

The Support and Resource Needs of Gay Men with HIV / AIDS, their Partners and Carers

A Report by Sigma Research

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Preface & Acknowledgements

Some minor changes have been made to the report which was originally completed in 1995. Notably, the section on sex and sexual health has been removed. There is a more comprehensive account of this which includes the data used in this study in the companion report to this 'The Sexual Health Needs of Gay Men with HIV' (also available through Sigma Research). Some other comments are due. With hindsight, we realise that the fieldwork for this study was carried out at a very bleak time indeed for people with HIV. AZT was perceived to have failed with no other treatment options on the horizon. A certain pessimism pervades this report which is reflective of this. Thankfully, we have more reasons for optimism now. There have been other changes, particularly to the gay scene, the gay press and health promotion practice. In late 1994, there was no 'positive' press and little coverage of HIV issues in the gay press. Gay prevention agencies were doing little or nothing for gay men diagnosed with HIV and there was no sexual health advice for this group. All this has changed, due in some small part to this report and its companion report.

Thanks are due to many people for their contribution to this piece of work. First, the gay men who took part in the focus groups merit a considerable vote of thanks. Confidentiality precludes them from being named individually but their individual contributions are what made this report possible.

We also need to thank all the team members at Sigma Research who contributed whenever asked. Special thanks to Dr. Peter Davies and Peter Weatherburn for advice and critical comments.

Thanks are also due to the organisations which served as venues for the focus groups: Body Positive, The Facts Centre, and especially the Link Centre in Camden. Thanks also to those individuals and organisations who allowed us access to their archives of health promotion materials for gay men: Gay Men Fighting AIDS, Gay Men's Health Crisis, New York and Mr. Simon Watney.

Of course the authors are responsible for all the views expressed herein.

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SECTION 1: BACKGROUND

1.1 Introduction

While the sexual behaviour and social lifestyles of gay and bisexual men is now well documented, there has been little research into gay men with a positive HIV diagnosis (hereafter HIV+). What research there is, has been mainly quantitative, clinical or with a heavy psychological emphasis and has tended to concentrate on well-being, quality of life, and adherence to treatment and care programmes. Furthermore, the samples for such research have invariably been recruited through GUM or HIV clinics.

Moreover, there has rarely been research which takes as its main motivation, the support needs of those men who are HIV+. The research that has been done in this area has subsumed HIV+ men into a general category of people with HIV. It has therefore failed to recognise the differences in social and sexual lifestyle that many gay men share. To address this, the Terrence Higgins Trust with Hammersmith and Fulham Social Services commissioned Sigma Research to carry out a wholly qualitative piece of research, the aim of which was to identify the support and resource needs of HIV+ gay men, their partners and carers.

We present a selection of the findings of this study here. Section one of this report presents the demographic information of our sample. Section two considers the social support networks of HIV+ gay men and the interplay of three separate elements within this network: the family, the partner and the gay community as embodied within the concept of the 'gay scene'. Section three explores a central concept which emerged from the research. This is the use of the 'coming out' process to cope effectively with an HIV diagnosis. In this chapter we draw parallels between this process and the reported experience of gay men with HIV. Section four is a critical review of health promotion materials aimed at gay and bisexual men produced within the UK and abroad. Finally, section five is a summary and discussion of the main conclusions of this report. It also includes recommendations.

1.2 Methodology

For the purpose of this study, focus groups were convened. The focus group differs from face to face interviews because although attitudes and opinions are still being examined, the group dynamic and the context in which statements are made are given equal importance. The most important advantage of focus groups is that statements made by one group member are either challenged or concurred with by other group members. It is the facilitators job to explore the nature of agreement or dissent within the group.

When considering the results of such research, it is vital to bear in mind that focus groups are useful for reporting a range of opinions and attitudes surrounding a subject. Their purpose is not to establish 'facts' or to gain consensus on a subject, but to 'unpack' and explore an area. Consequently, analysis focuses on identifying themes around which attitudes are held by

considering foci of discussion. Throughout this report, a number of opinions will be reported which may seem either too extreme or too muted. The purpose of reporting these opinions is to illustrate not only typical attitudes but also variations in the strength of attitudes held, and to ensure we encompass all sides of the debate.

1.3 Group and Participant Description

Six groups were held over the course of three months between October and December 1994. The groups comprised the following:

- 1 mixed group of carers and partners of gay men with HIV/AIDS in Cardiff.
- 1 group of carers in Cardiff.
- 3 groups of gay men with HIV/AIDS in London.
- 1 group of partners of gay men with HIV/AIDS in London.

The groups were recruited from advertisements in the London gay press, advertisements in Body Positive newsletters and through voluntary and independent sector AIDS Service Organisations.

The two groups of carers and partners in Wales were both recruited from existing support groups. Therefore, the participants knew each other and were used to interacting in a group situation. The group of carers in London were all recruited from various AIDS service organisations (hereafter ASO). This group comprised men who were HIV+ and men who assumed themselves to be HIV negative. In order to examine the attitudes of men who may not have been in receipt of services, we ensured that two of the groups of gay men were recruited entirely from advertisements in the gay press and the third was a mix of men recruited through the gay press and through ASOs.

Demographic information was gathered on all of the group participants. In addition, the carers were asked to give their relationship to the person they cared for and whether or not that person was living or deceased. The gay men's groups and the partners group were asked about the services they used and which (if any) benefits they were in receipt of.

Demographic Information

A total of 46 participants were recruited. The average group size was 8, the smallest group having six participants and the largest having nine. The demographic breakdown of participants is as follows:

Carers / Partners groups (N=16)

Age

Mean age: 42 years
Age range: 31 - 70 years

Ethnicity

White European: 15
White other: 1

Relationship to person cared for

Mother 2
Sister 8
Partner 4
Friend 2

Person cared for:

Still living 6
Deceased 10

HIV+ Gay Mens' Groups (N=26)

Age

Mean age: 36 years
Age range: 24 - 54 years

Ethnicity

White European: 24
African Caribbean: 2

Years Since first diagnosed

Average: 4 years
Range 3-120 months

No. with an AIDS diagnosis 3

Gay Partners Group (N=6)

Age

Mean age: 36 years
Age range 26 - 54 years

Ethnicity

White European 5
White other 1

HIV Status

No. HIV+ 4
No. HIV- 2

Partner:

Still living 2
Deceased 4

All of the family carers used self-help support groups. All but three of the gay partners had been to self help groups. Of the men who were recruited through advertisements in the gay press (N=14), all were registered at one of the main London HIV clinics. All but two used other services. Incomplete information was provided on service use for men recruited through ASOs (N=13). However, all were registered at one of the main London clinics and all used other ASOs for a variety of services. Eight of these men used other local authority services.

