2 PROBLEMS

29% of all respondents had experienced mobility problems in the previous 12 months (n=525)

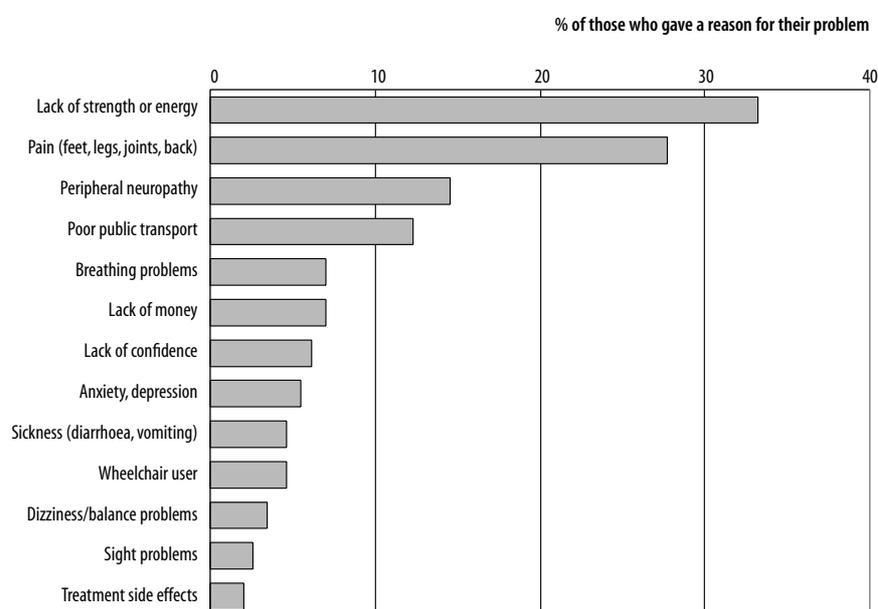
Respondents had problems with a wide range of daily activities: walking (widely identified), getting to shops and services, visiting friends and family, driving, carrying shopping and using public services.

Chart 8.2 illustrates the diversity of reasons for these mobility problems. They were often inter-related: although lack of strength, lack of energy, chronic pain and peripheral neuropathy were the most common problems, in many cases these physical problems were compounded by lack of money and/or poor public transport. Although physical problems increased the need for public transport, they also made public transport harder to use, especially if the service was unreliable or insensitive to less able users.

Mental health problems could also be debilitating and isolating. Anxiety and depression could easily be exacerbated by the prospect of having to leave the house and cope with the world. Respondents described agoraphobia, panic attacks, lack of confidence and insecurity or paranoia in crowds or social contexts.

The complexity of these inter-related problems was reflected in very diverse individual needs of respondents. Differences in personal circumstances and personal resources – strength, energy, money – made big differences to respondents’ ability to cope with the impact of illness and disability. Not only was the impact of HIV very different across the respondents, many were also dealing with other physical health problems such as haemophilia or arthritis and/or mental health problems.

CHART 8.2 Reasons for mobility problems



8.2.1 Changes over 12 months

A quarter (26%) of respondents who had experienced problems said the problem had improved or been resolved. The majority had seen improvements in their health, often linked to starting or changing a treatment regimen. Better diets, physiotherapy, exercise and gym sessions had also helped. Others had managed to get better access to transport – learning to drive, buying or obtaining a motability car, obtaining a taxi card – or had got more support from partners, friends or carers.

For 27% of those who had experienced problems, things had got worse. This was almost always because of a deterioration in health, although a few respondents mentioned increased financial problems, greater isolation and loss of local services, transport or shops.

At the time of the survey, half (49%) of those who had experienced problems were unhappy about their ability to get around locally (58% of those whose problems had not improved). Among those who did not report any mobility problems, only 2% were unhappy about their ability to get around locally.

8.3 GETTING HELP

Among the respondents who had experienced problems getting around locally in the previous 12 months, two thirds (66%) had received some form of help to deal with these problems (see Table 8.3). This leaves 34% of those with problems who had not received any help, or:

10% of all respondents had experienced problems getting around locally in the previous 12 months and had not received any help to address these problems (n=175)

The 'other' sources of help included carers, support workers, neighbours and buddies provided by HIV organisations; improvements in access to transport (taxi cards, motability cars, driving lessons); and therapeutic interventions such as physiotherapy, chiropody, psychiatry and a few complementary therapies (massage, acupuncture, osteopathy, chiropractic, reflexology).

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome them. Thirty-two percent did not think that any further help would make any difference. The remainder either felt that more help would make a difference (47%) or did not know what might be gained (22%). Combining these last two groups, we can say that overall:

18% of all respondents had ongoing mobility problems and felt that further help or support would be useful, or did not rule this out (n=321)

There were many suggestions for improving access to transport. These included enabling use of public transport through provision of travel passes and increasing the opportunities for independent travel, for example through motability cars, orange badges, better parking for disabled drivers, money for taxis or taxi cards and better hospital or volunteer transport. For some, the difficulty of getting to services and shops and frustration with available transport was reflected in a desire to move nearer to them.

Various other forms of support were described, reflecting the diversity of mobility problems described above. Some respondents wanted to overcome their problems through improving health and strength, and so identified better treatment or surgery, exercise programmes and physiotherapy. Others wanted more support in coping with their current disability through provision of more appropriate housing, home helps (especially for shopping) and childcare.

Personal support in building confidence and overcoming isolation was also important. This took many forms – suggestions included a partner, friends, local support groups and one-to-one support in (re-) learning how to drive or use public transport.

8.4 SUMMARY

Of all the respondents to the survey:

- **15%** felt unhappy about their ability to get around locally
- **29%** had experienced mobility problems in the previous 12 months
- **18%** had ongoing mobility problems and felt that further help or support would be useful, or did not rule this out.

TABLE 8.3 Sources of help in dealing with mobility problems

Source of help	no.	% those with a problem
clinic/hospital	131	(25)
friends	125	(24)
partner	113	(22)
HIV organisation	89	(17)
council/social services	69	(13)
GP	59	(11)
other family	48	(9)
parents	47	(9)
self-help group	22	(4)
advice or counselling agency	15	(3)
children	14	(3)
telephone helpline	1	(<1)
other	44	(14)

9 Money – getting enough to live on

Strictly, no-one needs money, but the things that money can buy. Nonetheless, when money is in short supply, this is commonly felt as a need, particularly when the available cash drops below the threshold required to maintain the basics of daily life.

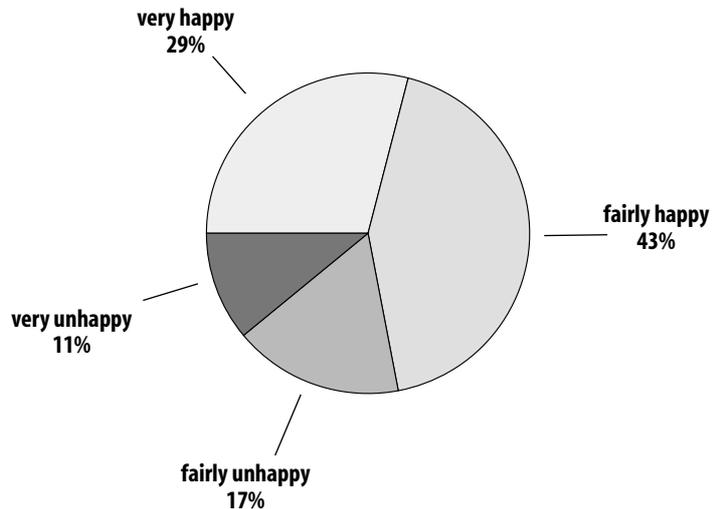
The emphasis of the survey was on getting ‘enough money to live on’. However, individual interpretations of this will vary, depending both on personal circumstances and personal aspirations. How much money you feel you need ‘to live on’ will reflect the costs of your current life and your sense of the greater possibilities of life, especially if you are currently coping with very little income.

9.1 FEELINGS

Respondents were asked how they felt about the money they got to live on. Overall, 72% felt very or fairly happy (Chart 9.1).

28% of all respondents felt unhappy about the money they were getting to live on (n=500)

CHART 9.1 Feelings about personal income



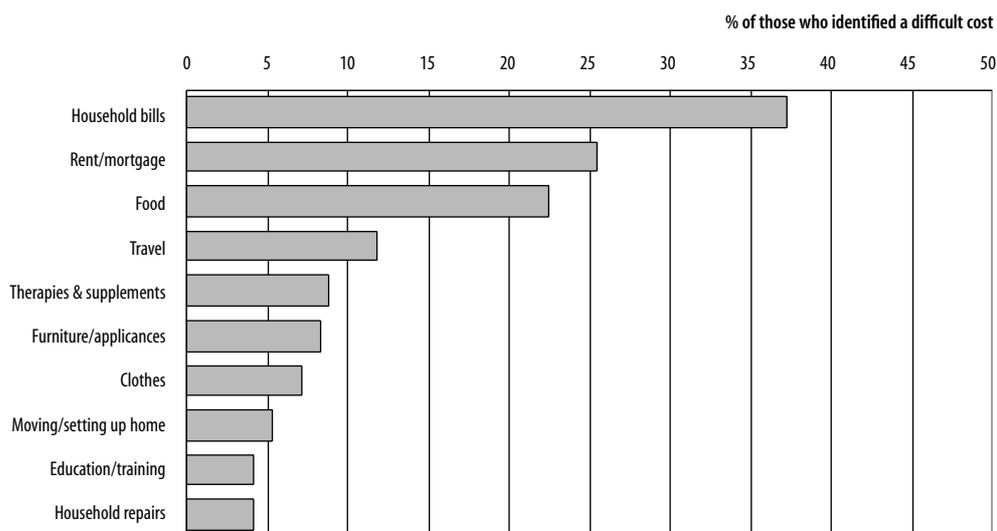
9.2 PROBLEMS

31% of all respondents had experienced problems getting enough money to live on in the previous 12 months (n=567)

Most problems were described in terms of the inadequacy of personal income and/or the difficulty of meeting the costs of living. The respondents with the lowest incomes were those seeking leave to remain in the UK, who were denied the opportunity to work and had to survive on vouchers and whatever social support they could find. However, the tension between income and costs was felt by respondents in many other circumstances, including some who were in paid employment. Benefits, pensions, vouchers, sick pay, savings, student loans and salaries were all singled out as being insufficient to meet personal needs. The majority of complaints about income were, however, focussed on the value of welfare benefits.

The costs that were most often identified as being difficult to meet were household bills, rent (or mortgage) and food (Chart 9.2).

CHART 9.2 Costs that are difficult to meet



The struggle to meet daily costs of living was compounded for some by debt and exclusion from financial services including mortgages, loans, (life) insurance, pensions and even bank accounts.

There was also very widespread dissatisfaction with welfare benefits administration. Failings included lengthy delays and administrative mistakes; the insensitivity and bureaucracy of the system; and refusal, withdrawal or depletion of specific benefits, particularly Disability Living Allowance. Collectively these problems provided no incentive to enter employment (especially part-time) since the prospect of the loss of benefits and likely difficulties of re-claiming them created a 'benefits trap'. Among some respondents this led to the frustration that they felt too sick to work full-time, but too well to stay at home all day.

9.2.1 Changes over 12 months

A quarter (24%) of the respondents who had experienced problems getting enough money to live on in the previous 12 months said that their problems had improved or been resolved. The most common reason for improvement was the award of a new benefit, restoration of old benefits or the resolution of problems obtaining benefits. Other respondents had moved in the other direction: giving up benefits for employment. Income improvements were also achieved through new sources of personal support, pay rises and debt clearance.

For 29% of those who had experienced problems, things had got worse. The dominant problems described by these respondents were the increased costs of living and burgeoning personal debt, both of which put ever greater pressure on static or declining incomes. Many respondents had lost crucial income through job losses, benefit reductions and the depletion of savings. Confidence in managing financial problems could also be undermined by illness, fatigue and depression.

At the time of the survey, three quarters (76%) of those who had experienced problems felt unhappy about the money they were getting to live on (88% of those whose problems had not improved). Among those who did not report any problems, 6% were unhappy about the money they were getting to live on, reflecting the aspirational character of the need for money.

9.3 GETTING HELP

Among the respondents who had experienced problems in the previous 12 months, 52% had received some form of help to deal with these problems (Table 9.3). This leaves 48% of those with problems who had not received any help, or:

15% of all respondents had experienced problems getting enough money to live on in the previous 12 months and had not received any help to address these problems (n=266)

The 'other' sources of help included the Department of Social Security, charities (for small grants and other payments) and Citizens Advice Bureaux.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Nine percent did not think that any further help would make any difference. The remainder either felt that more help would make a difference (76%) or did not know what might be gained (15%). Combining these last two groups, we can say that overall:

25% of all respondents had ongoing problems getting enough money to live on and felt that further help or support would be useful, or did not rule this out (n=451)

The obvious answer to the question 'what would help?' was simply more money. However, most respondents identified specific ways in which this could be realised. The most common wish was for an increase in the rates paid by benefits or fairer adjudication about personal entitlements to benefits. Many respondents said they wanted the benefits system to be more flexible and sensitive to the reality of living with HIV, especially for those who wanted to start working part-time but were concerned about the impact of this on their health – i.e. those facing the 'benefits trap'. Respondents also suggested improvements in the speed of the benefits system, the attitudes and understanding of staff to people with health problems and the availability of advice or counselling about benefits, debt and other money problems.

The respondents who were constrained by the Home Office typically wanted to get work but could not do so because of pending immigration applications or appeals. Many others saw employment as the way forward, expressed by some as a desire for training and advice in getting back to work. Those who were already in work wanted better working conditions to cope with managing HIV.

Poor or costly housing was mentioned by several respondents as the main drain on their resources. Others described aspirations for childcare, better nutrition, holidays and respite care for partners and carers.

9.4 SUMMARY

Of all the respondents to the survey:

- 28% felt unhappy about the money they were getting to live on
- 31% had experienced problems getting enough money to live on in the previous 12 months
- 25% had ongoing problems getting enough money to live on and felt that further help or support would be useful, or did not rule this out.

TABLE 9.3 Sources of help with problems getting enough money to live on

Source of help	no.	% those with a problem
HIV organisation	130	(23)
council/social services	77	(14)
partner	71	(13)
friends	65	(11)
parents	56	(10)
clinic/hospital	34	(6)
advice or counselling agency	34	(6)
other family	25	(4)
self-help group	8	(1)
telephone helpline	8	(1)
children	6	(1)
GP	5	(<1)
other	34	(6)

10 Drugs and alcohol

For many people, drugs and alcohol are experienced as a regular need: 'I need a drink' is a familiar refrain. This implies that alcohol and drugs are closely linked to other needs for relaxation, stress-management, social contact, etc. As such, they can be seen as offering solutions to other problems, support for other needs. However, drugs and alcohol are also commonly identified as problems that create needs. Dependence on, or excess use of, drugs or alcohol can affect many other daily needs such as health, self-confidence and well-being. Serious problems with drugs or alcohol can impact on all aspects of daily life.

