



HIV NEEDS ASSESSMENT

Executive Summary

**An assessment of the social support needs of
individuals living in Greater Glasgow with HIV**

2006

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Acknowledgements

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References

Weatherburn P, Anderson W, Reid D, Henderson L (2002) What do you need? Findings from a national survey of people living with HIV. London, Sigma Research.

Background

The number of individuals living with HIV in Glasgow has increased dramatically over the past few years. Since 1998 there has been a 341% rise in the number of newly diagnosed cases from 34 in 1998 to 120 in 2005. However the number of deaths has fallen dramatically. Compared to a peak of 42 deaths in 1994-1995 the average number of deaths per annum for the last five years is 6. This is mainly due to the effectiveness of Highly Active Anti-retroviral Therapy (HAART), which became widely available in 1997. This change in epidemiology has implications for the way in which HIV services are delivered.

In Glasgow the numbers of HIV positive people accessing non-clinical services is low compared to the numbers accessing treatment and there is a need to understand why this is the case. The purpose of this study was to examine the current social support and sexual health needs of HIV positive people living within the Greater Glasgow NHS Board Area, and whether the existing service providers adequately meet their needs.

This summary report presents the key findings and concludes with some recommendations.

Methods

Participants

The Brownlee Centre is a purpose build infectious disease unit and is the only treatment centre for HIV in Greater Glasgow. The majority of individuals with HIV in Glasgow attend the Brownlee, therefore the sample was selected from the Brownlee to ensure that information was gained from both those currently using non-clinical services and those who were not. In order to safeguard those who were newly diagnosed from any further distress, no-one who was diagnosed with HIV after the 31st of December 2003 was approached to take part in this study.

Procedures

Ethical approval was sought and granted from the West Glasgow Ethics Committee and the Research and Development Department.

The research commenced in March 2005 and a total of 478 individuals were eligible to take part. Questionnaires packs were administered to participants predominately during scheduled appointments by Brownlee staff. Patients who had previously given the Brownlee permission to send documents to their home address, were sent the questionnaire by post.

The pack contained an information sheet and questionnaire. The information sheet outlined the purpose of the research, that participation was entirely voluntary and gave details of people individuals could contact should they have any questions or if they required support to complete the questionnaire. There was also an information sheet and reply slip inviting people to take part in one-to-one interviews or focus groups. Two prepaid envelopes were supplied so that the names of those agreeing to participate in the focus groups could not be attributed to the questionnaire. Given the method of distribution, no reminders were sent or given to individuals. A deadline of 3 months was set for distributing the questionnaires.

Profile of Respondents

Response Rate

Of the 478-targeted patients, questionnaires were successfully administered to 374 individuals (78.2%). The response rate was 32% (n=129), which is reasonable for a self-administered questionnaire with no follow-up.

Of the 129 questionnaires returned, 98 (76%) clearly identified themselves as being from Greater Glasgow, 21 (16%) were from outwith Greater Glasgow and 10 (8%) did not supply their postcode. The data outlined within this report is for the 98 Greater Glasgow respondents.

The demographics were reasonably representative of the overall HIV cohort at the time the questionnaires were distributed. The majority of those responding were male (n=72, 73.5%), and just over a quarter were female (n=26, 26.5%).

Of the 72 males:

- 67 (93.1) identified as White
- 45 (62.5%) identified as being gay

- 32 (44.4%) reported being between the age of 35 and 44.

Most of the male respondents had been diagnosed for over 10 years (n=30, 41.7%), however there were similar numbers of males responding who reported having been diagnosed in the past 1-5 years (n=26, 36.1%).

Of the 26 females:

- 17 (65.4%) identified as Black
- 20 (76.9%) identified as heterosexual
- 11 (42.3%) reported being between the age of 35 and 44

By far the majority of females reported having been diagnosed in the past 1-5 years (n=21, 80.8%).