The groups covered the following topic areas:

- Gay Men's Groups

Experience of social and practical support, starting with diagnosis and continuing to the present.

Experiences of the 'gay scene'.

Partnerships and relationships.

Sex and sexual decision making.

- Carers and Partners Groups

The person cared for.

The carers' needs.

Sexuality (issues around sexuality in caring for a gay man).

- Partners Group

Experience of support, starting with diagnosis and continuing to the present.

Experience of the 'gay scene'.

Partnerships and relationships.

Discordance / concordance of HIV status.

Sex with their partner / with other men.

Whilst all of the groups were separate, there was some crossover of experience between the groups. For example, some of the men in the gay men's groups were also in long term partnerships or also cared for other gay men with HIV. Their experiences are also reported.

Questions regarding service use were dropped after the first group. The men tended to talk about a broad range of services that concentrated on individual service providers rather than the services themselves. We concluded that whilst an investigation of gay men's attitudes and experiences of services was necessary, this had to be done in a more systematic way (including face to face interviews and self-completion questionnaires mapping service use with a large sample). This would involve an entirely different approach and methodology.

SECTION 2: SOCIAL AND EMOTIONAL SUPPORT

2.1 Background

In the past few years, the emphasis on social services for the chronically and terminally ill has moved from providing direct care for the patient to empowering and supporting informal carers to care for the patient. This shift has been recognised in the Government White Paper *Caring for People: Community Care in the Next Decade and Beyond* (1989) when it states "the government acknowledges that the great bulk of community care is provided by family, friends and neighbours" (section 1.9).

Defining what constitutes a support and care network is difficult. If carers are to be empowered it is important to establish exactly who they are, how they relate to each other and what their needs are. That gay men with HIV/AIDS turn to informal carers and establish support networks is beyond doubt. In a non-clinic sample of gay and bisexual men, Hart et al (1994) report that 92% of the sample could identify one person who provided personal and emotional support. This person was usually a male friend or partner. In the same study, the majority (92%) said that they could turn to someone if they needed practical help during a period of illness. Again, this person was most frequently a friend or a partner, with only 18% saying that they could rely on a parent or other relative. McCann et al (1994) reported that 55% of a clinic based sample of HIV+ gay and bisexual men were able to nominate someone who gave them help or care on an informal basis. Again, these were close friends (45%) or partners (42%), with only 4% nominating a parent and 4% nominating a sibling. The majority of the carers were male and were significantly younger than other population studies of carers. Moreover, 10% of these carers were HIV+ themselves.

Although Hart concludes that support networks within the gay community appear to be strong both in terms of emotional and practical support, he cites a number of studies which demonstrate that during terminal illness, maintaining relationships outside of the immediate biological family are difficult and that informal terminal care depends upon close and intimate contact, not the kind of diffuse support available to gay men generally. The process of establishing care networks for gay men will therefore, almost certainly be problematic. Hart et al (1994) concludes that "the routine and long-term provision of practical support to gay men with chronic disease cannot be borne to any great degree at an individual level by members of the gay community".

Previous analyses of the support networks of gay men have been based mainly on quantitative data. Thus, a qualitative approach was necessary to address the following questions: First, how do the different groups in gay men's networks coalesce to provide supportive and caring environments? Secondly, are these networks sufficiently stable and resourced to bear the strain of dealing with advanced HIV disease and death?

Our analysis centred on three separate groups that emerged as important from the focus groups: families, partners and the gay social context or 'gay scene'. We analysed the experiences and attitudes of gay men with HIV disease towards these three groups. We also report here on the experiences of family members and partners who are themselves carers.

2.2 The Family

"Well you have two families, don't you. Your biological one and your gay one. Your gay friendships tend to be strong. So in many ways, your friends become your family."

It was in no way certain that the men would either disclose their HIV status or turn to their families for support with their HIV disease. The whole issue of one's family was seen as problematic by many of the men, their attitudes towards their families being informed by their past experience. Men were concerned about disclosure to family members often weighing up the following considerations:

- The family are likely to have a negative or problematic reaction to the news of a diagnosis.
- The family needs to be prepared for impending illness, death and consequent bereavement.
- The family might be able to offer emotional or practical support.

As many did not anticipate support from family members, decisions about telling the family were generally focussed on the first two considerations.

Anticipating Family Reactions

Many of the men recalled critical incidents from their pasts when deciding to tell their families. Some were related to health and support:

"Well I had an incident before I was diagnosed when I was staying with my parents. I was really unwell and in bed. I was feeling really panicky as well. I came downstairs and burst in on my parents. I said something like 'you're just sitting down here and I'm upstairs dying probably with AIDS.' My mother put her arm around me but I got the feeling that she was just going through the motions and it really didn't help. It turned out later that I had Hep. B. I feel like I went through a kind of 'dry run' with my parents and they were not very supportive. I haven't told them now that I am positive and I would hate to have to be looked after by them. "

Others were related to sexuality:

"I'm fairly close with my mother, not my father, I would tell him but he's never accepted me being gay so why should I tell him?"

Still others were related to AIDS itself:

"My parents think that anyone who gets AIDS deserves it."

There were also men who recalled their families conflation of homosexuality with HIV:

"My mother said that she was always expecting me to get HIV 'cause I'm gay."

There was thus a disincentive to telling the family because an HIV diagnosis will validate their perception that their son's lifestyle is somehow 'depraved':

"Both my parents don't approve of me being gay. They think that it's dirty and hide it from the neighbours. My mother always said that, you know, there were wicked people out there and that I'd get AIDS. Now if I tell them, they'll both think they're right."

Some men, however had experienced positive reactions in the past from their family:

"My parents were always very understanding. They're a bit too old to look after me, but I know that I will tell them in time."

"My mother was a nurse and she was also a buddy. I realised that I wanted her there when I took the test and she was really marvellous."

Experiences of family reactions

Men reported a range of experiences of their families reactions to disclosure of HIV status. For many, the reactions were negative:

"I told my family and they don't have much to do with me now. If I give presents to my nephews and nieces, then the kids don't get them, they're thrown out. I saw the rest of them recently and they were very cold, they didn't talk to me."

"My family weren't particularly supportive, My mother went lunatic and I had to cut her out of my life. I'm only now rebuilding the relationship with my brother."

Although these reactions caused some unhappiness, they were seen by many as useful in establishing where their families stood in relation to their HIV infection.

"Well I know where I stand now. I'm on my own."

In contrast, for others, the reaction was positive:

"I am privileged to have a wonderful family. My father and I, we are wonderful friends and he is proud of me. He is really proud of my achievements. I knew I could tell him about it and he has been wonderful even though I know that it has been really painful for him."

sometimes surprisingly so; a man who had recently lost his partner said:

"My partner was terrified about telling his family. We had never approached them about his illness or his sexuality. We didn't do it because of the fear of

rejection or of hurting them. Well, he finally told them and the response was so positive and for the previous seven years he had not included himself in the family. We tend to underestimate families in regards to many things."