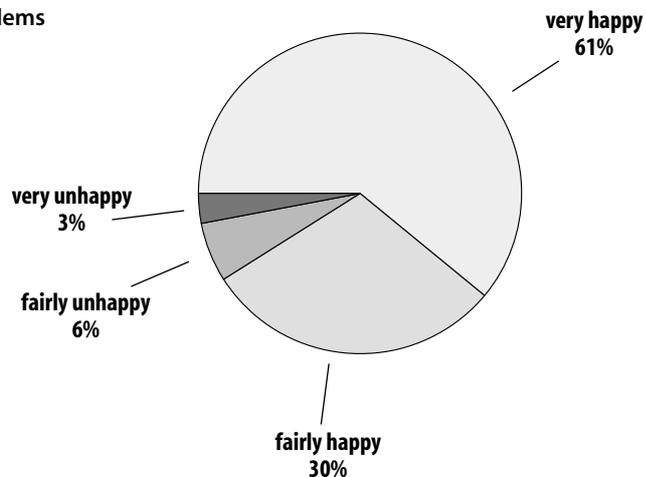
This section examines respondents' problems with drugs and alcohol and their feelings about their ability to cope with such problems. This focus on problems excludes any consideration of respondents' feelings about the positive impact of drugs and alcohol on personal needs.

10.1 FEELINGS

Respondents were asked how they felt about their ability to cope with drug or alcohol related problems (with any help they were getting). Overall, 91% felt very or fairly happy (Chart 10.1).

9% of all respondents felt unhappy about their ability to cope with drug or alcohol related problems (n=155)

CHART 10.1 Feelings about ability to cope with drug or alcohol related problems



10.2 PROBLEMS

14% of all respondents had experienced problems related to drugs or alcohol in the previous 12 months (n=254)

The cause of most problems – more than all the other drugs put together – was alcohol (Chart 10.2). Seven percent of all respondents described a problem related specifically to the ongoing use of alcohol. One in five of these respondents also described problems with other drugs.

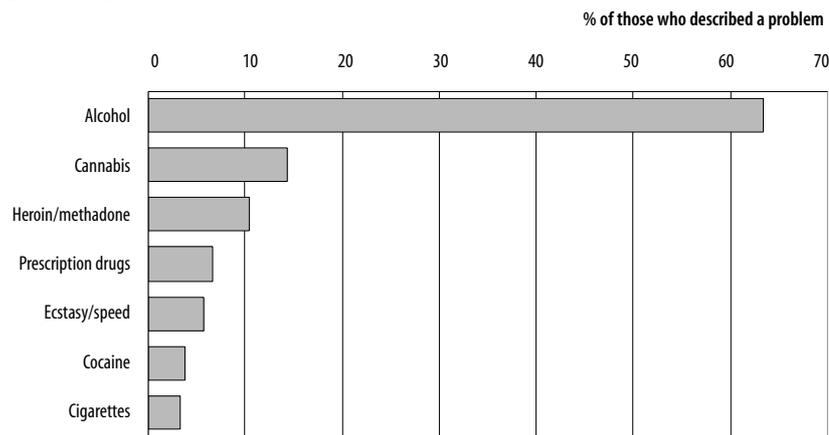
The low frequency of reported problems for each of the other drugs identified in Chart 10.2 suggests that many users of these drugs are able manage their drug use satisfactorily. The only data from the survey on actual drug use was the incidence of injecting drug use: among the 31 respondents who said they had injected drugs in the last year, 18 described a problem with drugs or alcohol (58%). However, although incidence of non-injecting drug use is much higher, problems

with cannabis, ecstasy, speed, cocaine and prescription drugs were relatively rare. Problems with cigarette use are likely to be under-reported, given the focus of the question on 'drugs and alcohol'.

Most of the respondents who described problems related to alcohol or drugs indicated only that they consumed too much or felt too dependent. A few alluded to related problems of stress, depression, social expectations, illness and treatment-taking.

Other than problems with dependency or excess use of alcohol or drugs, a few respondents also mentioned problems maintaining abstinence, sometimes because of hepatitis C (HCV) or other health problems; problems with the alcohol or drug use of partners; and problems with supply, particularly of cannabis.

CHART 10.2 Drugs causing problems



10.2.1 Changes over 12 months

A third (35%) of those who had experienced problems in the previous 12 months said their problems had got better or been resolved. Some had stopped drinking or taking drugs altogether, others had reduced their intake. Many felt that they had gained greater awareness of their circumstances and greater control over their lives – tackling both their alcohol/drug use and the aspects of their lives that created or sustained these problems. The support of partners, friends and counselling services had been important to some in achieving this new sense of control.

For 23% of those who had experienced problems, things had got worse. For many, this simply reflected increased consumption or a greater sense of dependence. However, respondents also described worsening stress and depression; increased isolation; the demands both of living with illness and coping with treatments, including treatment for HCV; and loss of support (or prescriptions) from services.

At the time of the survey, half (49%) of those who had experienced problems felt unhappy about their ability to cope with these problems (61% of those whose problems had not improved). Among those who did not report any problems, only 2% were unhappy about their ability to cope with drug or alcohol related problems.

10.3 GETTING HELP

Among the respondents who had experienced problems in the previous 12 months, 39% had received some form of help to deal with these problems (Table 10.3). This leaves 61% of those with problems who had not received any help, or:

8% of all respondents had experienced problems related to drugs or alcohol in the previous 12 months and had not received any help to address these problems (n=153)

The 'other' sources of help included drug dependency units, community drug and alcohol teams, psychiatrists, counsellors and Alcoholics Anonymous meetings.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Eighteen percent did not think that any further help would make any difference. The remainder either felt that more help would make a difference (46%) or did not know what might be gained (36%). Combining these last two groups, we can say that overall:

10% of all respondents had ongoing problems related to drugs or alcohol and felt that further help or support would be useful, or did not rule this out (n=180)

TABLE 10.3 Sources of help in dealing with drug and alcohol related problems

Source of help	no.	% those with a problem
friends	32	(13)
clinic/hospital	29	(11)
GP	25	(10)
advice or counselling agency	20	(8)
partner	19	(7)
HIV organisation	12	(5)
parents	9	(4)
council/social services	8	(3)
self-help group	5	(2)
other family	5	(2)
telephone helpline	3	(1)
children	0	(0)
other	25	(10)

Many respondents expressed a desire for some form of counselling or personalised support to talk through their problems. The need to address the specific challenges of dependency was acknowledged, but there was also a desire to explore changes in outlook and lifestyle: overcoming stress and anxiety, finding a more supportive social environment, improving self-confidence and developing a healthier lifestyle.

Achieving change was perceived to require not only clarity of mind, but also ongoing support from friends and services and, for some, improvements in living conditions and personal and social relationships. Several respondents mentioned the difficulty of getting appropriate and sensitive responses from medical professionals when dealing with these issues.

10.4 SUMMARY

Of all the respondents to the survey:

- **9%** felt unhappy about their ability to cope with drug or alcohol related problems
- **14%** had experienced problems related to drugs or alcohol in the previous 12 months
- **10%** had an ongoing problems related to drugs or alcohol and felt that further help or support would be useful, or did not rule this out.

11 Anxiety and depression

Anxiety and depression are problems, not needs, and do not relate to a single, clear need. Although 'mental health' is commonly used to describe this need, it is a technical term that is ambiguous in practice. No-one ever says that they 'need mental health', though they may say that they need peace of mind, strength to cope with daily life, or – simply – happiness and contentment.

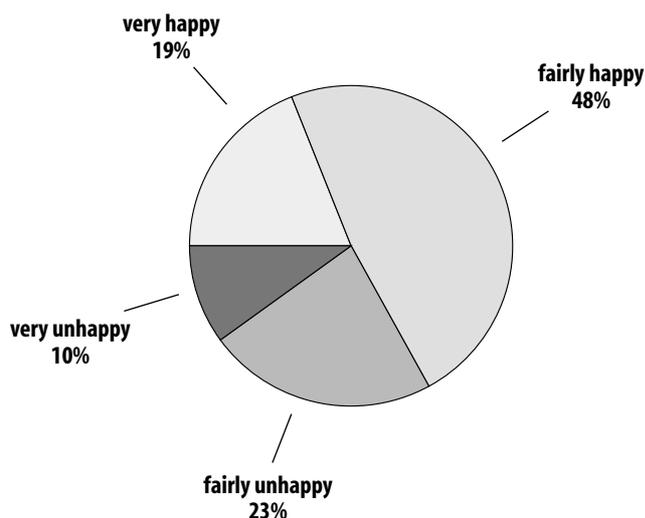
As the emphasis of this section is on the experience of anxiety and depression, it does not capture the aspirational character of mental health, which is clearly more than the absence or control of anxiety. Respondents who did not experience anxiety or depression may nonetheless have felt the need for greater purpose, security or happiness in their lives.

11.1 FEELINGS

Respondents were asked how they felt about their ability to cope with anxiety or depression. Overall, two thirds (67%) felt either very or fairly happy (Chart 11.1)

33% of all respondents felt unhappy about their ability to cope with anxiety or depression (n=582)

CHART 11.1 Feelings about ability to cope with anxiety or depression



11.2 PROBLEMS

67% of all respondents had experienced problems with anxiety or depression in the previous 12 months (n=1198)

The problems respondents described ranged from mild anxiety created by specific events to chronic, severe depression and psychiatric disorders. Given the ambiguity of the language of 'depression', this diversity is not quantified here. However, the scale of the problem is inescapable: most respondents had to cope with significant mental health problems that, for some, became overwhelming.

Many respondents described the causes of their anxiety or depression. These were also very diverse. In fact, every other need explored in this report (other than treatment knowledge) was cited by at least one respondent as a root problem. However, the most common cause was, unsurprisingly, living with an HIV diagnosis and the many uncertainties, particularly for prospects of health and well-being, that this created.

Beyond the shared reality of HIV infection itself, the following were identified as causes of anxiety and depression: isolation and loneliness; coping with illness, pain and disability; treatments and their side effects; loss of self esteem and confidence; breakdowns in relationships; and problems with employment, sleep and money.

Respondents also suffered from family separations and breakdown; from bereavement (in some cases multiple); from loss of motivation, energy and direction in life; from deterioration in physical appearance and body image (usually because of lipodystrophy); from the difficulties of disclosure and experiences of stigma and harassment; from increasing viral load and decreasing CD4 counts; from the daily grind of keeping life together; and from problems with sex, housing, immigration status, alcohol and drug use.

11.2.1 Changes over 12 months

Thirty-six percent of those who had experienced problems said the problem had improved or been resolved. There were four main reasons for improvements: treatment interventions, psychological interventions and support, changes in personal outlook and changes in personal circumstances.

Anti-depressants had worked for some respondents. Others had found that starting or changing (and in a few cases stopping) their anti-HIV treatment was what was needed to improve health and well-being. A handful of complementary therapies were also mentioned: yoga, hypnosis, homoeopathy, reiki, meditation and traditional Chinese medicine.

Various approaches to talking it through had helped: counselling, clinical psychology, psychiatry, self-help groups or simply discussions with doctors, partners and friends. Gaining the support of others was often linked to personal success in adjusting to HIV, accepting personal problems and finding inner strength and personal confidence.

All sorts of changes in circumstances helped respondents to overcome anxiety and depression such as finding a new partner, moving house, starting employment, returning to education and socialising more. Some respondents described the value of leading less stressful lives, others were enjoying more activity and excitement in their lives.

For 22% of those who had experienced problems, things had got worse. The reasons given for deterioration largely repeated the pattern of problems described above, including HIV diagnosis, poorer health, starting treatment (both for HIV and for HCV), loneliness, relationship and family breakdown, lack of support, bereavement, employment difficulties, debts, housing problems and harassment. Many respondents reported that specific incidents of anxiety or depression had become more frequent.

At the time of the survey, 49% of those who had experienced problems were unhappy about their ability to cope with anxiety or depression (66% of those whose problems had not improved). Among those who did not report any problems, only 2% were unhappy about their ability to cope with anxiety and depression.

11.3 GETTING HELP

Among the respondents who had experienced problems in the previous 12 months, 71% had received some form of help to deal with these problems (see Table 11.2). This leaves 29% of those with problems who had not received any help, or:

19% of all respondents had experienced problems with anxiety or depression in the previous 12 months and had not received any help to address these problems (n=351)

The 'other' sources of help included a variety of mental health professionals: psychiatrists, mental health teams, clinical psychologists, psychotherapists and counsellors. Many complementary

therapies were also identified: acupuncture/ traditional Chinese medicine, aromatherapy, Bach flower remedies, homeopathy, hypnotherapy, kinesiology, massage, NLP and reiki. Others mentioned exercise, religion, cannabis and pets.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. A quarter (24%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (48%) or did not know what might be gained (28%). Combining these last two groups, we can say that overall:

45% of all respondents had ongoing problems with anxiety or depression and felt that further help or support would be useful, or did not rule this out (n=823)

TABLE 11.2 Sources of help in dealing with anxiety and depression

Source of help	no.	% those with a problem
clinic/hospital	415	(35)
friends	288	(24)
GP	249	(21)
partner	236	(20)
HIV organisation	229	(19)
advice or counselling agency	188	(16)
parents	100	(8)
other family	94	(8)
council/social services	63	(5)
self-help group	51	(4)
telephone helpline	28	(2)
children	26	(2)
other	153	(13)

Respondents' suggestions of what might help them to reduce or overcome their problems with anxiety and depression were similar to the accounts above of what had actually helped. The main difference was the rarity of any mention of medications, although a few respondents complained of difficulties getting anti-depressants or wanted better anti-HIV medication, better symptom/side-effect control or access to complementary therapies. A few also identified cosmetic surgery as the medical intervention they needed usually as a consequence of lipodystrophy.

Most respondents wanted either appropriate counselling and support or some broader change in their life circumstances. The desire to talk through problems was expressed in many different ways. Some respondents wanted better access to counselling and psychology services (or better quality services); some wanted doctors and other professionals to listen to them properly and acknowledge the diversity of their needs; and some wanted friends, partners and family to be more supportive. Many respondents expressed a desire to meet and talk to other positive people who were facing similar problems. Advice, support and counselling were described as opportunities to come to terms with living with HIV, gain confidence, improve self-esteem and achieve greater self-understanding and control.

Respondents' suggestions for changes in life or circumstances reflected the diversity of causes of anxiety and depression. Respondents wanted to find employment, change or find a partner, go back to college, exercise and get out and socialise more. They also wanted greater financial security, better housing conditions and leave to remain in the UK.

11.4 SUMMARY

Of all the respondents to the survey:

- **33%** felt unhappy about their ability to cope with anxiety or depression
- **67%** had experienced problems with anxiety or depression in the previous 12 months
- **45%** had an ongoing problem with anxiety or depression and felt that further help or support would be useful, or did not rule this out.