With regards to the all respondents¹:

- 13 individuals (13.5%) said that they had ever injected drugs
- 17 individuals (20%) reported having Hepatitis C
- 25 individuals (29.4%) said that they had a physical impairment
- 3 individuals (3.5%) said that they had a learning disability
- 3 individuals (3.5%) said that they had haemophilia

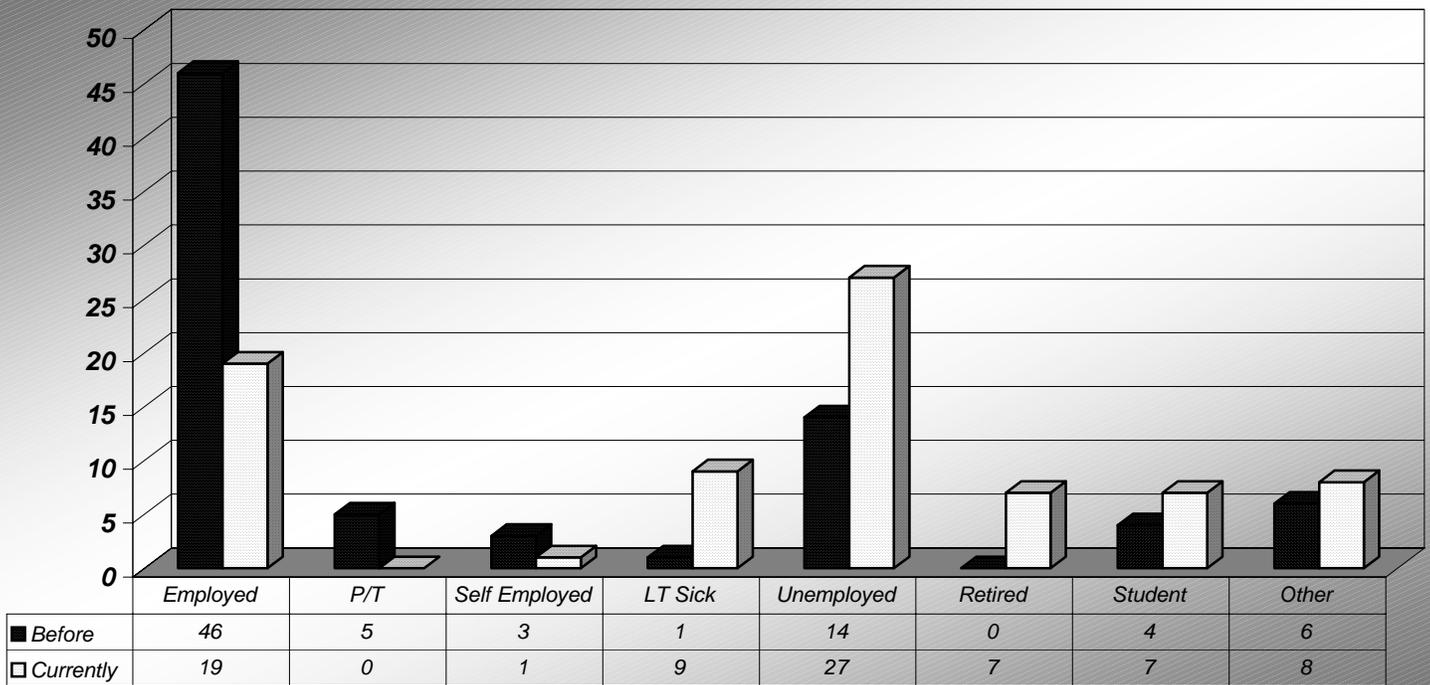
Employment History

79 individuals gave an indication of their employment status both currently and before their diagnosis. Although it is not possible to assess whether changes in employment status were a direct result of their HIV diagnosis, the data suggests that HIV status may be impacting on people's employment status. The findings from the Sigma research report "What do you need"² also suggest that employment is an area of need for people with HIV and that many are unhappy about the opportunities available to them. Respondents from this study and within the Sigma report talked about being stuck in a "benefits rut".

¹ Not every individual answered each question therefore these figures are a percentage of those answering specific questions

² "What do you need" is a piece of research undertaken by SIGMA looking at the needs of people with HIV across the whole of the UK.

Figure 1 Illustration of the changes in employment status before after HIV diagnosis



Drug Therapy Treatment

- 69 individuals (71.9%) said that they had ever used combination therapy, most of whom (n=60, 89.6%) were still taking it.
- Most reported having started in the past 1-5 years (n=34, 51.5%) although nearly equal numbers said they had been taking it for more than 5 years (n=30, 45.5%).
- 15 individuals (25.9%) reported having had a break from therapy, the most common reason given for taking a break being problems with side effects.

Relationship Status

- 43 individuals (44.3%) said that they were currently in a relationship.
- The mean duration of these relationships was roughly 8 years but the length varied between 2 months and 36 years.