This viewpoint was echoed by some of the family members in the carers group. Whilst they acknowledged that many families did indeed, reject gay sons and brothers with AIDS and that they were the exception to this, all of them would have preferred to have been told earlier than they had been. One mother said:

"I'm sorry for the sisters and brothers who are told later or maybe too late [...] because I knew for four years. I was never ashamed to say 'my son has AIDS'. Tell them [family] as soon as possible rather than worrying about it - It's a waste of time. Give them [family] the chance, the opportunity to care."

Another sister agrees saying:

"At least give them time to get used to it. Then they can decide if they don't want anything to do with you. If they [families] have more time, then they might even come round. [...] We didn't even have time to think. My parents didn't even know he was gay, and within four weeks of telling us, he was dead. We only got to see him a few times in a hospital in London."

There was agreement that *when* one told one's family was important. Most of the men saw it as appropriate to tell families later on in their illness, but needed to strike a balance between rejection on the one hand:

"I wouldn't risk losing my family by talking about it too much."

and the need to prepare their family for bereavement on the other:

"There is a point where you have to tell them. It would be bad if they only found out after you had died and I wouldn't like them to find out after I got ill. [...] There comes a point, however, when you realise your body is changing and that you are getting nearer to the end of the road so you have to tell them before becoming sick. It's hard to tell when that point is."

Many men fear that their families will be affected by the worry

"But, the longer they know, the longer they worry."

and the effects that this worry may have on them:

"I haven't told the family because if I'm feeling low or unwell or erratic, I don't want the pressure of my family always thinking - well this is it. I don't want their first reaction to be 'is this a sign' because if I get enough of that from people, I might start thinking, well, maybe they're right, maybe I am getting sick."

This concern is borne out in the experiences of some of the gay men who told their families and got positive reactions. For some, coping with their family's reactions is like reliving their own initial reactions or having to provide support to their family when they need it themselves:

"I had to give my father a pep talk about living and life, life, life. I can't keep this up. I can't be a participant and an observer."

Family reactions can be particularly upsetting:

"I told my sister over the phone. It was selfish of me because it puts a lot of pressure on her and anyway I wanted someone to talk to in my family. But it hasn't worked out that way, now she phones me up drunk and hysterical in the middle of the night and later she denies having done it."

Family concern can be a burden for men who are not used to being close to their families:

"They are all worried and they all come to see me now. They didn't come to London except twice in the last ten years. This year [since they've known] they've all been down about eight times each. Weird! It's nice but I really don't like the pity. I like them coming down but now I find that I have to push them away quite a bit. I don't want their heads getting screwed up and they have their own problems. "

Experiences of family members

There is a tendency for men to confide in one member of the family. This is usually the one who is closest to them or to whom they have 'come out' to in the past. However, this knowledge can be a burden for the family member, as a sister who cared for her brother said:

"What was unbearable was having to keep it from the rest of the family. I got no support from my brothers or my mother. So I told my husband and my best friend. I hated the secrecy and deceit - I found it horrendous because everything was on my shoulders."

For some, this burden was lightened when the rest of the family were told:

"In the end, about six months before he died, he told them (parents) that he was gay and that he had AIDS [...] After he told them it was a reversal, for the last six months of his life, they were really supportive. I was glad when he did tell them because it lifted the burden from me."

For others however, the isolation continued, this sister said:

"If my mother had not been so ashamed of it, she would have been able to tell more people and we would have got more support. Even now, my mother says that he died of cancer."

Sometimes when the son or brother becomes ill, the only person who can care for him is a supportive and often isolated family member. There was also a sense that this carer had to shield the patient from the attitudes of the rest of the family and shield the family from the patient's illness. A mother says:

"My daughter wouldn't accept it. Her attitude is that it was his own fault. I had to keep this from him, he would have been so upset. I mean she did make him welcome when he came home but [he] died never knowing how she felt".

The attitudes of other family members also affected the care and well-being of the family member with AIDS in a very practical way. Another sister reports:

"My mother gave me a hard time [my brother was in my mother's house next door]. I had a two year old son whom my brother adored. He had CMV and I didn't want the lad going in there because of the drip and his drugs about and also to keep the room sterile. I wanted my mother to put a lock on the door so that we could control when the boy went in. She was saying that we shouldn't bring the child in at all but I couldn't do that. My mother loved him dearly and did all she could, but she never accepted his gayness or the illness so that he found it hard to make it clear to her what he wanted."

The feeling of isolation in the family was exacerbated by the community and keeping it a secret from neighbours and friends.

"There was all this about you know, shut the windows when you're talking about that [her brother's AIDS], but I say they [neighbours] shouldn't be listening in the first place and if anyone were to ask me straight out if my brother died of AIDS, I'd say 'Yes', but I know my family would cringe at the thought"

Partners and Families

The disjunction between the attitudes of the family and the gay lifestyle of the son in their care is brought into sharp relief by the reports of men who shared the care of their partners with their partner's family:

"When he told them that he was ill, they [partner's parents] just arrived and sort of took over our flat. I mean they were staying with us all the time. That was the end of our life together. They were basically there until he died."

Even when relations between partners and families are friendly, the difference in attitudes can be extremely stressful for the partner:

"We couldn't show any affection for each other in front of his family and they were around all the time. When he had to go into hospital, he was in an infectious diseases ward, not an AIDS ward, so we couldn't be close there either."

These difficulties can worsen and continue to the man's death:

"When he died, his father was still not talking to me even though we had both cared for him together for the last two weeks."

Men who were in relationships were sometimes reluctant to seek support from their families for fear that their families might blame their partners for having infected them. They felt that they would be forced to choose between their supportive family and their loving partner:

"My family know that I'm gay and they know C. They've never totally accepted C. and I think that they would blame him and see him as the one who 'did it'."

Other men expressed concerns about seeking help from their family, even when they were supportive. This man, whose partner had died and whose own family shared his partners care and supported him through his bereavement, says:

"My diagnosis came within four months of P. dying . Within my family, they all knew that P. was positive and they all saw the way that he died. All the way through his illness, I was tested regularly and tested negative. Up 'till now I still haven't brought myself to tell anyone in my family that I am positive. About half my friends know. The reason I've held back is because of the effect it would have on them because they've seen what has happened to P. "

It is clear therefore that family relationships both past and present can have a profound influence on the levels and types of support gained by a HIV+ gay man. Relationships with families can also impact heavily on partners and the relationship existing between the HIV+ gay man and his partner.