12 Self-confidence

There are many ways of characterising the internal resources people need to get through their lives: courage, determination, inner strength, sense of purpose, integrity, *etc.* 'Self-confidence' is one of the least ambiguous. It was used in the survey to capture something of the complexity of these personal internal needs.

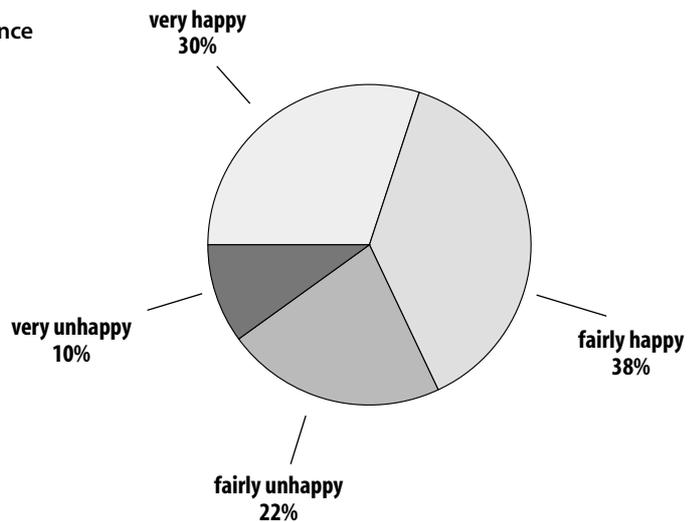
Self-confidence is not usually thought of as a 'basic need' but, without it, life can become a real struggle to sustain. Self-confidence is crucial to negotiating daily life and meeting many of life's needs, including needs for happiness and fulfilment.

12.1 FEELINGS

Respondents were asked how they felt about their self-confidence. Overall, 68% felt either very or fairly happy (Chart 12.1).

32% of all respondents felt unhappy about their self-confidence (n=558)

CHART 12.1 Feelings about self-confidence



12.2 PROBLEMS

48% of all respondents had experienced problems with self-confidence in the previous 12 months (n=855)

Many respondents did not give a reason for their problems but simply described their lack of confidence or assertiveness. Some indicated that they had lost confidence, whereas for others lack of confidence was a long-standing problem.

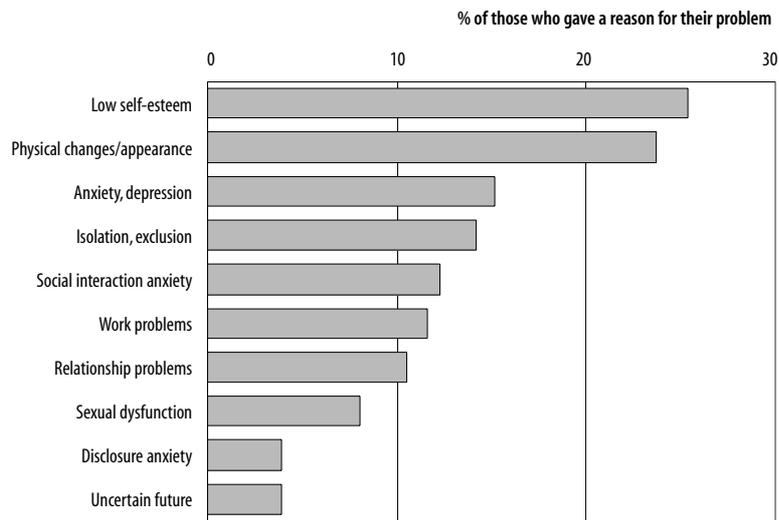
The reasons given for loss of lack of confidence are illustrated in Chart 12.2. Not surprisingly, self-confidence is strongly linked to self-perception: the most common reasons for low self-confidence were poor self-esteem or self-worth and unhappiness about physical appearance. Most of those who were worried about their appearance had experienced physical changes due to HIV, illness or treatments. Lipodystrophy and weight changes (mostly loss) were common problems with profound effects.

Anxiety and depression undermine self-confidence, which generates further anxiety. Isolation and loneliness, fearfulness of social interaction, sexual dysfunction and anxiety about disclosure all diminished self-confidence and so contributed to a downward spiral, damaging the personal

resources needed to address these problems. Some respondents described a turning away, principally from new contacts and social situations but also from existing friends and familiar patterns of socialising.

Within relationships, bereavement, breakdown, rejection, loss of trust or loss of support all had major effects on self-confidence, as did the serial rejection encountered by some of those seeking new relationships. Similarly, loss of a job, problems within work or struggles to find employment could all damage self-confidence.

CHART 12.2 Reasons for problems with self-confidence



12.2.1 Changes over 12 months

Twenty-seven percent of those who had experienced problems in the previous 12 months said the problem had improved or been resolved. Some had turned to counsellors or other sources of support, including partners, to talk through the issues and recover a sense of self-worth. However, many had either come to a greater acceptance of their circumstances or had made an active effort to change them by socialising more, looking for work, studying or finding a new partner. Physical improvements had been achieved through starting treatment, changing treatment or regularly going to the gym.

For 26% of those who had experienced problems, things had got worse. This was often due to a deterioration in health or physical appearance, though for some it was just the impact of another year trying to live with chronic problems – including the attitudes and insensitivity of other people. Respondents also described getting older, poorer, more isolated and more depressed. Separation from partners or loss of other sources of support contributed to the sense of isolation.

At the time of the survey, 66% of those who had experienced problems felt unhappy about their self-confidence (80% of those whose problems had not improved). Among those who did not report any problems only 2% were unhappy about their self-confidence.

12.3 GETTING HELP

Among the respondents who had experienced problems with self-confidence in the previous 12 months, half (51%) had received some form of help to deal with these problems (Table 12.3). This leaves 49% of those with problems who had not received any help, or:

23% of all respondents had experienced problems with self-confidence in the previous 12 months and had not received any help to address these problems (n=412)

The 'other' sources of support included many mental health professionals such as psychiatrists, psychologists, counsellors and therapists. Dieticians, dermatologists and cosmetic surgery had also helped. Help also came from religion, colleagues, pets and complementary therapies (aromatherapy, homeopathy, meditation, NLP and reiki).

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Twenty-two percent did not think that any further help would make any difference. The remainder either felt that more help would make a difference (44%) or did not know what might be gained (34%). Combining these last two groups, we can say that overall:

33% of all respondents had ongoing problems with self-confidence and felt that further help or support would be useful, or did not rule this out (n=598)

TABLE 12.3 Sources of help in dealing with self-confidence problems

Source of help	no.	% those with a problem
clinic/hospital	185	(22)
friends	145	(17)
advice or counselling agency	122	(14)
HIV organisation	113	(13)
partner	109	(13)
GP	56	(7)
parents	53	(6)
other family	48	(6)
self-help group	43	(5)
council/social services	31	(4)
telephone helpline	11	(1)
children	8	(<1)
other	77	(9)

Suggestions for what might help were very diverse, ranging from clarifying personal goals to changing the attitudes of society.

Direct interventions such as counselling, psychotherapy and assertiveness training were frequently identified. However, many respondents felt that they needed more structure and activity in their lives in order to overcome isolation and lack of self-confidence. Getting a job was perceived to be difficult, but there were other options: studying, retraining, volunteering or simply socialising more. Finding the right people to talk to and rebuild a social life with was itself a challenge and many respondents wanted more opportunities to meet other people with HIV, including potential partners who could provide more long-lasting support. The lack of support (and self-help) groups and drop-in centres was noted by many.

The substantial role played by lipodystrophy in undermining self-confidence was reflected in suggestions for appropriate treatment interventions to deal with facial wasting and body change, including cosmetic surgery and facial injections. More generally, respondents wanted their doctors to take a more holistic approach and recognise the seriousness of changes to physical appearance.

There were a variety of suggestions for improving the attitudes of wider society. A few respondents wanted to see better policies and attitudes among employers and stronger advocacy from unions for people with HIV. However, most suggestions involved widespread public education addressing the attitudes of society as whole, which were perceived to perpetuate stigma, secrecy and fear.

12.4 SUMMARY

Of all the respondents to the survey:

- 32% felt unhappy about their self-confidence
- 48% had experienced problems with self-confidence in the previous 12 months
- 33% had ongoing problems with self-confidence and felt that further help or support would be useful, or did not rule this out.

13 Friendship

Like partners, friends can both meet needs and create them. If there is a distinct 'need for friendship', this is always closely related to other needs: for support, intimacy, self-expression and quality of life.

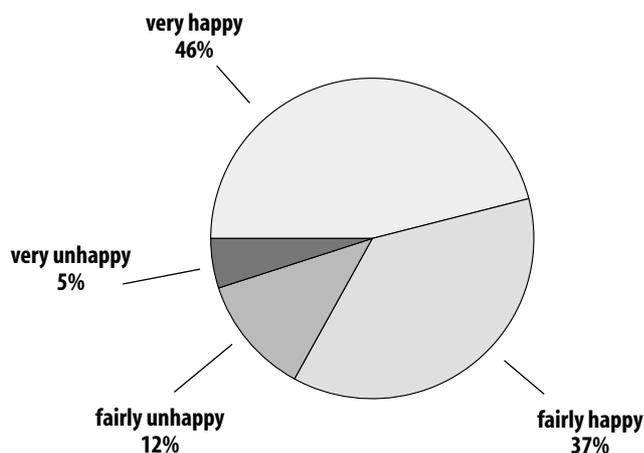
This section treats friendship as a meaningful need in itself. However, this need is very dependent on personal priorities and aspirations: some people are happy to live with few or no friends; others lead lives in which friends are central. Feelings about friendships will therefore reflect these attitudes as much as they reflect the state of current friendships.

13.1 FEELINGS

Respondents were asked how they felt about their friendships. Overall, 83% felt either very or fairly happy (Chart 13.1)

17% of all respondents felt unhappy about their friendships (n=295)

CHART 13.1 Feelings about friendships



13.2 PROBLEMS

25% of all respondents had experienced problems with their friendships in the previous 12 months (n=447)

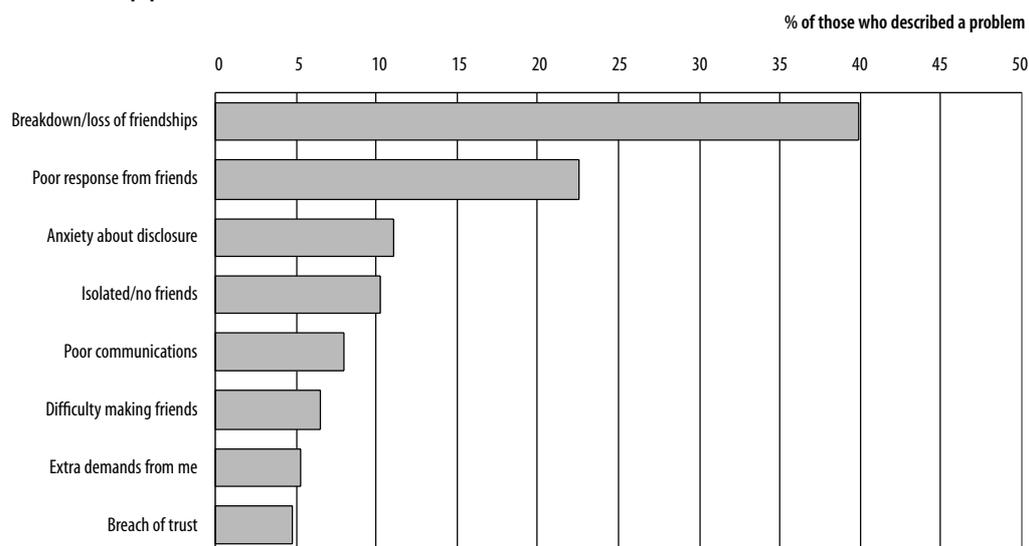
Many respondents described the breakdown and loss of friendships (Chart 13.2). There were four main reasons for this: failure by friends to cope with respondents' disclosure of HIV infection, contraction of social life, geographical separation and bereavement. The first of these was the most frequent. Friends had disappeared, distanced themselves or reacted so badly that respondents had turned away themselves. For others, the challenge was to maintain the lifestyle that sustained friendships: the impact of HIV on physical and emotional strength, income and confidence could all lead to a loss of opportunities to see existing friends or make new ones.

The failure of friends to be supportive through HIV diagnosis and subsequent life changes did not always lead to breakdown of friendship (and so is also illustrated separately in Chart 13.2) Friends who stuck around after HIV diagnosis could still be unsympathetic to illness, fatigue, depression and the demands of living with HIV. But friends displayed much more than a lack of understanding – explicit prejudice and discrimination had been encountered by a few respondents from their supposed friends.

Not surprisingly, anxieties about the disclosure of HIV status to friends were also expressed, anxieties that typically led to keeping HIV a secret. A few respondents described how disclosure to a friend had led to a breach of trust, undermining the foundations of the friendship.

Although HIV diagnosis was often a critical time for friendships, many of the problems described by respondents are more universal: isolation and loneliness; the difficulties of communication and the negotiation of different interests; and the day-to-day challenges of making and sustaining friendships in a busy world.

CHART 13.2 Friendship problems



13.2.1 Changes over 12 months

Eighteen percent of those who had experienced problems with their friendships in the previous 12 months said that their problems had improved or been resolved. For some, this was achieved by separating from the friends causing the problems or actively seeking out new friends. However, more respondents described critical changes in themselves: acceptance of personal circumstances, adjustment to living with HIV and increased confidence, self-awareness and control over life.

For 30% of those who had experienced problems, things had got worse. Many described the loss of friends (for all the reasons described above) and the effects of increased isolation. This could become a vicious circle: loss of confidence or strength leading to greater isolation, which in turn undermined any sense of control over life. Depression, anxiety and stress were all described. However, a few respondents had less time for friends because of the increased demands of a working life.

At the time of the survey, 61% of those who had experienced problems were still unhappy about their friendships (70% of those whose problems had not improved). Among those who did not report any problems, only 2% were unhappy about their friendships.

13.3 GETTING HELP

Among the respondents who had experienced problems with their friendships in the previous 12 months, one third (32%) had received some form of help to deal with these problems (Table 13.3). This leaves 68% of those with problems who had not received any help, or:

16% of all respondents had experienced problems with their friendships in the previous 12 months and had not received any help to address these problems (n=291)

The 'other' sources of support were almost all mental health professionals such as psychiatrists, psychologists and counsellors.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Twenty-nine percent did not think that any further help would make any difference. The remainder either felt that more help would make a difference (40%) or did not know what might be gained (31%). Combining these last two groups, we can say that overall:

15% of all respondents had ongoing problems with their friendships and felt that further help or support would be useful, or did not rule this out (n=281)

TABLE 13.3 Sources of help in dealing with friendship problems

Source of help	no.	% those with a problem
friends	56	(12)
advice or counselling agency	43	(10)
HIV organisation	41	(9)
clinic/hospital	34	(8)
partner	29	(6)
parents	21	(5)
other family	14	(3)
GP	13	(3)
self-help group	13	(3)
council/social services	12	(3)
telephone helpline	8	(2)
children	2	(<1)
other	24	(5)

Respondents wanted help both for themselves and for society as a whole. The most frequent suggestions were for more opportunities to meet other people with HIV, such as peer support, self-help or social (drop-in) groups. There was a widespread perception that such groups were becoming less common and harder to access. Others saw public education campaigns as an important means to reduce the stigma of HIV and help people to understand what it is like to live with the virus.