- 30 of the 43 individuals (69.8%) said that their partner had not been diagnosed with HIV; a quarter (n=11, 25.6%) said their partner was positive and 2 (4.7%) said that they did not know if their partner had been diagnosed with HIV.

Children

- 24 individuals (25.5%) said that they had children under the age of 16.
- 17 individuals of these 25 individuals (68%) said that all or some of these children lived with them.
- Most of those with children who were living with them were Black African women.

Living Arrangements

- Council/Housing Association let was most commonly reported by individuals when asked to describe their living arrangements (n=49, 50.5%).

Main Findings

The following section provides a summary of the key findings in relations to HIV related needs, sexual health needs and service knowledge and usage. Further details of the findings are available in the full report, which is available through the Sexual Health Team within NHS Greater Glasgow.

Needs

Section two of the questionnaire asked questions specifically about individuals' needs; specifically if they had needs as a result of being HIV positive. Fifty-four respondents (56.3%) reported having specific needs as a result of being HIV positive, the top 3 of which were in relation to general health and wellbeing, financial support and nutritional advice, although the needs varied slightly depending on ethnicity, sexual orientation and gender. Forty-two respondents (43.7%) said they did not have specific needs in relation to HIV.

Although a number of people reported having needs, about a quarter of these individuals reported that their needs were being met. Those whose needs were being met most

commonly reported that their needs were managed through the Brownlee Centre and/or were self managed which supports findings from the Sigma research “ What do you need” which states

“Many people with HIV have very few needs or have found satisfactory ways of meeting their needs. HIV can be a chronic manageable condition.”

For those individuals who reported that their needs were not being met the top 3 most commonly reported unmet needs were in relation to housing, financial support and physical activity. When these unmet needs were examined according to gender and ethnicity male and white respondents were most likely to report unmet need in the order outlined. However for women and Black respondents the focus changed slightly. Women most commonly reported physical activity as an unmet need followed by financial assistance and housing. Black respondents most commonly reported financial assistance followed by housing and then support in finding employment.

Only a few people identified that they needed support with activities of daily living (n=26, 27.4%) and the majority of those who did, had a carer (n=21, 80%). There were however a small number of individuals who said they needed support with activities of daily living but who were without a carer (n=5, 19.2%). None of the 5 who were without a carer were in a relationship, 2 had a physical impairment and 2 were co-infected with Hepatitis C.

The question was posed as to whether there was a need for a specific HIV support service and the majority of respondents indicated that they thought that there was a need and that this should offer a range of activities. Although there was little clear definition as to what an HIV support service should offer, social support and having other people with HIV to talk to did appear to be something that people thought was quite important.

When asked as to whether there was adequate support for families and partners, the views of the whole cohort who responded were split with 41 individuals (52.6%) saying there was adequate support and 37 (47.4%) saying that there wasn't sufficient support. There was no consensus from those in relationships with 17 individuals (45.9%) saying no and 20 (54.1%) saying yes. Suggestions as to what support should be available to families

and/or partners included education about HIV, treatment updates, emotional support and advice about sexual practices.

Sexual Health Needs

The majority of respondents felt that they had enough information on sexual health (n=68, 73.1%) and knew where to access a sexual health service (n=80, 87%). However this did not appear to be the case for a small number of individuals who felt they had insufficient information (n=9, 9.7%) or were unsure as to whether they had adequate knowledge in this area (n=16, 17.2%).

Respondents appeared to think that the sexual health services they had used catered reasonably well (n=17, 36.7%) or extremely well (n=15, 30.6%) for the needs of people with HIV. However for individual services there were range of different views and these services might be advised to see where improvements could be made and what roles they might have in meeting individuals unmet information needs.

Many of the respondents seemed to be having issues with regards to sexual health, particularly in relation to low self-esteem or difficulties in having relationships and these issues were statistically more significant amongst those not in relationships. Similar findings were found in the Sigma research where 40% of individuals reported being unhappy with their sex lives and 51 % reported having experienced difficulties similar to those in this study within the 12 months prior to the Sigma research. Relationship support and advice was a need commonly reported by Black respondents, female respondents and heterosexuals and was the 4th most commonly reported area of unmet need.