2.3 Partnerships

In this section, we examine the experiences of the gay men in partnerships. By 'partnership' we mean those men who were in long term loving and, for the most part, sexual partnerships with another man. We will deal with sex in partnerships in section 4. This section also touches briefly on some of the attitudes towards partnerships in general expressed by the men in the groups.

Many men felt that their partnership suffered when they were first diagnosed with HIV. It was common for men to report that relationships ended. This was either through rejection by their partner when he learnt of the diagnosis:

"I was in a relationship for a eighteen months when he found out he left me."

Or through initial difficulties:

"I thought I was going insane; I was abusive to everyone, especially him. I feel I drove him away."

In addition to being left by their partner, some men chose to end long-term relationships after being diagnosed. Sometimes this was to protect the partner:

"I had to end it with him, I didn't want him to go through what was going to happen to me."

or because the person wanted to make major life changes and could not do so with their partner:

"I knew that he wasn't the person I wanted to be around for the rest of my life."

"There were all these things I suddenly wanted to do and they didn't fit in with our plan of the way things were going to be. So I had to think of myself."

For men who were presently uninvolved, the fear of rejection because of their HIV status was very real. This was either because they had themselves been rejected or because they had known others who had been. For some, falling in love made them vulnerable and they did not feel that they could afford to be so:

"Since my partner left me, I don't want to find anyone else. It took me so long to get over him and I really don't feel I have that time to spend. I don't think I'll ever fall in love again."

In other cases, the men perceived the differences in life expectancy to be too great:

"How can I commit to someone when I don't know how long I can commit for?"

Finally, there was an amalgam of reasons associated with the risk of infecting the partner and a general feeling that there would be a very different outlook on life between a positive and a negative man. The following was said by an HIV+ man to an HIV- man with an HIV+ partner:

"I find it hard to understand you and your partner. I couldn't go out with someone who is not HIV positive. The whole diagnosis did my head in so I could not go out with a negative partner, the risk for him and all that, and all the psychological stuff. I think it must be really hard when someone is HIV positive and the other isn't."

Another man who was HIV+ said:

"If you are negative, you've got something to lose. If you love someone who's positive, you'll probably lose them. If you become positive, you've got a good forty years of your life to lose. I'm not going to live till I'm 80. But I don't have anything to lose now."

Although some HIV+ men expressed a preference for relationships with other men who were positive, this view was by no means universal. However, there was a view that a partnership provided a type of support which, though not obviating the need for support from other sources, could not be replaced. This man who was not in a relationship said to a man who was:

"It's OK when you've got the support that you do. But when you don't have a partner then there are places like this [an ASO] where you can meet people which is not as good as being with someone but it's better than being on your own."

Although a successful relationship was seen as a definite advantage, many of the men identified a range of disadvantages. Firstly, where both partners were HIV+, differences in lifestyle and health choices brought about friction:

"My ex. who died a while ago, he was into staying out extremely late. He was always the last to leave at closing time at Heaven. I know that that kind of lifestyle can bring on full-blown AIDS. He used lots of poppers and drugs like ecstasy. He never had enough sleep and he never ate properly. I didn't want to live like that. I really need to take care of myself. Anyway, he died much sooner"

than he should have."

Differences in attitudes caused friction:

"When I was first diagnosed, the first person I told was my partner. It was only after I told him that he told me that he'd been tested a few weeks before and that he was positive. I mean, he hadn't even told me that he'd had a test. After that he wanted to be very secretive. He said that it must be our secret and that we shouldn't tell anybody. He was really afraid of telling anyone. We finally broke up because that was not the way that I wanted to deal with it. I just found the secrecy too much."

Differences in rates of disease progression cause the most difficulties:

"One thing that was difficult though was that my partner was ill and I wondered why am I healthy and my partner ill. I wasn't doing anything different than he was."

Often when one partner is sick, the other can neglect his own health:

"My lover was sick. I simply hadn't got the time to think about it and that is the way it is. If there is someone sick, the day to day business of having to deal with their health comes first. If you appear to be fit and healthy then your own diagnosis and looking after yourself, well, it's just a long way off. "

This attitude can continue even after the death of one partner when bereavement must also be dealt with:

"My diagnosis came within four months of my partner dying in Christmas '92. I was particularly low anyway, I was still in a state of shock at that time, I really didn't need that extra weight put on me. I just couldn't think about it."

There are also difficulties experienced by couples with discordant serostatus. Firstly, the negative partner experienced a loss of friends and needed to re-define his social circle on receiving his partner's diagnosis. This man was asked how he reacted to his partner's positive diagnosis:

"I was surprised most of all by the circumstances. We'd been seeing each other for over a year and it wasn't a shock. What shocked me more afterwards were other people's reaction towards me. They all changed. They weren't at all supportive. Even now [after partner's death] I still need support."

Another said:

"Some of my friends just assumed that I was going to leave him. Like he'd done something wrong. I found a lot of friends suddenly thought that it was OK to tell me that they'd never liked him in the first place."

Often this loss of friends and traditional support is accompanied by an increased dependency by the positive partner:

"For nearly a year after he was diagnosed, he kind of crumbled. I had to be everything for him. I was used to depending on him for things and I couldn't anymore. I used to resent that a bit."

Often the HIV- partner feels that he cannot get support. This man reports bringing his partner to hospital:

"I remember the first time I had to take him to hospital and just feeling like I was invisible. He was really ill and I was so upset. No-one even asked me was I alright. I was worried sick and no-one was telling me anything. When I left him, I had to go home to the empty house to spend the night alone. It was terrible."

The partner may not recognise that he needs support, even through the direst of circumstances:

"There was a very short time between him starting to get ill and him dying. During that time, he tried to kill himself twice. There was just no-one supporting me at all and I felt I didn't need it. When he got very ill, I was just giving, giving, giving and then I realised that something was going wrong with me and then I saw a counsellor, but I couldn't keep it up [the sessions] because there was always a crisis and I didn't have the time. I ignored my care and what I needed because I had never been in this situation before. After L. died I had to have therapy for eight months."

Sometimes the positive partner's attitudes or the nature of the relationship may prevent the HIV- partner from accessing support:

"I don't know why it was that I didn't connect with other people [for support / help], probably because he didn't at the time. He was very private, and didn't want anyone to know what was going on. No parents, no family, no nothing. I'm angry now with him and with myself for not being able to look after myself."

Estrangement from traditional support structures such as the family can make the situation much worse:

"If his family were around, it might have helped. I really needed someone other than him [partner] who I was close to but there was nobody. We had always been enough for each other and that was the problem, We'd been too self-sufficient."