Respondents also wanted greater personal support to increase their confidence and enable wider social contact. This included emotional support – such as counselling, buddying and assertiveness training – and practical improvements such as better public transport, living conditions and personal income.

13.4 SUMMARY

Of all the respondents to the survey:

- **17%** felt unhappy about their current friendships
- **25%** had experienced problems with their friendships in the previous 12 months
- **15%** had ongoing problems with their friendships and felt that further help or support would be useful, or did not rule this out.

14 Looking after children

This study could not make any assessment of the needs of children and young people living with HIV, given the limitations of a self-complete questionnaire. However, the study did include an investigation into the needs of people caring for children and young people; i.e. for the energy, time and resources to ensure that the needs of their children are adequately met.

There are other needs created by children that were not addressed directly, such as the emotional needs generated by separation from children. This section only addresses the needs of respondents who were living with children.

There were 173 respondents living with children: 10% of the whole sample. Three fifths of these were women (n=104) and two fifths were men (n=69).

There were 117 White respondents, 46 Black African, six Asian, two Black 'other' and one Black Caribbean. The Black African respondents were predominantly women (36 women and 10 men), whereas the White respondents were more evenly divided (64 women and 53 men). The great majority of respondents were heterosexual: nine of the men (13%) and five of the women (5%) identified as gay, lesbian or bisexual.

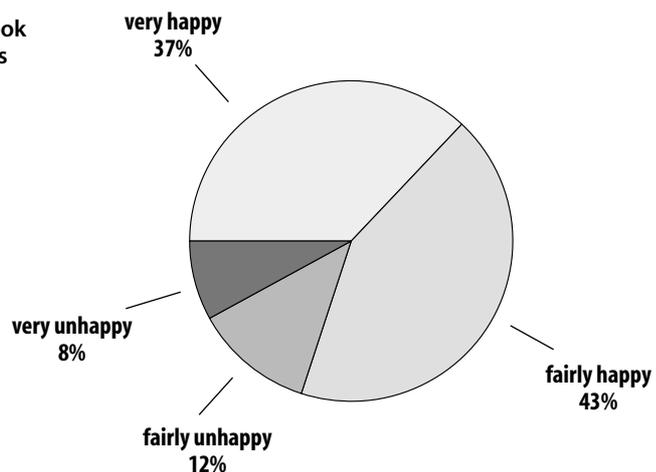
Although a majority lived with a partner as well as children (57%), many did not (43%). Less than half (46%) were in any form of paid employment.

14.1 FEELINGS

The respondents who lived with children were asked how they felt about their ability to look after their children. Overall, 80% (n=129) felt either very or fairly happy (Chart 14.1). Hence:

20% of respondents living with children felt unhappy about their ability to look after their children (n=33) (2% of all respondents)

CHART 14.1 Feelings about ability to look after children (respondents living with children)



14.2 PROBLEMS

42% of respondents living with children had experienced problems looking after their children in the previous 12 months (n=69) (4% of all respondents)

The problems described were, for the most part, closely related. The biggest complaint was of tiredness and exhaustion. This was linked to the difficulties of meeting the needs of children and coping with their daily demands: getting them to school, keeping them occupied and feeding and

clothing them. For some, these problems were exacerbated by personal health problems or by the illness or disability of their children. This burden of was also increased by lack of money, childcare or personal support.

HIV clearly made childcare problems worse for many of these respondents, through ill-health, problems with service providers (and the Home Office) and the need for time to focus on personal needs. However, most of the problems were the general problems of looking after children, including the 'usual' problems of coping with teenage behaviour. Only three respondents mentioned disclosure of their own HIV status as a problem.

14.2.1 Changes over 12 months

Thirty percent of the respondents who had experienced problems looking after their children in the previous 12 months said the problem had got better. Several said that their children were now a bit older or had started to communicate better. Others had seen improvements in their personal health and mobility or had found support from local agencies or the church.

For 23% of those who had experienced problems, things had got worse. Most had experienced a deterioration in their health, energy or mobility. However, older children were identified as a problem: i.e. the older they get, the more demands they make.

At the time of the survey, 48% of those who had experienced problems looking after their children were unhappy about their ability to look after their children (57% of those whose problems had not improved). Only one of the respondents who did not report any problems in the previous 12 months was unhappy about their ability to look after their children.

14.3 GETTING HELP

Three-fifths (59%) of the respondents who had problems looking after their children in the previous 12 months had received some form of help to deal with these (see Table 14.2). This leaves 41% who had not received any help, or:

17% of respondents living with children had experienced problems looking after their children in the previous 12 months and had not received any help to address these problems (n=28) (2% of all respondents)

The 'other' sources of help included health visitors, teachers, child-minders and childcare organisations.

Respondents were asked whether they felt that further help or support would reduce or overcome their problems. Eighteen percent did not think that any further help would make any difference. The remainder either felt that more help would make a difference (65%) or did not know what might be gained (17%). Combining these last two groups, we can say that overall:

31% of all respondents who were living with children had ongoing problems looking after their children and felt that further help or support would be useful, or did not rule this out (3% of all respondents)

TABLE 14.2 Sources of help in looking after children

Source of help	no.	% those with a problem
friends	14	(20)
parents	14	(20)
council/social services	13	(19)
partner	12	(17)
other family	9	(13)
HIV organisation	7	(10)
clinic/hospital	6	(9)
GP	6	(9)
children	5	(7)
advice or counselling agency	4	(6)
self-help group	2	(3)
telephone helpline	0	(0)
other	7	(10)

Overwhelmingly, respondents wanted more childcare, more personal support to help them cope at home and more money. A few described the potential for improvement in their circumstances: new employment, leave to remain from the Home Office or better health.

Several respondents also expressed a desire for greater understanding from their children and from other adults and service providers. Support in gaining this understanding was particularly needed at the time of disclosure of HIV status to children.

14.4 SUMMARY

Of all respondents living with children:

- **20%** felt unhappy about their ability to look after their children (2% of all respondents)
- **42%** had experienced problems looking after their children in the previous 12 months (4% of all respondents)
- **31%** had ongoing problems looking after their children and felt that further help or support would be useful, or did not rule this out (3% of all respondents).

15 Relationships

Relationships are an important means of meeting needs, such as need for intimacy, support, sex, family and continuity. However, relationships do not always fulfil these needs adequately and they can also create needs, especially when things go wrong.

This section focuses on the needs generated within relationships rather than the needs fulfilled by a relationship or the need for a relationship.

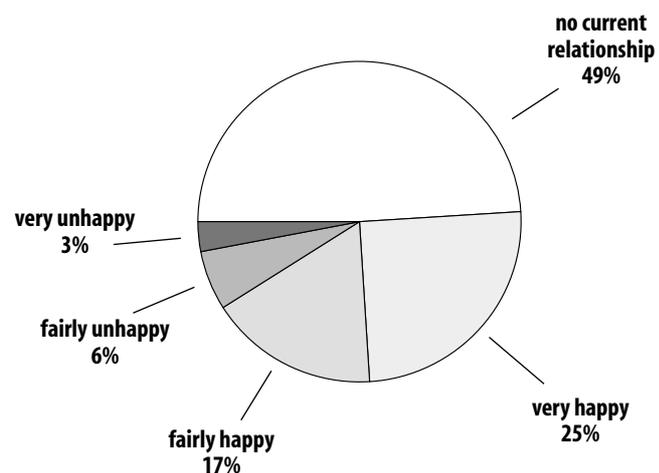
Half of all respondents (51%, n=920) had a partner, husband or wife at the time of completing the survey, though more had been in a relationship at some point in the previous 12 months.

15.1 FEELINGS

Respondents were asked how they felt about their current relationship, if they had one. Overall, 83% of those who had a partner felt very of fairly happy (42% of all respondents) (Chart 15.1).

9% of all respondents were unhappy about a current relationship (n=149)

CHART 15.1 Feelings about current relationships



15.2 PROBLEMS

29% of all respondents had experienced problems within a relationship in the previous 12 months (n=527)

Over a third of these respondents (36%) no longer had a partner at the time of the survey. Inevitably, the problems they described almost all concerned break-up and loss. A few had been bereaved, which had proved to be an overwhelming blow to their ability to cope with everyday life.

Relationships had broken down for many reasons: difficulty in disclosing HIV status or the impact of disclosure on a new partner; dishonesty, mistrust and infidelity; problems with sex, money or drinking and drugs; and general failures of communication, understanding and support.

The problems described by the respondents who did have a partner at the time of the survey were complex and could not be satisfactorily quantified. Relationship problems necessarily affect both people, regardless of where the problems begin and, in describing their problems, different respondents focussed on different aspects of this dynamic: the nature of the problem itself; who had the primary experience of it; the response of the other person; and the impact on the relationship as a whole.

Most respondents did not mention HIV in their descriptions of relationships problems and many clearly felt that their problems were just 'the usual': arguing, failing to communicate, loss of intimacy or trust, jealousy, stress, etc. Many respondents also described problems with drink, money, depression and sex that clearly may have been affected by HIV, though this was not always indicated. Sex was a common source of problems, including loss of interest or potency and anxieties about HIV transmission.

Many respondents focussed on their partner's inadequate response to their own experience. Partners had failed to understand or accept the impact of HIV diagnosis and illness or the impact on personal confidence and anxiety. Some partners had responded particularly badly: failing to offer support; becoming distant, selfish or excluding; or being verbally and physically abusive. Other respondents were sympathetic to the demands they were placing on their partners, acknowledging the difficulties their partners faced in dealing with their mood swings, anxiety, illness and side effects.

Whether relationships were HIV sero-discordant or sero-concordant, support had to be given as well as received. Several respondents described the challenges of supporting partners who were dealing with their own diagnosis or illness, or who were depressed, habitually drunk or generally in need of their attention.

Changes in personal priorities and daily routines, such as going back to work or developing divergent interests, also created problems and could lead to couples drifting apart or feeling trapped within their relationships.

15.2.1 Changes over 12 months

The respondents who had lost their partners in the 12 months prior to the survey had experienced the biggest changes. For them, problems within relationships were a thing of the past – they now had to deal with the loss and the difficulties of building a new relationship.

Among those who had a partner at the time of the survey and had experienced relationship problems in the previous 12 months, 30% said the problems had got better or been resolved. A few had in fact split up and found new partners. But, for most, improvements had been achieved through working at the relationship. They described improvements in communication, attitudes and willingness to compromise and the achievement of greater honesty and understanding. Some had addressed root problems such as drink and money disputes; others had experienced changes in circumstances – such as starting or stopping treatment – that had a positive impact on their relationships.

For 28% of those who had experienced problems in a relationship (but still had a partner), things had got worse. Sexual problems, stress, the demands of treatment and communication breakdowns were all prominent reasons for deterioration.

At the time of the survey 45% of those who had experienced problems (but still had a partner) were unhappy about their relationship (61% of those whose problems had not improved). Among those who had not experienced any problems, only 1% were unhappy about their relationships.

15.3 GETTING HELP

Among those who had experienced problems within relationships in the previous 12 months (including those who no longer had a relationship), 43% had got some form of help to deal with these problems (see Table 15.2). This leaves 57% of those with problems who had not received any help, or:

16% of all respondents had experienced problems within a relationship in the previous 12 months and had not received any help to address these problems (n=294)

The 'other' sources of help included psychiatrists, psychologists and other mental health professionals; nurses, solicitors, ex-partners, work colleagues and religion.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. A quarter (27%) did not think that further help would reduce or overcome their problems. The remainder either felt that further help would make a difference (43%) or did not know what might be gained (31%). Combining these last two groups, we can say that overall:

14% of all respondents had ongoing problems within a current relationship and felt that further help or support would be useful or did not rule this out (n=219)

TABLE 15.2 Sources of help in dealing with problems with relationships

Source of help	no.	% those with a problem
friends	89	(17)
clinic/hospital	78	(15)
advice or counselling agency	69	(13)
HIV organisation	61	(12)
partner	51	(10)
GP	33	(6)
other family	29	(6)
parents	27	(5)
council/social services	16	(3)
self-help group	14	(3)
telephone helpline	6	(1)
children	5	(<1)
other	28	(5)

Most of these respondents felt that some form of counselling, advice or support might help. Some wanted joint counselling, others wanted counselling either for themselves or their partner alone. Some respondents were concerned about the absence of respite or other support for carers and partners, and the inability to privately fund 'replacement care' to give partners any break from looking after them. Other suggestions for more general support included support groups and opportunities to meet other couples facing similar problems.

Some of the respondents who identified sexual difficulties as the core of their relationship problems suggested sex therapy/counselling or wider provision of Viagra. Similarly, other respondents wanted help to resolve the basic problems – with money, alcohol, depression and immigration law – that undermined their relationships. They also wanted to spend more time within the relationship talking, listening and building mutual respect.

15.4 SUMMARY

Of all the respondents to the survey:

- 51% had a current relationship
- 9% were unhappy about a current relationship
- 29% had experienced problems within a relationship in the previous 12 months
- 14% had ongoing problems within a current relationship and felt that further help or support would be useful, or did not rule this out.

16 Sex

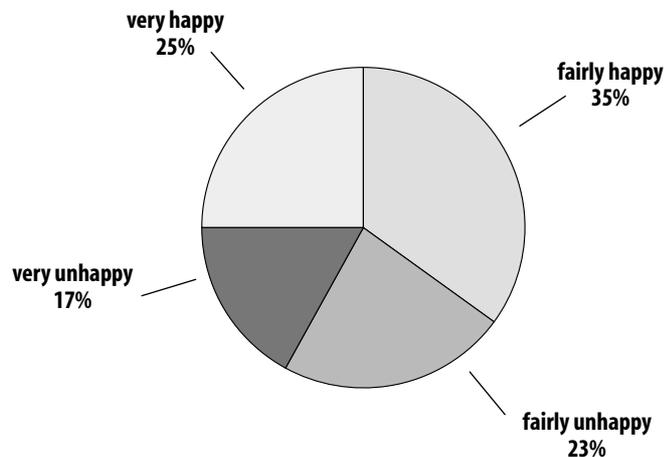
The need for sex is clearly defined by both aspirations and problems. Some people have little or no interest in sex, whereas others feel that sexual pleasure is central to their life. Some people have no difficulty getting and having sex, but others face intractable problems. As aspirations for sex can be very strong, and problems rapidly undermining, the need for sex is especially prone to changes in personal circumstances.