Although there is clearly a need to examine ways of addressing some of the issues individuals are experiencing, the idea of groupwork for people with HIV around sexual health and relationships was met with mixed responses implying that whilst group work may be useful for some people, a variety of approaches will be required.

Knowledge and Usage of services

Within NHS Greater Glasgow, there are a number of organisations who offer some level of support around HIV and sexual health. Within the questionnaire, questions were asked about each of these services to get an overview of usage, benefits and barriers.

Most people had a reasonable awareness of the services asked about in this study. However there were again small numbers of individuals for whom this was not the case and who had never heard of certain services or who were not aware of aspects of these services. Similarly the usage of these services was mixed with not all of those who had heard of the services choosing to use them and with others only using certain parts of the service³. Those individuals who had heard of certain services⁴ but never used them were asked why. Respondents gave a variety of reasons as to why they were not using some of the services; the most common reason given was because they didn't feel the need.

"I feel great." (R 1)

"I have never needed that type of support" (R 17)

"Don't feel the need" (R 47)

"Never really felt the need, nice to know that support is there if needed. Got really good support from friends and family" (R77)

Other reasons given for not accessing particular services within those asked about⁵ were around not knowing what was on offer, issues around accessing HIV support services, disclosing status or having heard negative things about the service.

"Because I didn't {know} that all this services are provided" (R 66)

"I feel I would feel uneasy at such an organisation" (R 55)

"Word of mouth about how dysfunctional and damaging its endless infighting has affected the people involved (R57)

³ It should be noted that the HIV-AIDS Carers & Family Service Providers Scotland are predominately set up to support carers/families and partners of people with HIV, therefore asking people with HIV as to their usage or their parents/carers usage may not give an accurate reflection of the overall usage of the service. Additionally the Lesbian and Gay Switchboard is a telephone support line predominately used by people experiencing problems with their sexuality and therefore although they offer support and advice around sexual health and HIV, many people with HIV may not utilise this service for support on this issue, particularly as it is targeting a specific group of individuals.

⁴ This question was asked of individuals who had heard of PHACE Scotland, Body Positive Strathclyde and the HIV-AIDS Carers & Family Service Providers Scotland.

⁵ Not all comments apply to each of the services. Similarly not all of the comments apply to one service. These comments are a summary of some of the reasons given for not accessing particular services.

Similarly those who had attended in the past but were not longer doing so were asked why, reasons people gave for no longer attending services included bad past experiences or just no longer feeling the need to attend such a service.

“The staff have a bad attitude, they are self centred, vindictive and not very nice people no matter what their leaflets say.” (R5)

“No need at the moment” (R31)

People’s experiences of using the services asked about were also varied. For some services, most had received a satisfactory service and had derived benefits from attending, including financial support and talking to other people with HIV.

“Financial assistance” (R86)

*“Being able to talk/confide in someone almost 24 hours.
Someone else who is HIV and understands” (R71)*

However for others their experiences of HIV support services had not been good with people stating that their experience had been unsatisfactory or very unsatisfactory; these comments were mainly made in relation to Body Positive Strathclyde, which ceased to operate in 2004 due to on-going internal difficulties. It is not surprising therefore that some dissatisfaction was expressed by respondents. However equally there were many people who said they had received a satisfactory or very satisfactory service from Body Positive Strathclyde. This appears to be historical, as comments illustrated that people perceived that the quality of service received in recent years was less than adequate. The question was not specifically asked about how individuals rated social work services on the whole, however individuals were asked about particular aspects of the service within which they could indicate whether they had found it beneficial or not. Some people had clearly found aspects of their services useful.

“ Very helpful” (R70)

“ Good help with housing info”(R74)

Individuals were also asked about any barriers/difficulties they had experienced and for PHACE Scotland, very few were reported, those that were, were in relation to access or dissatisfaction about a particular aspect of the service. However, for Body Positive 28

individuals (62.8%) reported barriers most of which were in relation to staff attitude (n=18, 64.3%) and not feeling welcome (n=12, 42.9%). Although only small numbers reported attending (n=10) the HIV-AIDS Carers & Family Service Providers Scotland, around one third of those who had, experienced barriers (n=3) mainly in relation to staff attitude (n=2). Of the 10 people who had used the Lesbian and Gay Switchboard, 3 individuals reported difficulties all of whom reported these difficulties were in relation to getting through. For social work some individuals had experienced some difficulties with certain aspects of their services.