2.4 The 'Gay Scene'

In order to examine the possible effects of a positive HIV status upon gay men's use of gay social venues and gay media for relaxation enjoyment or as a source of sexual partners and friends, we asked the groups to talk about how they perceived the scene how these perceptions had changed since their diagnosis. Discussion of the scene was problematic because for many men it meant radically different things. Some defined it as the place where they socialised and had sex. Others defined it as merely a sexual meeting place depending

upon other venues and groups for their social interaction. For some 'the scene' included gay magazines and newspapers, shops, saunas etc. For others, it was clubs and pubs. Others again described it in terms of their gay social networks. There was a great deal of commonality in the discussion of clubs and pubs. We have therefore concentrated on these venues for this section of the report.

Overall, the men reported little change in the frequency of their use of scene venues since their diagnosis. However, their perceptions and attitudes towards 'the scene' were clearly influenced by their diagnosis. As will be discussed in Section Three, men rarely disclosed their HIV status to casual acquaintances on the scene. Most of the men felt that HIV was not apparent at gay social venues. They displayed a range of reactions to this. Some found it preferable as they themselves saw the scene as an escape from their status. For others however, the reactions of those on the scene were problematic. Reactions varied from excusing others:

"A lot of the attitude is a front. It's people's protection. They see that they are protecting themselves like that and they don't realise that they are having an adverse affect on you while they're doing it."

To those who were more condemnatory:

"Yea, all gay men do is take drugs and have sex and that is all, they never do anything. They never get angry, they never think."

There was a sizeable minority who perceived the gay scene very differently. This man said to the rest of the group:

"Most of you said that you've felt that sort of stigma, I haven't felt that. I mainly go to places where you have sex on the premises. [...] Like, most of the people I know are [positive] and the one friend who isn't positive doesn't go to those places. I don't get negative vibes from people. Normally, it's normal that I meet someone and if it is discussed at all then they turn out to be positive as well."

There were men in the other groups who also identified with this viewpoint. They reported that most, if not all, of their friends were HIV+ and felt that most of the people they met were also HIV+. For these men, this was an important element to their social enjoyment and adjustment.

"I feel I take it for granted that most people are positive. When I walk into [a particular London gay pub] I look around me and I just know that most of the men there are positive. That's why I go there."

"I think the majority of people out there are HIV. You've got to look at everyone as being HIV. There are a lot of people accepting cause a lot of people have already got it."

Thus, experiences and perceptions of the commercial scene fit into two broad categories. Those for whom, for better or worse, their HIV disease was not integrated into or part of their commercial scene use, and others whose social lives seemed to be informed by their positive

serostatus. The latter group, however, were in the minority. Nevertheless, all of the men, when asked, agreed that at some stage they had felt stigmatised from other gay men because they were HIV positive. For these, their drop-in centre or ASO or even their HIV clinic was seen as vital to their social support, especially if they felt that their HIV status alienated them from the scene:

"It's alright if your boyfriend is around, but for most of us, it's really important to come here [an ASO]. It's like an alternative to when we go out [...] At least here, you know you don't have to take any crap from anyone."

Others saw their ASO as an important social venue because they experienced the gay scene as physically unhealthy:

"Here [an ASO], the emphasis is on your health. I go out a lot, but sometimes I think that it's so unhealthy, all that smoke and standing around and late nights. Sometimes I just don't have the energy. Here, I can meet other gay men and I don't have to worry that it might be damaging my health. It's more relaxing as well."

For others, their concern was for their mental health.

"I'm convinced that the thing that will make me most ill is if I'm stressed out. When you think about the stress that a normal night in a gay bar puts you under [...] just chatting someone up is enough to give you a nervous breakdown, and everyone in pubs are really judgmental about the way you look, so you have to be really careful. There isn't that at [an ASO]."

For some men, the social element to an ASO was important because it was their only contact with other gay men. For many others however, it was seen as a valuable additional alternative to the scene and one which they used and appreciated. For the majority of the men the social contact that an ASO provided was seen as vital.

2.5 Discussion

For the majority of the men in the study, their families' knowledge of their disease was important. They did, however, make quite detailed assessments about whether and when to tell their families. The men were used to making these assessments because many had kept significant parts of their lifestyles separate from their family life in the past. Families reacted in a number of ways when they were told. Some parents rejected their sons. Others were equivocal, often with a sibling or parent acting as a go-between. This had a detrimental affect on that person.

In some cases, the family's support was experienced as burdensome with the son often coping better than the rest of the family. This would appear to be due to a disjunction of experience. Most of the gay men in our study will have been in contact with the epidemic before they were diagnosed and for the most part, they will have experienced or thought about the realities of living with the disease. It is likely that their parents or siblings will not have had this experience. Hence, their concern may be experienced by some gay men as an over-reaction.

Where families are supportive, there is the danger that their lifestyles and values will clash with that of their sons. This is especially the case if the son has a partner or is surrounded by a network of gay friends. This possibility was borne out by the reports of partners of men who had been ill. However, whilst we must report on possible difficulties, it must be emphasised that many men experienced none of these problems.

Many of the men felt inhibited about starting relationships, recognising difficulties with either having a positive or a negative partner. Consequently, men denied themselves the support and companionship which a partnership can bring. There is no doubt that a positive diagnosis can, and often does, put an intolerable strain on many partnerships. This strain may worsen as the disease progresses. The descriptions given in this section may be extreme circumstances, but there was general agreement amongst all of the groups that there was insufficient support for the partners of gay men who were actually ill. This support was needed regardless of the partner's serostatus. However, the *type* of support needed differed according to the partner's HIV status and health status. The absence of family who can provide emotional and practical support can make this situation far worse. However, sometimes the family's presence can also be problematic.

On the broader gay scene, men felt inhibited about being open regarding their HIV status. There were also issues raised about the visibility and representations of gay men with HIV on the scene. Consequently, many men relied on ASOs and clinics with a large clientele of gay men for their social support.

Overall, there seemed to be a disparity for many of the men between the three constituencies from which they can build their support networks (family, partners and gay social networks).

What is acceptable within one arena is entirely unacceptable within another. Many gay men have learnt to keep elements of their lives separate and to take on different identities according to their needs. They have learnt to keep their partnership separate from their broader sexual activities. Many keep their families separate from their friends and from their partners. Many use the gay scene merely for sex and others have anonymous sex. Thus for some, their sex lives are divorced from their social lives. A crisis such as a positive diagnosis has the effect of drawing all of these disparate elements together, often to dramatic and sometimes devastating effect. The process of a gay man's illness can thus have damaging consequences for himself, his partner and his family. Instead of consolidating to create a supportive environment for him, a gay man with HIV can often find his support environment to be quite fraught.

Within this study, most of the experiences reported are of men who have not experienced serious illness or whom have not needed long term medical care. Establishing social support networks has not been without difficulties for these men, especially if they have sought this support from within their own circle of gay friends. These problems are exacerbated when family becomes involved. We have seen how this process can be extremely stressful for all parties. There may therefore be the need for a resource which identifies the very particular problems associated with support and care networks for gay men and which encourages a gay man with HIV to think about where, when and who he will call upon for both care and social support before he actually needs this support.