16.1 FEELINGS

Respondents were asked how they currently felt about their sex lives. Overall 60% felt either very or fairly happy (Chart 16.1). Hence:

40% of all respondents felt unhappy about their sex lives (n=700)

CHART 16.1 Feelings about current sex life



16.2 PROBLEMS

51% of all respondents had experienced problems with sex in the previous 12 months (n=914)

The most frequent problem was simply not having any sex, or having very little (Chart 16.2). For many, this was linked to a loss of libido or interest in sex. Although many respondents did not explain why their sex lives had diminished, the other problems described in the rest of the chart give some indication of the challenges that they may have faced.

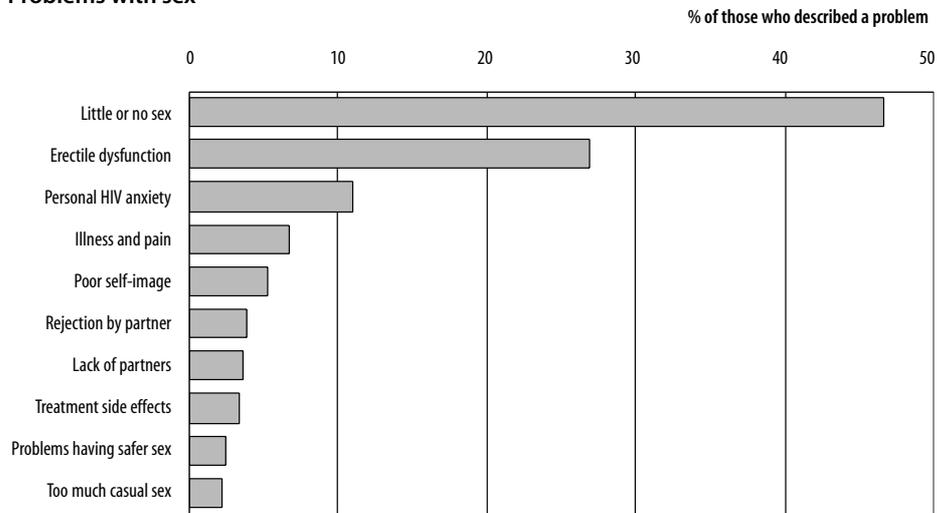
The most common problem associated with actually having sex was erectile dysfunction, identified by 205 respondents (11% of all respondents, 13% of all male respondents). Few respondents went into any more detail, though problems relating to illness, treatments and anxiety were all mentioned. Many other respondents described sex being undermined by illness and pain, treatment side effects and anxieties about HIV.

Anxiety about HIV took several forms. Some respondents described being too worried about passing on HIV to have sex, including sex with established partners. Others were anxious about disclosing their HIV status to new partners and were fearful of rejection should they do so. The actual experience of rejection by partners (new and old) was common.

Anxiety was also expressed in poor self-image or a lack of self-confidence. This was sometimes the direct result of diagnosis – feeling ‘dirty’ or ‘unclean’ – or alternatively arose through experience of illness and treatment side effects, such as lipodystrophy.

Few respondents described specific problems performing safer sex, such as difficulties using condoms or experiences of unprotected sex. However, the challenge of safer sex was implicit in the anxieties about HIV transmission described above.

CHART 16.2 Problems with sex



16.2.1 Changes over 12 months

A fifth (18%) of those who had experienced problems in the previous 12 months said the problem had improved or been resolved. Reasons for improvement encompassed everything from the basic mechanics of sex to the structure of people’s lives. The single most common source of help was Viagra, reflecting the prominence of erectile dysfunction in Chart 16.2. Testosterone had also been used to improve performance. Other respondents had found that improvements in their general health (including changes in treatments) had led to a recovery in their sex lives.

Changes in mental health and personal outlook had also contributed to better sex lives: respondents described coming to terms with living with HIV; gaining greater self-confidence, in some cases through counselling; and developing new sexual interests. Within relationships, talking and reaching greater mutual understanding had led to improvements in sex, although for some respondents this had been achieved by finding a new partner altogether.

For 27% of the respondents who had experienced problems, things had got worse. Many respondents described a continuing deterioration of potency (a vicious circle), health and confidence. Several described a sense of isolation, with the prospect of meeting a supportive partner ever more distant, not least because of the ongoing stigma of HIV. Relationships had also deteriorated, with partners expressing increasingly divergent needs – some for less sex, others for more. Age, frustration with HIV and increased anxiety all contributed to worsening sex lives.

At the time of the survey, 71% of those who had experienced problems were unhappy about their sex lives (81% of those whose problems had not improved). Among those who did not report any problems, a sizeable minority were unhappy about their sex lives (9%), reflecting the aspirational aspect of the need for sex.

16.3 GETTING HELP

Among the respondents who had experienced problems with sex in the previous 12 months, 36% had received some form of help to deal with these problems (see Table 16.3). This leaves 64% of those with problems who had not received any help, or:

31% of all respondents had experienced problems with sex in the previous 12 months and had not received any help to address these problems (n=568)

The 'other' sources of help were almost all mental health professionals such as psychiatrists, psychologists and counsellors, with only one mention of complementary therapies: traditional Chinese medicine.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. A quarter of these respondents (24%) did not think that any further help would make any difference. The remainder either felt that more help would make a difference (38%) or did not know what might be gained (38%). Combining these last two groups, we can say that overall:

34% of all respondents had ongoing problems with their sex lives and felt that further help or support would be useful, or did not rule this out (n=612)

TABLE 16.3 Sources of help in dealing with sexual problems

Source of help	no.	% those with a problem
clinic/ hospital	196	(21)
GP	64	(7)
partner	56	(6)
advice or counselling agency	53	(6)
friends	46	(5)
HIV organisation	44	(5)
self-help group	16	(2)
parents	6	(<1)
other family	5	(<1)
council/social services	3	(<1)
telephone helpline	3	(<1)
children	0	(0)
other	45	(5)

These respondents offered a wealth of suggestions for what might help them in improving their sex lives.

Viagra was again a popular choice, with many respondents currently unable to obtain it or afford it on private prescriptions. Other improvements in physical health were envisaged through treating specific conditions more effectively; starting, changing or stopping anti-HIV medications; and putting more effort into exercise.

Most respondents made suggestions that addressed their emotional health and well-being. Many identified counselling, or at least talking to someone, as a possible way forward both for themselves and, in some cases, for their partners. Gaining confidence, dealing with personal fears and improving self-image were all identified as important goals. However, some respondents just wanted to talk about the complications of having sex as a positive person.

This related to a wider desire to meet sympathetic people – typically people in the same situation – and thereby avoid having to deal with discrimination and ignorance about HIV. Many respondents did not know where to turn to find like-minded people, including people who wanted more than sex. A supportive and loving partner was, for some, the clearest solution to their problems – a solution that a few felt could only be realised by finding a partner who also had HIV.

One of the main obstacles to addressing sexual problems was medical attitudes. Many respondents felt that their doctors would not take sexual problems seriously. For them, a key improvement would be for these professionals to look beyond immediate health issues and understand the impact that sexual problems could have on their patient's lives, relationships and well-being.

16.4 SUMMARY

Of all the respondents to the survey:

- **40%** felt unhappy about their sex lives
- **51%** had experienced problems with sex in the previous 12 months
- **34%** had ongoing problems with their sex lives and felt that further help or support would be useful, or did not rule this out.

17 Knowledge of HIV treatments

The need for knowledge of HIV treatments is very dependent on individual attitudes – different people will be happy with very different levels of personal knowledge. It is possible to survive and live well with almost no knowledge of HIV treatments at all. There are people with HIV who are well and choose to ignore medicine as long as they can; people who leave all treatment decisions to their doctors; and people who have no faith in medicine at all. However there are many people for whom knowledge of personal treatment choices is a priority.

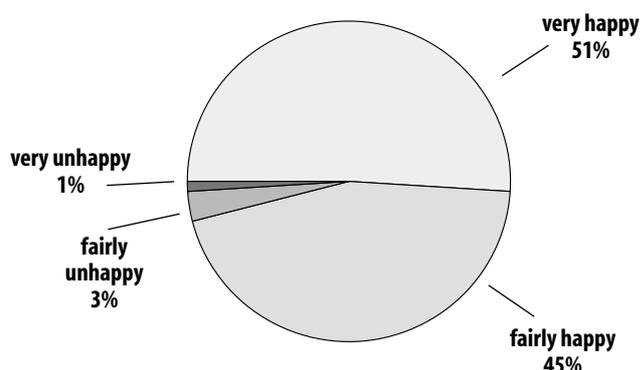
The emphasis in the survey was on problems gaining knowledge; or, more precisely, problems finding out about HIV treatments. It did not directly address ‘problems with knowledge’, such as making sense of what you know, applying what you know to the mess of daily life and resolving the contradictions in what you know. By concentrating on the more fundamental need of gaining knowledge, this analysis excludes these subtle, but nonetheless important, problems.

17.1 FEELINGS

Respondents were asked how they felt about their knowledge of HIV treatments. Overall, 96% felt very or fairly happy (Chart 17.1).

4% of all respondents felt unhappy about their knowledge of HIV treatments (n=76)

CHART 17.1 Feelings about knowledge of HIV treatments

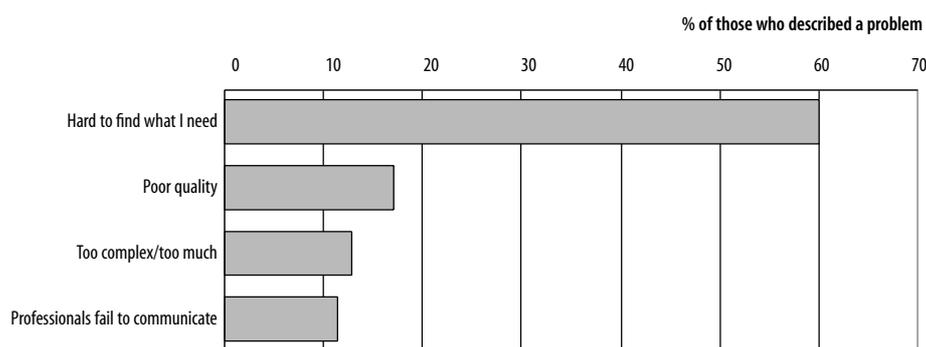


17.2 PROBLEMS

5% of all respondents had experienced problems finding out about HIV treatments in the previous 12 months (n=91)

The most common problem was simply finding the relevant information to answer the questions raised by personal circumstances and interests. Few respondents were concerned about the adequacy or complexity of the treatment information available, or the ability of professionals to communicate it (Chart 17.2).

CHART 17.2 Problems finding out about HIV treatments



17.2.1 Changes over 12 months

Two fifths (39%) of those who had experienced problems finding out about HIV treatments in the previous 12 months said that their problems had improved or been resolved. Most had either found a better service or put more effort in to getting information, including building better relationships with their treatment providers. However, for a few, it was a change of circumstances – i.e. the treatments they were taking – that removed the primary need and so resolved the problem.

For 20% of those who had experienced problems, things had got worse. This was usually because a change in circumstances, such as a change of treatment or new illness, increased the need for treatment knowledge and so exacerbated the problem of getting the necessary information. However, two respondents said their problems had increased through improvements in health – because they were now more willing and able to engage with information or busier doing other things.

At the time of the survey, half (49%) of those who had experienced problems felt unhappy about their treatment knowledge (68% of those whose problems had not improved). Among those who did not report problems finding out about HIV treatments, only 2% were unhappy about their treatment knowledge.

17.3 GETTING HELP

Among the respondents who had experienced problems in the previous 12 months, 63% had received some form of help to address their problem (Table 17.3). This leaves 37% who had not got any help, or:

2% of all respondents had problems finding out about HIV treatments and had not received any help to address this problem (n=32)

The ‘other’ sources of help were predominantly websites and the internet.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Eight percent did not

TABLE 17.3 Sources of help in finding out about HIV treatments

Source of help	no.	% those with a problem
clinic/hospital	26	(29)
HIV organisation	21	(23)
friends	10	(11)
partner	9	(10)
GP	9	(10)
telephone helpline	7	(8)
advice or counselling agency	5	(5)
self-help group	3	(3)
council/social services	3	(3)
children	1	(1)
parents	1	(1)
other family	1	(1)
other	14	(15)

think that any further help would make any difference. The remainder either felt that more help would make a difference (68%) or did not know what might be gained (24%). Combining these last two groups, we can say that overall:

4% of all respondents had ongoing problems finding out about HIV treatments and felt that further help or support would be useful, or did not rule this out.

Their suggestions for what might actually help included more information (and more accessible information) both in and out of HIV centres; information tailored to individual circumstances including one-to-one advice and holistic approaches to health; improvements in the knowledge and attentiveness of doctors and other professionals; and better quality information in general.

17.4 SUMMARY

Of all respondents to the survey:

- 4% felt unhappy about their knowledge of HIV treatments
- 5% had experienced problems finding out about HIV treatments in the previous 12 months
- 4% had ongoing problems finding out about HIV treatments and felt that further help or support would be useful, or did not rule this out.

18 Taking treatments regularly

Taking treatments, and taking them regularly, is not a personal need but a clinical requirement. People take treatments in order to meet needs for health and well-being, needs that would otherwise be undermined by illness. Nobody wants to take treatment.

Nonetheless, once someone has accepted the clinical requirement to take treatment, she/he has to cope with the consequences. This section explores some of these consequences, particularly the challenge of adherence, and the needs they generate.

18.1 TAKING ANTI-HIV TREATMENTS

Out of all respondents, 77% (n=1335) were taking anti-HIV treatments at the time of the survey. Only 16% (n=285) of the entire sample had never taken anti-HIV treatments.

Respondents' experience of taking anti-HIV treatments ranged from two who claimed to have first taken anti-HIV treatments in 1983 to one who had started on the day he completed the survey. The average time since first starting anti-HIV treatments was four and a half years.

There were some differences in treatment-taking between demographic groups:

- A larger proportion of men were taking anti-HIV treatments (76%) than women (68%)
- A smaller proportion of respondents with experience of injecting drug use were taking anti-HIV treatments (56%) compared to the rest of the respondents (76%); and only 42% of respondents with experience of injecting drug use in the previous 6 months were taking treatments.
- A larger proportion of the respondents in paid employment were taking anti-HIV treatments (78%) compared to those who were not in paid employment (71%)

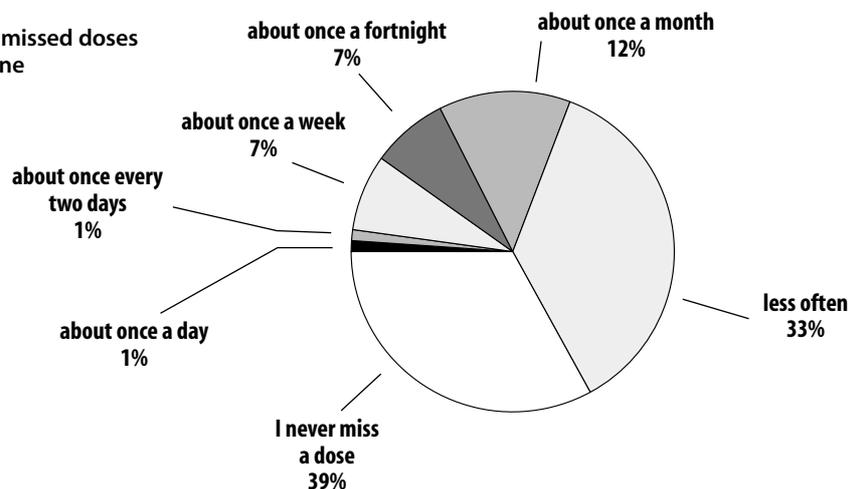
There were no differences by ethnicity, sexuality, education or co-occurrence of haemophilia.