“Very limited support too 9-5” (R40)

“Service is overly intrusive at times. It is supplier driven {than} user driven” (R69)

Individuals were asked if they would change anything about specific services. Although some suggestions were put forward these are not easy to summarise into a general theme. The responses were very specific to each of the individual services asked about and varied between changing the location, staffing to creating a service for people with all chronic illnesses rather than just HIV.

Summary

The purpose of this study was to examine the current social support and sexual health needs of HIV positive people living within the Greater Glasgow NHS Board Area.

Whilst a relatively small sample, the demographics of the sample that took part in this study were fairly representative of Glasgow’s HIV population at the time the questionnaire was administered. The findings of this study can therefore be seen as giving a reasonably accurate picture of the views of people with HIV living in Glasgow at that time. In addition many of the key findings are similar to the findings of the Sigma report ‘What do you need’, which was a national survey of the needs of 1821 respondents with HIV.

From this sample, it is clear that not everyone living with HIV has stated needs associated with their infection, however some of these individuals have developed strategies to deal

with these needs and these can include the use of HIV support services. For those individuals who have needs that are not being met by current service provision or through personal coping mechanisms there is an obligation to ensure that these needs are adequately addressed. In addition, people's needs are not defined upon diagnosis – they will shift and change according to circumstances and therefore those people and their requirements in terms of support, advice information and help will also shift and change. Many of the needs that people have could be addressed through social work services and other mainstream services and there is a need to ensure people with HIV are aware of what these services can offer and how to access them. Training for mainstream services around HIV will be vital in ensuring some of the barriers for people with HIV are tackled.

A number of people were clearly experiencing difficulties with regards to aspects of their sexual health particularly in relation to self esteem and ways of addressing some of the issues for people, particularly those not currently in relationships need to be examined. Group work should not be the only solution on offer as it was met with mixed responses.

The use of HIV support services was mixed. Many people did not use such services because they did not feel they currently needed to and often this was cited as a reason as to why people no longer used such services. For many these services did appear to bring some benefits mainly in relation to financial assistance and peer support and there is a need to ensure that this is still available to people. However for others the use of HIV support services was not been beneficial and in some cases people indicated had made things worse. Many of reasons given for bad experiences related to the organisational set up.

Given the results of this study, it is unlikely that one model will suit all individuals with HIV. HIV is a chronic but manageable condition; some people will require more support, some may require none. When looking at ways of meeting the needs of people with HIV an approach is required that will be accessible to all individuals with HIV and maximise the support/benefits for people with HIV as and when they require it throughout their life.

Recommendations

Having reviewed the data arising from the questionnaire, the following recommendations have been made.

1. Development of a resource (or review of existing resources) to ensure maximum awareness amongst people with HIV as to where and how they can access services which may better meet their needs. This should be available upon diagnosis and readily available to people with HIV within the Brownlee Centre.
2. Services such as the “ Live Active” service⁶ should be promoted by all staff within the Brownlee who are involved in the treatment and care of individuals with HIV. Exercise Counsellors from the scheme could come to do an input to staff and or patients highlighting what the service offers and how it could benefit individuals with HIV.
3. Stronger links need to be made between HIV services and mainstream services who might be able to meet some of the needs of people with HIV for example employment agencies. Training should be provided where appropriate to ensure that this happens and barriers are minimized.
4. Ways of helping people in terms of employment and training should be examined. Employment This support could involve working with individuals to find courses or develop skills for the workplace but it could also involve working with workplaces to ensure they are equipped to deal with an HIV positive employee and are informed about employment laws around HIV. A common wish amongst individuals taking part in the Sigma research was for a more flexible benefits system that did not put individuals at risk of losing their benefits because of enrolment in education and it maybe that whatever programmes/training opportunities are developed would need to consider this.
5. Ways of addressing sexual health problems experienced by individuals needs to be investigated.

⁶ The ‘Live Active’ service is a service that supports people in becoming physically active. All staff have recently been trained in exercise counselling and providing appropriate programmes for people with HIV. The service currently accepts referrals from the Brownlee Centre.

6. Social support needs need to be considered as part of service delivery. This has traditionally been in form of drop-ins sessions within services, although these may not necessarily be the best use of resources. Talking to someone else with HIV does appear to be important for many individuals with HIV, therefore ways of providing social opportunities may need to be looked at i.e. social events and peer support.