SECTION 3: 'COMING OUT' WITH HIV

"When they give you the result, they give you information really and make you feel that your HIV is simply something to be managed. You know, they show you a long corridor and just say 'complementary therapy on the left, counsellors on the right'. It's not something to be managed, it is part of you."

There was no doubt that a positive diagnosis had a profound effect on all of the men's lives. The experience of living with HIV was one of deep personal change. Coping successfully with HIV meant becoming someone who *is* HIV positive rather than merely *having* HIV. It is not surprising that HIV would be dealt with in this way by many gay men since this is the paradigm used in the process of coming out and dealing with the adverse social implications of a gay sexuality. Consequently however, the day-to-day experiences of being HIV+ were closely associated for most men with the day-to-day experiences of being gay.

'Coming out' is central in the lives of lesbians and gay men. Coming out begins with a man who is either unaware of his sexuality or shares the general antipathetic attitude towards homosexuality and ends with one who not only accepts his sexuality but positively values it. There are, on the one hand, those who believe that the term refers to the single moment at which the derided 'other' is applied to oneself in a sudden recognition of the 'truth' (e.g. Simon and Gagnon, 1967; Dank, 1971) or the moment at which the new identity is announced and affirmed by, for example, entry into a gay venue. On the other hand, a far greater number of writers acknowledge that coming out is a process which takes place over a longer period of time. Much effort has been expended in the attempt to describe stages of the coming out process (Cass 1979 & 1984; Troiden 1988; Weinberg 1978; Lee 1977; Berzon 1979) and, while it is inappropriate here to comment in detail on these approaches, we can identify the following stages which characterise the process of coming out: (i) identity formation - the process in which beliefs and attitudes are re-assessed and re-evaluated in the light of a new identity; (ii) disclosure - the process whereby a new sense of self is gained from the reactions of others; (iii) exploration - the process of immersion in and evaluation of the possibilities of the gay 'scene'; (iv) experimentation - the investigation of new sexual possibilities. The processes identified in these studies are necessarily accompanied by practical changes in lifestyle. For example, necessary changes in friendship networks, a difference in the articulation of support needs, a shift in political priorities and allegiances etc. We have therefore found the concept of coming out to be extremely useful in characterising a more successful response of some of the men we interviewed to their positive HIV status.

However, the process which we have identified here is not without its attendant pains. The process of coming to terms with a new identity of a gay man with HIV can involve both emotional strain and the loss of friends and partners. However hard the struggle is, this process can lead to a positive and affirming HIV+ gay identity. It is thus worthy of some attention. What follows therefore is the results of the analysis of the themes associated with 'coming out as HIV+'.

3.1 Disclosure

Telling Family

As in 'coming out' as a gay man, telling one's family of one's status was seen by nearly all of the men in the study as crucial. Many of the men anticipated their family's possible attitude to their HIV by examining what the attitude had been to their homosexuality. Most of the men had already thought about the implications of telling family members soon after diagnosis and, within time, had assessed the possible utility of this disclosure. Pivotal to this assessment were the following two criteria:

- Whether the family had been generally supportive in the past, particularly in regard to their son's sexuality:

"When I told my family that I was gay, they just didn't want to know. When I tried to tell them that I was happy and had fallen in love, my mother just said 'spare me the details of your sordid sex life'. They really haven't been interested in any of it. I don't want to tell them I've got HIV"

- What the families reactions had been to previous illnesses or health crises.

"My father died a few years ago of lung cancer, it was awful because he hung on for nearly a year at the time. It was up to my sister to look after him. My mother could hardly bear to look at him and the rest of the family were the same. My family just isn't good where illness is concerned"

Telling Casual Acquaintances:

The men did not generally tell casual acquaintances of their HIV status or discuss HIV for the following reasons:

- They felt that it was private. For some men, this was reasonably straightforward:

"I don't talk about my mortgage or my bank balance, why should I talk about my health? It's my business and no-one else's".

For others, this was more problematic:

"For a long time I didn't go out because I felt that there was something wrong with me that I couldn't share at all."

- Many felt that mentioning HIV might turn other men off them either socially:

Participant 1: "I didn't get any problems or prejudice. None at all. No one has run away from it."

Participant 2: "Yes, as long as you don't say that you have HIV of course."

Or sexually:

"No-one wants to be made to think about death when they're going to pick you up."

"If you said that you were positive they wouldn't have sex with you."

These feelings can often be fearful:

"Well a friend of mine had a bad experience with telling someone straight off and he was battered badly."

- Because they felt that no-one wanted to be reminded of HIV/AIDS when they were enjoying themselves:

"...just pushed the issue away to the back of their minds. No-one ever thinks or talks about it."

"Bring an evening down? HIV brings your life down. Yes, I've been out having a good time and suddenly someone says something to remind me of it or I see someone and I come right down. I try to prepare myself for that kind of thing these days."

Telling Friends:

For many, *who* they told was an important element in the process of dealing with HIV. There were some for whom disclosure was only important if they were going to have sex with someone.

"In the normal walk of life, you don't need to tell people; if I'm not going to bed with them, why should I tell them?"

Others, however, challenged this view, mainly because it was seen as therapeutic to disclose:

Participant 1: "After I'd told him, it was easier to start telling other people. As soon as I started telling people, I felt better in a way"

Participant 2: [agreeing] "It's really important because once you verbalise it, then you start to accept it".

Non-disclosure could also have negative effects:

"I told no-one for the first six months, not even my partner. I just started knocking back the whisky like there was no tomorrow."

As well as being personally therapeutic, disclosure was seen as an important way of 'testing the water'. Most of the men felt that they needed to gauge the reactions of those close to them. There was a sense in which the men needed to know who would stick by them through the course of their HIV disease.

"I told my family; I suppose I knew what their attitude would be, but I needed to know. They won't have much to do with me any more."

"Some of the people I told were very supportive and they're still with me. Others were not. They're gone now, dropped off the face of the earth."

Few of the men regretted having told others of their diagnosis. If they did, it was because their disclosure was uncontrolled, erratic or didn't serve any strategic purpose.

Participant 1: "In the first few months I told quite a few people who I didn't know very well. I couldn't contain it. I really regret that now. I feel that if I'd had some support in the first place, I would have been a lot more careful who I told."

Facilitator: "Who did you tell?"

Participant 1: "Work colleagues"

Facilitator: "What kind of support did you want?"

Participant 1: "Something that could have helped me."

3.2 Changes in Friendship Networks

If disclosure was seen as way of situating yourself as a person with HIV (PWHIV) in relation to friends and family, the net result of this process was generally a loss of some friends.