18.1.1 Doses and adherence

Respondents were asked how many times a day they had to take any kind of medicine. The results relate to all treatments – among the respondents taking anti-HIV medications, 56% were also taking some other form of medicine. The majority were taking treatments twice (61%) or three times (24%) a day, with smaller proportions taking them four (9%) or more (5%) times a day.

Chart 18.1 illustrates respondents' estimates of how often they missed a dose of medicine. Nine percent of respondents estimated that they missed a dose at least once per week and 27% missed a dose at least once per month.

CHART 18.1 Frequency of missed doses of any medicine



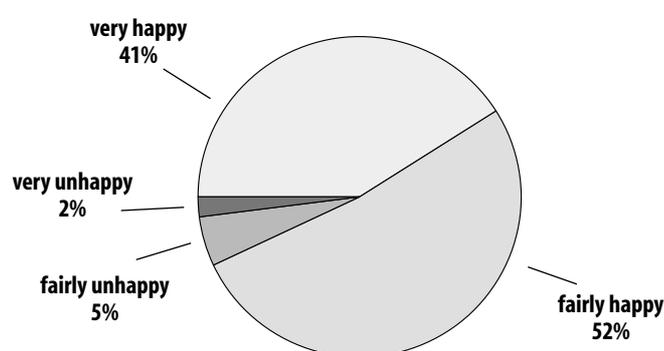
18.2 FEELINGS

Respondents were asked how they felt about their ability to take anti-HIV treatments regularly. Chart 18.2 illustrates their responses. As the question focussed on ability to take treatments regularly and not on feelings about taking treatments *per se*, the results are not an indication of overall happiness with treatment-taking. Rather, they are a measure of personal confidence in the specific challenges of treatment-taking, particularly adherence.

Overall, 93% of those who were taking anti-HIV treatments felt very or fairly happy about their ability to take treatments regularly.

7% of respondents taking anti-HIV treatment felt unhappy about their ability to do so regularly (n=92) (5% of all respondents)

CHART 18.2 Feelings about ability to take anti-HIV treatments regularly



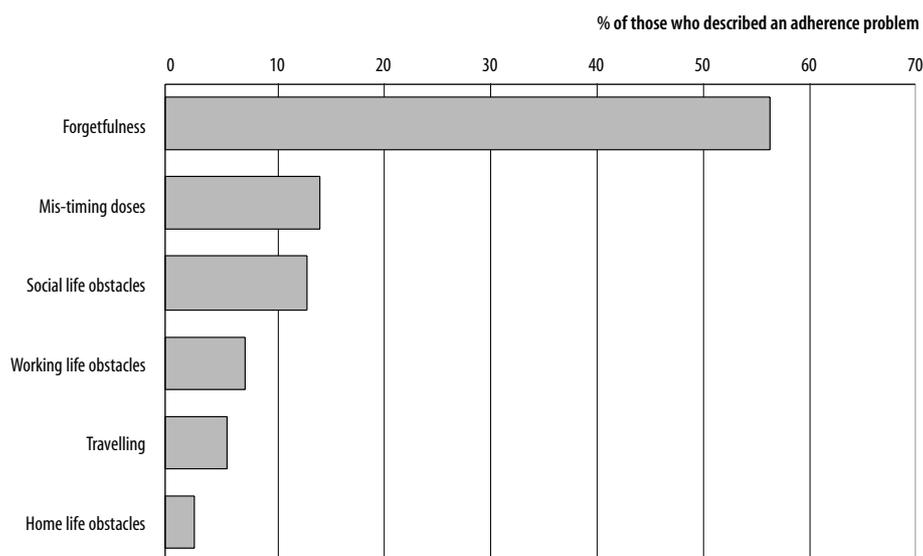
As doses of medicine increased, respondents were no more or less happy about their ability to take anti-HIV treatments regularly. However, there was a very strong relationship with frequency of missed doses: those who reported more missed doses were much more likely to be unhappy about their ability to take anti-HIV treatments regularly.

18.3 PROBLEMS

32% of respondents taking anti-HIV treatments had experienced problems doing so regularly in the previous 12 months (n=419) (24% of all respondents)

Problems with adherence and the routine of treatment-taking were cited by about half of those who described a problem. Chart 18.3 illustrates the main issues identified by these respondents. For most, forgetfulness was the basic problem, described either as the ease of forgetting or the ongoing difficulty of remembering. Some described the particular difficulties of fitting treatment-taking into daily life – at home, at work and when out socialising. These difficulties included unpredictable routines, the inconvenience of carrying and taking medicines and loss of confidentiality in public. These could all be problems when travelling, further complicated by time zone changes and lack of refrigeration.

CHART 18.3 Adherence problems



About half of the respondents who described problems taking anti-HIV treatments also mentioned side effects. However this is unlikely to reflect the entirety of respondents' experience of side effects, given the question's focus on problems with the regularity of treatment-taking. A separate question ascertained that 86% of those currently taking anti-HIV treatments had experienced side effects from such treatments at some point in their experience of taking them (rather than in the last 12 months).

The most common side effects were nausea, vomiting, diarrhoea, lipodystrophy and neuropathy. These were widely identified elsewhere in the study as causes of need, sometimes with profoundly debilitating effects. Lipodystrophy, for example, could have a major impact on self-confidence and levels of anxiety and depression, leading to a loss of sexual confidence and experience of discrimination.

Other treatment-taking problems described by respondents were the size, number and taste of pills; the complications of changing treatment regimens; coping with treatment failure and drug resistance; and weariness or loss of motivation to keep on taking the medicines. A few respondents outside London were concerned that they were not getting access to the full range of treatment choices.

18.3.1 Changes over 12 months

Forty-three percent of those who had experienced problems in the previous 12 months said the problem had improved or been resolved. Much the most common reason for improvement, cited by over half of these respondents, was a change in treatment regimen. Others described a process of adjusting to treatment, which could include physiological adjustment (getting over initial side effects or controlling them with other drugs); psychological adjustment to the change in daily life; and changes to lifestyle and behaviour to accommodate the demands of the treatment regimen. Other reasons for improvement included personal determination to see the treatment succeed, support in learning how to live with pills and a range of devices to help remember: pill-boxes, timers and vibrating watches.

For 14% of those who had experienced problems, things had got worse. Some had only recently begun anti-HIV treatments, others were dealing with a change in treatment regimen. Deterioration of health and persistent side effects could also make treatment-taking more difficult, not least through undermining motivation. Motivation also waned simply through the boredom of the daily routine. Changes in personal and work routines (or loss of these routines) made it difficult to sustain treatment-taking.

At the time of the survey, only 20% of those who had experienced problems felt unhappy about their ability to take anti-HIV treatments regularly (31% of those whose problems had not improved). Among those who did not report problems taking anti-HIV treatments, 1% were unhappy about their ability to do so.

18.4 GETTING HELP

Among the respondents who had experienced problems in the previous 12 months, 63% had received some form of help to deal with these problems (Table 18.4). This leaves 37% of those with problems who had not received any help, or:

12% of respondents taking anti-HIV treatments had experienced problems taking them regularly in the previous 12 months and had not received any help to address these problems (n=154) (9% of all respondents)

The 'other' source of help included pharmacists, nurses, dieticians and other people with HIV. A few people found their drug tolerance was improved by acupuncture/ traditional Chinese medicine, homoeopathy and hypnotherapy.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Forty-three percent did not think that any further help would make any difference. The remainder either felt that more help would make a difference (30%) or did not know what might be gained (27%). Combining these last two groups, we can say that overall:

15% of respondents taking anti-HIV treatment had ongoing problems taking them regularly and felt that further help or support would be useful, or did not rule this out (n=204) (12% of all respondents)

TABLE 18.4 Sources of help in taking anti-HIV treatments regularly

Source of help	no.	% those with a problem
clinic/hospital	200	(48)
partner	67	(16)
friends	50	(12)
HIV organisation	49	(12)
GP	38	(9)
advice or counselling agency	20	(5)
parents	19	(5)
other family	17	(4)
council/social services	12	(3)
self-help group	8	(2)
telephone helpline	8	(2)
children	3	(<1)
other	29	(7)

Most of the suggestions for what might help fell into three groups. First, respondents wanted improvements in the treatments themselves: fewer pills, fewer doses (ideally one per day), pills that are smaller and easier to swallow and fewer side effects. Second, respondents wanted better services, particularly from their doctors, including more attention to individual needs and appropriate advice and support about living with treatments and coping with their side effects. Third, respondents wanted tools to help take their treatments regularly: pill-boxes, timers and alarms – or ideally something combining all three.

18.5 SUMMARY

Of all the respondents taking anti-HIV treatments:

- 7% felt unhappy about their ability to take treatments regularly (5% of all respondents)
- 32% had experienced problems taking treatments regularly in the previous 12 months (24% of all respondents)
- 15% had ongoing problems taking treatments regularly and felt that further help or support would be useful, or did not rule this out (12% of all respondents).

19 Dealing with health professionals

Anyone who requires the support of modern medicine has to deal with the many professionals who deliver it: doctors, nurses, health advisors, pharmacists, dieticians and a range of therapists. The need for medicine (which is itself driven by a need for health) creates the further need to relate, communicate and negotiate with health professionals.

Need is often created in relationships with health professionals when things go wrong, either in the relationship itself or in the wider service which supports the relationship. However, this need is also aspirational: in any relationship, particularly one that is critical to personal health, there is scope for improving communication, understanding and shared decision-making. Having a good relationship with your doctor does not mean that you are completely satisfied with how decisions are made within it.

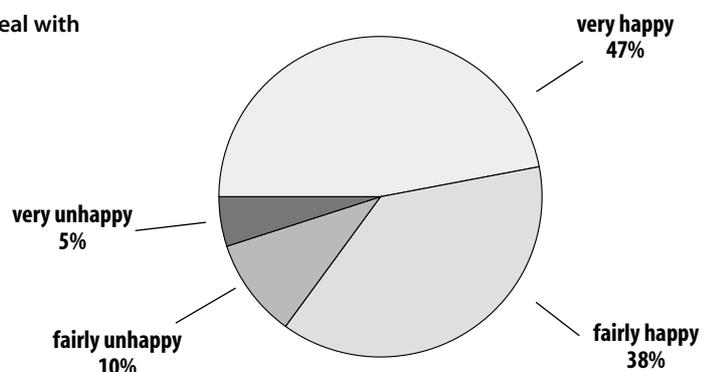
The survey could not address in detail the complex and subtle questions of the quality of relationships with professionals (for which there is a large literature). The emphasis was on the more fundamental issue of whether people with HIV feel able to deal with professionals at all, and what problems they encounter in trying to do this.

19.1 FEELINGS

Respondents were asked how they felt about their ability to deal with doctors and other health professionals. Overall, 85% felt either very or fairly happy (Chart 19.1)

15% of all respondents were unhappy about their ability to deal with health professionals (n=265)

CHART 19.1 Feelings about ability to deal with health professionals



19.2 PROBLEMS

27% of all respondents had experienced problems dealing with health professionals in the previous 12 months (n=488)

Chart 19.2 illustrates the range of problems reported by respondents. The most common problem was being on the receiving end of 'bad attitudes' of varying kinds. Respondents had experienced arrogance, abruptness and dismissiveness; a lack of sensitivity; and a failure to consider the person rather than the illness. Twenty-four respondents felt that attitudes had been explicitly discriminatory, mainly because of HIV status, but also because of sexuality, immigration status and age.

Respondents also complained of communication problems with health professionals, particularly those who failed to listen to them or make any effort to understand their concerns. Respondents did not always get enough information from professionals and even felt that information was

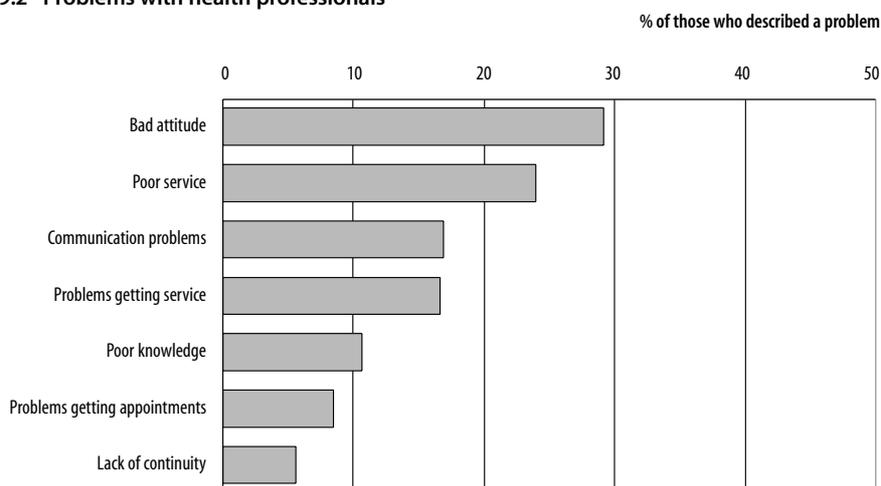
deliberately withheld. However, a few respondents also acknowledged that their own perceptions of professionals as authority figures inhibited communication.

Professional knowledge of HIV was also a problem: respondents complained that certain professionals, predominantly GPs, simply did not have the understanding of HIV to give them an acceptable service.

Many of the problems concerned the overall delivery of the service received rather than the specific character of their relationships with professionals – good relationships are unlikely to thrive if there are basic problems accessing and using the service. The single biggest problem was finding a dentist willing to treat someone with HIV, followed by similar problems with GPs. Some also reported difficulties accessing HIV out-patients services because they worked full-time and evening and weekend appointments were not possible. Very few respondents described professional unwillingness to provide certain treatments, including only two who had been refused anti-HIV treatment.

The respondents who had experienced a poor service included people who were rushed through appointments, had to wait for hours before their appointments, had to cope with mistakes by both administrative and professional staff, and had suffered loss of confidentiality. Other aspects of poor service (described separately in Chart 19.2) were lack of continuity of care – i.e. being switched between different doctors – and difficulties and delays in getting appointments when needed.

CHART 19.2 Problems with health professionals



19.2.1 Changes over 12 months

Twenty-nine percent of those who had experienced problems in the previous 12 months said that the problem had improved or been resolved. This was either because respondents were now dealing with someone else (by going to a different service or due to a change of staff at the existing service) or because the attitudes and behaviour of the staff concerned had improved. Although only six respondents had complained, many more had tried to improve their relationships through being more assertive, challenging professional attitudes and getting other providers to advocate for them.