"My friends were awful. After I told them, they never rang, it was always me doing the ringing so I thought there was nothing for it but to start chopping out the dead wood and start building up my friends again."

Sometimes these friends were replaced. For many of the men, old friends are replaced by ones who are gay and HIV+:

"I don't know anyone now that I knew before I had HIV; all my friends are gay and I only know one man who isn't positive."

However, this strategy often brings its own problems:

"More and more I'm replacing friends because my old ones are dying so fast."

Sometimes friends are not replaced, however, and feelings of isolation ensue:

"A lot of my friends deserted me and the contact with my ex-wife and children isn't as good as it has been. I don't know whether it was that or not, but I've felt very lonely for a long time now."

3.3 'Joining a club'

The change in friends was mirrored closely by the sense of joining another community:

"It's sort of like being in a club, a club for positive people."

This community was one which consisted predominantly of other gay men with HIV.

"My social circle is mostly from the gay community. I've had to make new friends. The people I know now are quite recent. Nearly all of them are gay and I've made them through centres like this."

"All of my friends are gay and positive and I wouldn't have it any other way."

This community is vital in so much as it provides day to day support and acceptance:

"I just don't get negative vibes like you do when you go to other places."

and that it provides a forum for common understanding which people who are not HIV positive cannot enter in to.

"People who work in HIV, they'll just never understand because they simply don't have it."

It also allows taboo subjects to be discussed,

"You don't have to pussy around and be all PC. We all think about the fact that we're going to die and we can talk about it. Not in a really precious way. For me that's really helpful."

often with humour:

"My friends always joke about it saying things like 'I'm not going to let that bitch die before me.'"

The desirable qualities of this 'club' were reflected in the perceptions of some men that others (HIV- ones) desired to join it:

"A friend of mine saw all of his friends who were positive and saw that they all had each other and all the benefits and that he had nothing. You know, he wanted to get in."

However, this 'club' can have its negative aspects with some feeling excluded:

"I don't like [a certain ASO] because it's full of cliquey queens. If you don't fit into the skinhead-dance-your-tits-off mode you're out and then where do you go?"

and

"Sometimes I feel like I'm surrounded with HIV, like I sleep, breath and eat it."

3.4 Taking on an identity

Often the process of re-defining one's friendship networks and joining a club contributed to the sense that dealing with HIV meant taking on a new identity which encompassed one's HIV status:

"Since I've become positive, I've found my own identity."

This process sometimes consisted of forgetting what it was like before the diagnosis:

"You adapt yourself completely and forget what it was like not to be positive."

and for some can be very radical:

"For me, it was about completely changing my life, completely changing who I was. I had to find a new way of living."

For many this experience can be intensely painful:

"Finding who I was after it all happened, I had to find myself in all the mess."

"You kind of break down and then you have to rebuild yourself from scratch, reinvent yourself."

However, this new identity is often accompanied by pride and a certain defiance:

"I'm really proud now of what I am. I'm gay and I'm HIV positive. It's not that I wouldn't like to be negative and I'm not going to say that HIV is the best thing that's ever happened to me, [...] but I really feel improved by the experience of dealing with it, really strong."

3.5 Changes In Support

Many of the men reported a change in the type of support they needed from their friends. Many went to traditional counselling for initial support but found it insufficient to meet their needs. Some also went to friends for support, but found this problematic:

"I've told most of those friends. I didn't notice a change in them but I did notice a change in me, a change in the way I reacted to them. So I made new friends. Most of them from place like this [ASO's]."

Some of the men reported relating to old friends in different ways:

"Mostly, it was like speaking a different language. Suddenly I wasn't relating to them anymore. The friends who I still have I relate to in a very different way, much deeper."

Others felt that they might not be able to trust friends to deal with their problems:

"I wanted to go out and have a laugh with them, but I knew that sometimes it would be hard for me to keep it up. Sometimes, I'd just break down. I didn't trust them to be able to deal with that if I did."

Still others felt burdened by what they saw to be inappropriate concern:

"Then there are the ones that say 'but how are you really?' just when you're about to pick someone up or something. It's almost as if they're saying 'don't forget now, you've got HIV' every time you might be looking happy or like you're going to have fun or you might just be about to forget! So I decided that it was them with the problem."

Men tended to relate to old friends in different ways and to adopt new ones finding support from in a very different way.

3.6 Discussion

The approach which we have outlined in this section was not adopted by all men. Some men clearly did not feel the same need for a change in their relationships or their lifestyles. Some turn successfully to support outside of their gay circles.

What is significant however, is that a number of people with HIV have clearly used the fact that they are gay men and belong to a gay culture to cope with their HIV disease. For many of the men, these changes were a necessary part of coping and acceptance. They were useful in empowering the men in relation to their disease and were seen as vital by many for setting up support structures later on. It was also useful in accessing more formal support as most of the men seemed to get their information on support services from other gay men.

We believe that the concept of coming out is a useful one to utilise when designing support interventions for gay men who are HIV+, as it would appear to be a method (albeit amongst others) which has been seen to be successful for people who are making what is perhaps the most difficult transition they will ever have to make. Moreover, this approach is one that is familiar to and would appear to be used by many gay men.

As in the process of coming out as a gay man, the process of adopting an HIV+ gay identity is often difficult and accompanied by change and loss. However, the following factors did seem to contribute to this pain and make the process all the more difficult:

- Negative reactions of family.
- The support which a gay social network had provided in the past was often insufficient to deal with a positive diagnosis.
- Many men felt that there was an ignorance regarding living with HIV within the gay community. This perception was contributed to by the experience of negative reactions from casual acquaintances and casual sexual partners.

These difficulties were experienced by partners of HIV+ gay men also (see Section 2). Thus, there is often an extra strain on relationships where one or both partners finds out that he is HIV+. There is therefore a need not only to change attitudes towards HIV within the general population, but also to do so amongst gay men. If men who are recently diagnosed are to

develop a positive image of themselves as HIV+ gay men, then their friends and casual acquaintances must see HIV+ gay men in a positive light whilst also being educated about the practical difficulties and health issues associated with an HIV diagnosis.

Some men experienced non-acceptance from within their own community when they were open about their positive HIV status. Still more perceived that they would be rejected if they were open. Whether this rejection is a reality or merely imagined, it does cause difficulty for many men where they are used to finding support. There is a need to counter both the rejection and the fear of this rejection. The simple exercise of creating positive images or role models for HIV+ gay men might be effective in this respect (see Section 4).

It is clear from both this and the preceding chapter that setting up a social network of other HIV+ gay men is vital to adjusting successfully to a positive diagnosis. Some of the men found this 'on the scene' either through actual positive friends or through the assumption that most of the men that they met were also HIV+. For others however, they chose not to disclose their status to friends and partners whom they met on the scene. For these men, the social function of ASOs and clinics was important.