For 19% of those who had experienced problems, things had got worse. The most common reason was a general deterioration of the service, often because it had become much busier. This compounded existing problems of access, communication and service quality. The loss of a key relationship because of changes in staff could also have a major impact, especially when such relationships were well established.

Changes in personal circumstances – particularly in health and treatment – could make problems dealing with health professionals better or worse, depending on how they affected dependence on services. However most changes in need were the result of changes in the service (or use of service) rather than changes in personal circumstances.

At the time of the survey, 54% of those who had experienced problems were unhappy about their ability to deal with health professionals (68% of those whose problems had not improved). Among those who did not report any problems, only 1% were unhappy about their ability to deal with health professionals.

19.3 GETTING HELP

Among the respondents who had experienced problems dealing with doctors and other health professionals in the previous 12 months, 35% had received some form of help or support to address their problems (Table 19.3). This leaves 65% who had not received any help, or:

17% of all respondents had experienced problems dealing with health professionals and had not received any help to address these (n=302)

The 'other' sources of help included clinic staff who supported respondents in dealing with problems both within the clinic and elsewhere (e.g. writing to GPs). Others had sought support from trades union representatives, solicitors or their MP.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Eighteen percent did not think that any further help or support would make any difference. The remainder either felt that more support would make a difference (59%) or did not know what might be gained (23%). Combining these last two groups, we can say that overall:

18% of all respondents had ongoing problems dealing with health professionals and felt that further help or support would be useful, or did not rule this out (n=328)

TABLE 19.3 Sources of help in dealing with health professionals

Source of help	no.	% those with a problem
clinic/hospital	81	(17)
HIV organisation	60	(12)
friends	35	(7)
partner	30	(6)
GP	22	(5)
advice or counselling agency	17	(3)
self-help group	12	(2)
council/social services	12	(2)
telephone helpline	11	(2)
other family	10	(2)
parents	9	(2)
children	2	(<1)
other	42	(9)

Their suggestions of what might help directly reflected many of the problems described above: better continuity of care and more communication between health professionals; better staff or better training for staff about HIV and the needs and lives of people living with HIV; more accessible services, with a wider range of opening times and longer appointments; and more holistic care with better communication between professionals and patients.

Many of these suggestions are for 'help and support' for service providers, rather than for the respondents themselves.

19.4 SUMMARY

Of all the respondents to the survey:

- 15% were unhappy about their ability to deal with health professionals
- 27% had experienced problems dealing with health professionals in the previous 12 months
- 18% had ongoing problems dealing with health professionals and felt that further help or support would be useful, or did not rule this out.

20 Discrimination

Discrimination is a problem, not a need. As such, it potentially increases many different needs such as needs for health, security, self-confidence, social contact and quality of life. A life 'free from discrimination' would mean many different things to different people. Nevertheless, discrimination was included in the survey because it was perceived to be an important problem for people with HIV.

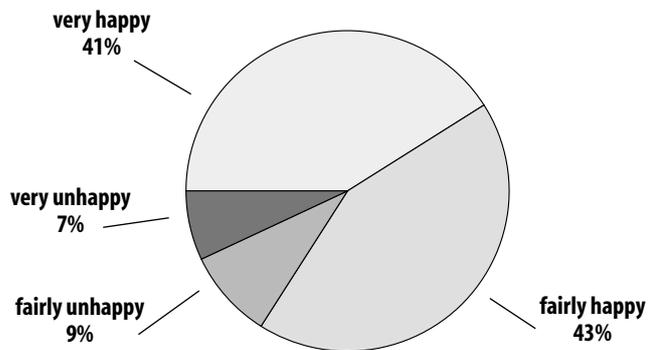
The emphasis of this section is on experience of discrimination and respondents' feelings about their ability to cope with discrimination. The latter is the most direct need created by discrimination and is crucial to minimising the impact of discrimination on all other personal needs.

20.1 FEELINGS

Respondents were asked how they felt about their ability to cope with discrimination. Overall, 84% felt very or fairly happy (Chart 20.1).

16% of all respondents felt unhappy about their ability to cope with discrimination (n=277)

CHART 20.1 Feelings about ability to cope with discrimination

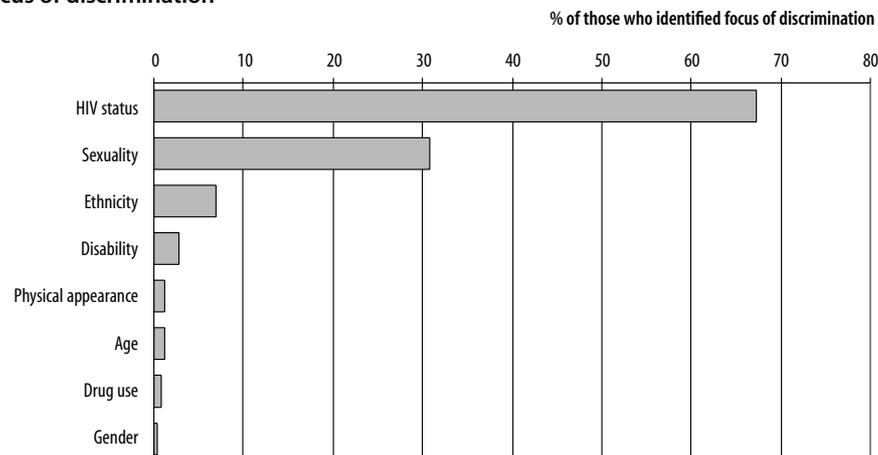


20.2 PROBLEMS

20% of all respondents had experienced discrimination in the previous 12 months (n=361)

Discrimination on the basis of HIV status was widely identified, but respondents also described discrimination on grounds of sexuality, ethnicity, disability, physical appearance, age, drug use and gender (Chart 20.2). Six percent of all the gay, lesbian or bisexual respondents described experiences of discrimination on the basis of their sexuality and 6% of all the Black and Asian respondents described experiences of discrimination on the basis of their ethnicity (five white respondents also reported racism).

CHART 20.2 Focus of discrimination



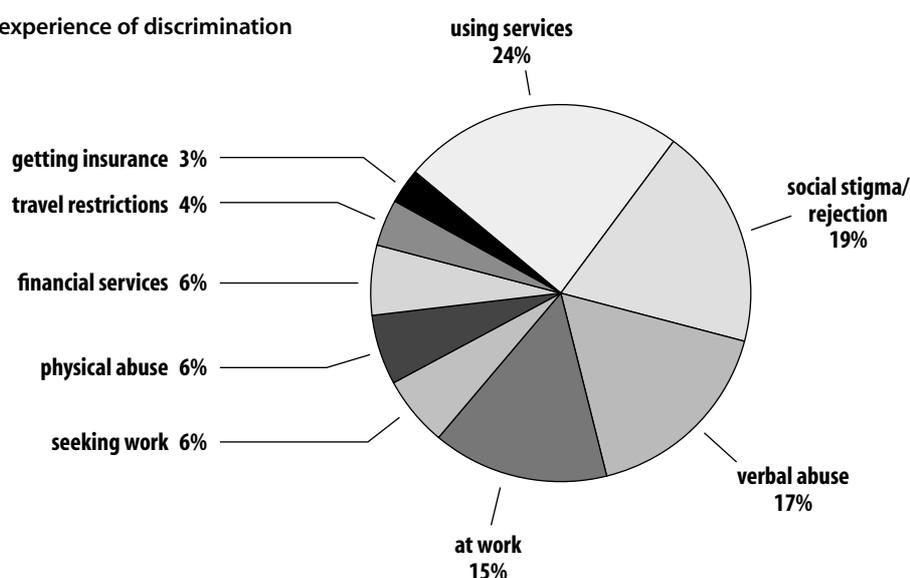
The locus of respondents' experience of discrimination is illustrated in Chart 20.3. A quarter of discrimination was experienced when using, or trying to use, public services. The worst offenders were hospital staff, particularly those in departments or wards without HIV specialist experience. Respondents were most likely to encounter discriminatory attitudes when they had to use health and social services for reasons other than HIV treatment and care. Discrimination was also encountered from other 'generic' service providers: housing department staff, GPs and dentists. The characteristic problem with dentists was almost always outright refusal of a service.

Social rejection and exclusion came from many different directions: from friends, partners, families, neighbours, acquaintances and communities in general. Although many experiences were very explicit, such as family members who refused to have any contact or friends who turned away, respondents also described more subtle but pervasive forms of exclusion, particularly the attitudes and ignorance that bred gossip, suspicion and rejection both in specific communities (gay, African) and in society as a whole.

The more direct and violent forms of social rejection – verbal and physical abuse – were predominantly homophobic in nature, reflecting the visibility of sexuality on the streets: most abuse came from neighbours or strangers and included comments and jibes from passers-by, threats, spitting and beatings. A few people described similar experiences targeting their HIV status.

Problems at work included overt prejudice, such as gossiping and bullying, and more subtle forms of discrimination: marginalisation, obstacles to career development, pressure not to take time off, exploitation of sick leave and a lack of sensitivity to personal circumstances. The respondents who described problems getting work felt that their HIV status had been a crucial factor in their rejections.

CHART 20.3 Locus of experience of discrimination



20.2.1 Changes over 12 months

A quarter (26%) of the respondents who had experienced discrimination in the previous 12 months said that their problems had improved or been resolved. Usually this was because of a change in circumstances such as moving house, leaving a job, stopping using a service or finding a new service. However, some respondents had found greater confidence either to cope with discrimination or to challenge it.

For 17% of those who had experienced problems, things had got worse. In some cases, this was because of greater isolation or new incidences of discrimination or abuse. For others, problems arose through new circumstances, wider knowledge of HIV status, loss of confidence or loss of support. However, for a few, it was greater confidence and outspokenness that generated further experience of discrimination.

At the time of the survey, three fifths (61%) of the respondents who had experienced discrimination felt unhappy about their ability to cope with discrimination (73% of those whose problems had not improved). Among those who did not report any problems, 5% were unhappy about their ability to cope with discrimination. This suggests that a significant proportion of people with HIV live in fear of discrimination despite having no direct (or recent) experience of it.

20.3 GETTING HELP

Among the respondents who had experienced discrimination in the previous 12 months, one third (34%) had received some form of help to deal with these problems (Table 20.4). This leaves 66% of those with problems who had not received any help, or:

13% of all respondents had experienced discrimination in the previous 12 months and had not received any help to address these problems (n=229)

The 'other' sources of help included crime-related agencies – the police, victim support, lawyers, GALLOP – and sources of advocacy or complaint such as trades unions, discrimination officers at work, housing associations, health authorities and the General Dental Council. A few had sought support from therapists, psychologists or the church.

Respondents whose problems had not been resolved were asked whether they felt that further help or support would reduce or overcome their problems. Twenty-eight percent did not think that any further help would make any difference. The remainder either felt that more support would make a difference (52%) or did not know what might be gained (20%). Combining these last two groups, we can say that overall:

TABLE 20.4 Sources of help in dealing with discrimination

Source of help	no.	% those with a problem
HIV organisation	41	(11)
friends	32	(9)
clinic/hospital	28	(8)
partner	24	(7)
council/social services	23	(6)
parents	14	(4)
other family	12	(3)
advice or counselling agency	12	(3)
self-help group	10	(3)
GP	10	(3)
telephone helpline	7	(2)
children	4	(1)
other	40	(11)

11% of all respondents had ongoing problems with discrimination and felt that further help or support would be useful, or did not rule this out (n=207)

Respondents' suggestions of what would make a difference included interventions for themselves – advocacy, support, information, better housing conditions – and (more often) interventions for society and service providers. The most common suggestion was for public education and awareness campaigns about HIV, targeting both service providers and broader society. It was hoped such campaigns would reduce stigma and help overcome discrimination and possibly even aid disclosure. Beyond professional education, respondents also wanted service providers to set clearer standards and ensure anti-discriminatory practice.

The law provided a further focus for change. Some respondents wanted stronger anti-discrimination legislation or inclusion of (asymptomatic) HIV infection in disability legislation. Others wanted legal recognition of same-sex relationships and the repeal of legislation that they perceived to be discriminatory, particularly Section 28.

20.4 SUMMARY

Of all the respondents to the survey:

- **16%** felt unhappy about their ability to cope with discrimination
- **20%** had experienced discrimination in the previous 12 months
- **11%** had ongoing problems with discrimination and felt that further help or support would be useful, or did not rule this out.

21 Skills, training and job opportunities

Paid employment is a means of meeting a wide range of needs. As well as providing an income, employment can give structure and purpose to life, enable social contact and build self-confidence. But not necessarily – employment can also become a burden and a source of anxiety and poor health.

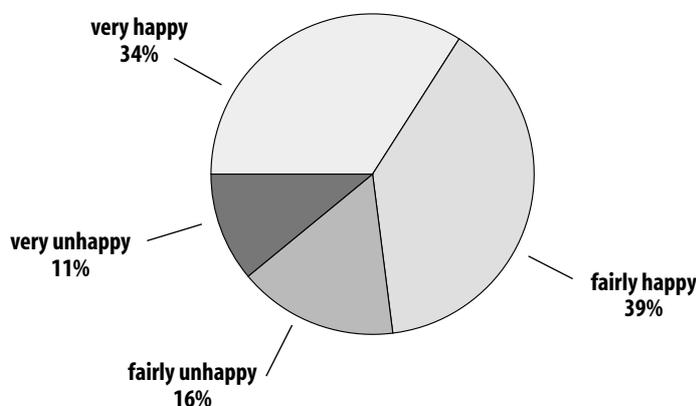
The survey explored respondents' feelings about their opportunities in the job market and their interest in learning new skills or retraining. Education and training are highly aspirational: they are pursued to increase the possibilities of life both within and beyond the job market. Although training needs are often linked to problems getting work, they need not be. Consequently, for this need area the focus of the survey was on respondents' interests, not their problems.

21.1 FEELINGS

Respondents were asked how they felt about their opportunities in the job market. Overall, 73% felt either very or fairly happy (Chart 21.1).

27% of all respondents felt unhappy about their opportunities in the job market (n=459)

CHART 21.1 Feelings about job opportunities



21.2 INTERESTS

39% of all respondents had been interested in learning new skills or retraining in the previous 12 months (n=694)

Respondents described a very wide range of training interests (Table 21.2). However, one need dominated: almost two thirds (64%) of those who identified a specific training interest mentioned computing and IT skills.

Other interests mentioned by at least two respondents included HIV awareness and HIV treatments, DIY, self-confidence, office skills, communication, photography, garden design and horticulture, customer care, driving, maths, fitness, dress-making, self-defence, cookery, film and television, proof reading, music, marketing, tourism and animal welfare.

21.2.1 Changes over 12 months

Over half (56%) of those who had an interest in learning new skills or training said their interest had increased over the previous 12 months. Many described improvements in health, energy and confidence and better expectations for the future. Such changes had opened up the possibilities of learning, but personal motivations for learning or training were diverse. Some respondents wanted to get work or improve their opportunities in the job market. They wanted to improve their income, get off benefits (or cope with the potential withdrawal of benefits), change their job or career, or realise personal ambitions. However, getting work was one feature of a bigger picture. More often, respondents described their motivation to learn more generally, as a desire to make the most of life and fulfil their potential for learning, productivity, achievement or personal development. Some wanted to overcome boredom and dissatisfaction, but most were more positive in their outlook, emphasising the many potential benefits of learning. A few stressed the immediate enjoyment and rewards of learning itself.

For 7% of those who had an interest in learning new skills or retraining, interest had decreased. The most common reason was a deterioration of physical and/or mental health. Personal confidence was also undermined when training failed to bring about any change – in particular, if employment remained just as elusive. A few respondents also described the frustrations of the ‘benefits trap’ (see Chapter 9).

At the time of the survey, 49% of those who had an interest in learning new skills or training were unhappy about their opportunities in the job market. Among the respondents who did not report any interest in learning new skills or training, 13% were unhappy about their job opportunities.

21.3 GETTING HELP

Among the respondents who had an interest in learning new skills or training, 53% had received some form of training or other help in learning new skills (see Table 21.3). This leaves 47% of those with an interest who had not received any, or:

17% of all respondents had an interest in training or learning new skills but had not received any help to address this interest (n=318)

The most common ‘other’ answer was some form of college: university, adult or further education college or local authority college. Respondents were studying part-time and full-time, through evening classes and by distance learning, and at every level from GCSE, NVQ and

TABLE 21.2 Training and learning interests

Source of help	no.	% specifying interest
Computing & IT	341	(64)
Languages	54	(10)
Management/business admin.	29	(5)
Complementary therapies	26	(5)
Counselling	22	(4)
Art & design	20	(4)
Teaching	12	(2)
Nursing	10	(2)
Accountancy/finance	9	(2)
Sign language	9	(2)
Writing/ journalism	9	(2)
Social care	9	(2)

TABLE 21.3 Sources of training or help learning new skills

Source of help	no.	% those with an interest
HIV organisation	102	(15)
partner	47	(7)
friends	40	(6)
council/social services	34	(5)
self-help group	21	(3)
parents	10	(1)
clinic/hospital	9	(1)
other family	9	(1)
advice or counselling agency	8	(1)
telephone helpline	7	(1)
GP	6	(<1)
children	1	(<1)
other	186	(27)

'A' levels through to Masters degrees and PhDs. Other sources of learning and training were employers, the internet and volunteering for charities.

Respondents with an interest in training were asked whether they felt that they could further improve their skills with more help or support. Twelve percent did not think that any further help or support would make any difference. The remainder either felt that more support would make a difference (81%) or did not know what might be gained (7%). Combining these last two groups, we can say that overall:

30% of all respondents had an ongoing interest in training or learning new skills and felt that further help or support would be useful, or did not rule this out (n=546)

Most respondents wanted to engage in some process of education or training, ranging from a computing primer to a degree. But all sorts of obstacles had to be overcome. The main problems were the availability or accessibility of courses and the financial implications of joining them.

Many respondents were unclear about what opportunities were available to them or wanted advice about how they could find courses which would suit their circumstances. A few respondents wanted to see more courses run specifically for people with HIV, but most just wanted something local, relevant and/or useful. In general, learning opportunities were perceived to be too distant, too demanding on time or health, too inflexible or too insensitive to personal needs.

But the biggest problem was money. Many respondents wanted help with the funding of particular courses or the provision of free or cheap training. There was a sense of frustration that personal willingness to develop new skills and become more productive was not matched by any willingness by the state to enable people to do this. A more flexible benefits system that did not put you at risk of losing benefits because of enrolment in education was a common wish.

For some respondents, fairly basic personal obstacles had to be overcome. Some needed childcare or access to a computer or the internet at home. Others wanted to gain confidence, direction and motivation, possibly through the encouragement of other people in similar circumstances or simply through good careers counselling and advice. Poor health and fatigue were also a problem, though the problem was usually perceived to lie with the inflexibility of education providers to allow for, or even try to understand, personal needs.

A few respondents stressed the discriminatory or inflexible attitudes of employers as a major disincentive to investing time and energy in training or education that might not lead anywhere.

21.4 SUMMARY

Of all the respondents to the survey:

- **27%** felt unhappy about their opportunities in the job market
- **39%** had been interested in training or learning new skills in the previous 12 months
- **30%** had an ongoing interest in training or learning new skills and felt that further help or support would be useful, or did not rule this out.

22 Implications for service providers

The needs described here present a number of challenges for service providers. The first is to avoid drawing quick conclusions about what the patterns of need mean for service delivery. Needs have deliberately been separated from service use because the question of what services are 'needed' cannot be answered simply by identifying the extent of personal needs. The overall pattern of need is a useful starting point, but this pattern is complex.

22.1 KEY FEATURES OF THE PATTERN OF NEED

The pattern of unmet need is summarised in Chapter 3, including the analysis for different socio-demographic groups (Table 3.6). The following are some very broad observations:

- Many people with HIV have very few needs or have found satisfactory ways of meeting their needs. HIV *can* be a chronic manageable condition.
- The most common needs concern quality of daily life rather than the practical problems which help to secure this. They relate to the intimate details of personal experience: how people feel about themselves; how people cope internally with the pressures of life; the value of sexual pleasure; the importance of rest and recovery.
- The practical and physical needs of daily life continue to be a burden to many people with HIV. Basic problems with housing, mobility, household chores, self-care, sustenance and child care may be the experience of a minority, but their impact on all aspects of life and personal opportunities is considerable.
- Dissatisfaction with job opportunities is as prevalent as dissatisfaction with personal income, though the relationship between these is not straightforward.
- Educational services about anti-HIV treatment and treatment-taking appear to be particularly effective – relatively little unmet need is reported in these areas. Negotiating the healthcare system and its professionals is a greater problem.
- The widespread experience of discrimination and social isolation both point to the particular harshness of living with HIV, compared to most other chronic conditions.

These observations may help service providers to think about where their priorities lie, but the questions of how and where to act remain open. There may be considerable 'capacity to benefit' among people with HIV, but decisions about how to deliver these benefits have to take account of the complexity of the experience and causes of need.

22.2 THE COMPLEXITY OF NEED

In each of the need chapters, respondents' own accounts of their problems are described. These accounts expose the complexity of need. Each need is closely linked to a variety of similar or dependent needs. Each need has many different possible causes ranging from things over which individuals have great control to others over which they have no control. Each individual perceives the need and its impact in a different way. Each individual has different ideas about how best to tackle the need. Some needs may be resolved by a single intervention; others may require ongoing support; others will persist despite everything.

It is precisely because of this complexity that quantitative measures of need are useful in identifying broad trends. However, service providers must address this complexity directly. Two key issues are the individuality of need and the many possible causes of need (and interventions to address them).

The complexity of need may make it difficult for service providers to decide exactly how and where they should focus their efforts, but every service provider should take seriously the individuality of need, which lies at the heart of the problem. This means doing some fairly basic things consistently: listening to what people say; respecting individual values and how people prioritise their own needs; taking seriously the secondary or unexpected impacts of interventions (especially medical ones); and ensuring that decisions are shared, not imposed. According to respondents, needs that affected quality of life, rather than simply health and illness, were often disregarded, especially in medical environments.

The causes of need range from physical health problems to the quality of housing conditions to the pervasive impact of political and social attitudes. Perceptions of where the causes of problems lay varied considerably, as did suggestions for interventions to address these problems. Consequently, the options for intervention are usually considerable. For example, different respondents identified all of the following kinds of intervention for most of the need areas in the survey (the examples are for anxiety/depression and sex):

- Medical intervention (e.g. anti-depressants; Viagra)
- Resolving contextual problems (e.g. speeding up Home Office or welfare benefit procedures; finding a new partner)
- Finding practical support or assistance (home help; taxi-cards)
- Building inner resources (e.g. counselling; assertiveness training)
- Enabling peer/community relationships (e.g. support groups; social events for people with HIV).
- Improving access and delivery of existing services (e.g. reducing waiting times for mental health services; training doctors to be more sensitive to sexual problems)
- Changing social attitudes (e.g. public education about living with HIV; community education about sex and HIV)

These interventions are directed at individuals, communities, existing services and society as a whole. Every service provider is likely to have commitments or strengths that will partly determine where among these choices its energies should be directed. However providers should recognise, at least collectively, the importance of addressing every level of potential influence over need.

22.3 CURRENT PROVISION OF HELP AND SUPPORT

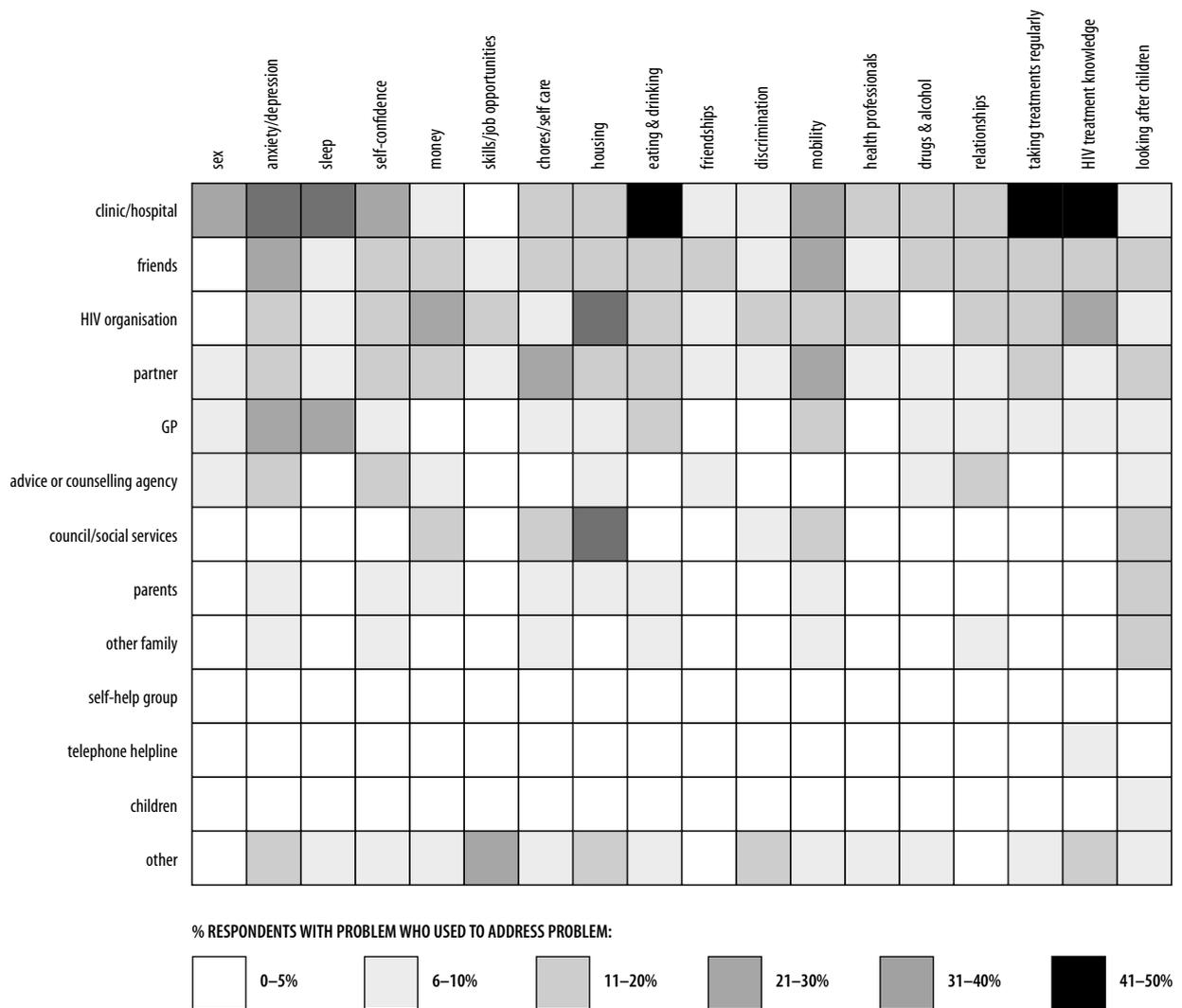
In each need area, respondents turned to a different combination of people and places for help and support (Chart 22.1). On this chart the service and support categories, which were predefined in the survey, are listed in descending order of their overall use. The need areas are listed in the order of Chart 3.2.

Chart 22.1 demonstrates the dominance of clinical services in meeting the needs of people with HIV. It is striking that such services, which can include a whole range of professions, are the most common source of help in addressing the four most common needs – related to sex, anxiety/depression, sleep and self-confidence – as well as the needs related to treatments and appetite/eating problems.

To some extent, clinical services have a captive client group as almost everyone uses them for HIV treatment or monitoring. However, some clinical service providers need to consider how they can address this broad range of needs in a clinical setting. For example, a common complaint among the 40% of respondents in full-time employment was the difficulty of accessing clinics (or any other HIV services) outside standard working hours.

HIV organisations continue to play an important role in many need areas, though there is clearly scope for them to do more. Unlike clinical services, HIV organisations have more freedom to choose where to act – they can deliver at all the levels described below except the medical. This may mean

CHART 22.1 Sources of help and support



that their role is slightly under-represented here, given the focus of the question on personal help and support. National anti-discrimination campaigns or lobbying to improve clinical services would not be picked up here, for example.

The chart also confirms the essential role of informal sources of help and support – especially friends and partners but also parents and other family. This is consistent with Table 3.6, which shows that respondents with partners are less likely to report the vast majority of needs. Rejection from partners, friends, families and communities was also profoundly felt. Answers across all needs also highlight the importance of peer support. Many respondents said they wanted more opportunities to meet and talk to people with similar experiences. For some this was perceived to be a means of overcoming isolation and loneliness, but it was also seen as an opportunity to deal with treatment issues, sexual problems and the many needs of everyday life. Although ‘self-help group’ barely features in Chart 22.1, this may in part reflect the lack of a clear distinction between this category and ‘HIV organisation’. Furthermore, many respondents recognised and regretted the reduction in the number of services that provided social spaces for people with HIV.

22.4 CONCLUSION

In the era of combination therapy, the challenge for service providers is to respond sensitively, flexibly and creatively to the variety of needs of people with HIV. Medicine may have shifted the pattern of need, but it has not transformed it. Interest in gaining skills and retraining is now more common than problems with mobility or coping at home, but HIV still takes its toll on mental health, personal relationships and quality of life. Lots of people remain constrained by their immediate circumstances – by poor housing, illness and disability, immigration problems, treatment side effects, discrimination and poverty.

Shifting the pattern of need further will require greater attentiveness to the particularity of individual need as well as action at all levels to remove the obstacles to the full participation of people with HIV in communities and society as a whole.

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