SECTION 4: REVIEW OF HEALTH PROMOTION MATERIALS

4.1 Background

As we have seen, the way in which HIV+ gay men perceive the gay social scene is important in their social support and security. It is also important to examine how HIV+ gay men are represented both to themselves and to others in health promotion literature. To do this, we collected a convenience sample of sexual health materials aimed at gay and bisexual men. The sample is not intended to be exhaustive or representative. Neither is this review an audit or evaluation of print materials. We are looking in addition for gaps and issues not addressed in existing print materials. We will also make some suggestions for filling these gaps in the light of the findings of this study. The review does not address issues of style or format, it merely examines the content of and messages in materials in the light of these and other research findings. Except to list its country of origin, no single resource will be identified by name.

4.2 The Materials

We used as our selection criteria health promotion materials clearly targeted at gay and bisexual men. The materials were gathered from three separate archives (listed at the beginning of this report). The materials were divided into their country of origin and were then analysed to determine the dominant subject matter of each. A second analysis divided the materials into those which make no mention of gay men with HIV/AIDS, those which mention them in a broader context and those which deal exclusively with the subject. A full content analysis was carried out on all three sections to identify the dominant themes in each one.

This review is the result of an analysis of 233 posters, postcards and leaflets specifically targeted at gay and bisexual men and which deal with sexual health, social and community support and mental health issues. Materials were from the following countries and (when discernable) organisations.

- **United Kingdom (39%)**
(Terrence Higgins Trust, Gay Men Fighting AIDS, Health Education Authority, London Lesbian & Gay Switchboard, Scottish AIDS Monitor and others)
- **Australia (19%)**
(AIDS Council of New South Wales and The Victoria AIDS Council)
- **U.S.A. (6%)**
(San Francisco AIDS Foundation, Gay Mens Health Crisis, and others)
- **Germany (6%)**
(Deutsche AIDS-Hilfe)

The following countries made up the remaining 30%:
Belgium, Canada, Denmark, Finland, France, Ireland, Netherlands, Spain, Sweden, Switzerland,

The materials consisted of the following:

| | |
|-----------------|------------|
| Posters | 81% |
| Postcards | 12% |
| Folded Leaflets | 7% |

4.3 Results

The overwhelming majority (98%) of the materials mentioned HIV/AIDS, even if this was within the context of other health promotion issues. Although the materials dealt with a range of subjects, our first analysis identified a dominant subject for each one. Percentages of materials dealing with each subject are presented below:

| | |
|---|------------|
| Safer Sex (Unspecific) | 14% |
| Safer Sex and: | |
| Condom use | 39% |
| Drug use | 16% |
| Young gay men | 14% |
| Diverse sexual environments / practices | 9% |
| Themes associated with gay community / solidarity | 2% |

Just over 6% of the materials dealt exclusively with gay men with HIV/AIDS (9 posters/print advertisement, 2 leaflets and 5 postcards). One of these leaflets was clearly targeted at bisexually identified men.

We then considered the number of materials which dealt with gay men with HIV/AIDS in a larger context. The selection criteria was those which mentioned, represented or addressed gay men with HIV/AIDS either directly or through a clear image. Just over 5% of the materials did so (10 posters/print advertisements, 3 leaflets and 2 postcards). Two of the posters were targeted at people with AIDS and included images of infected woman and children as well as gay men.

In sum, of all health promotion materials for gay and bisexual men reviewed, despite targeting a diverse range of constituencies and being almost exclusively concerned with the subject of HIV/AIDS - 89% did not target, address, mention nor represent gay men with HIV/AIDS in any way at all.

The remainder of this paper will provide a detailed analysis of:

- those materials which did not mention gay men with HIV/AIDS in any way.
- those which did mention gay men with HIV/AIDS.
- those which deal exclusively with the issue of gay men with HIV/AIDS.

Occasionally, quotes from the focus groups of HIV+ gay men will be used to illustrate points.

Materials which did not mention gay men with HIV/AIDS.

These materials shared the common assumption that the reader either knew or presumed his status to be HIV-. The materials did this in the following ways:

- By explicitly addressing the reader as if he were HIV-.

For instance, advertisements which, in addition to giving advice about safer sex, encouraged the reader to *"think about taking the test"*, thus ignoring the possibility that the reader may have already tested positive.

Information and advice was often limited to that which prevents the reader from acquiring HIV, rather than transmitting it. For example:

"There are two things you can do to protect yourself from the HIV virus..."

Other advertisements congratulated the reader on remaining HIV negative throughout the course of the epidemic. Others used imagery associated with war and borders, eg. *"know your enemy and fight it, don't let HIV in"*.

Whilst certain advertisements constructed an association between positive gay identity and the practice of safer sex, others went further by associating being a 'good' gay man with being HIV negative and one told the reader that he had a responsibility to his community to remain negative. This approach not only undermines an HIV+ gay man's identity but suggests that a positive test result excludes him from an active role within a wider gay community.

- By giving advice and information which is meaningless or incomplete when read by an HIV+ reader.

A man with HIV disease will be using a condom for a very different reason to a man who assumes himself to be negative. Consequently, advice such as the following becomes meaningless for someone who is HIV positive:

"...anyone could be HIV positive, you can't tell by simply looking at them".

Materials (particularly those produced by community organisations as opposed to those involved in health care) tended to concentrate on the dangers of HIV infection to the exclusion of all other STD's. Given the devastating nature of HIV infection, this is entirely understandable. However to a man who is HIV+, advice on other STD's will be as important if not more important than advice on avoiding becoming infected with HIV.

- By simply not representing or mentioning gay men with HIV.

Whilst it is naïve to expect any one advertisement to represent all constituencies, there were

many advertisements which took diversity as their focus: ethnic diversity or diversity of sexual practice, drug use, sexual contexts, dress codes etc. but which simply omitted to list difference in HIV status as another facet in the diversity of the gay male population. There were also whole series of materials which were clearly meant as a series but which did not represent gay men with HIV at all.

This paper does not seek to provide a critique of any of the approaches outlined above. Indeed, many if not all of these approaches may be entirely appropriate in advertising for HIV prevention with groups of HIV- men. However, it does illustrate the difficulty of attempting simultaneous sexual health advertising to both HIV+ and HIV- men. The issues and hence the advice are necessarily different and HIV+ gay men may therefore perceive type of advertising to be irrelevant to them. This review found a lack of materials which either address and advise HIV+ men directly or which address and advise HIV- men about HIV+ men.

HIV+ men seem to be all but invisible within health promotion materials aimed at gay men. In the 233 separate materials reviewed, we found only 27 characters who could be unequivocally interpreted as being HIV+ and gay (either represented by models, symbolically or actual HIV+ men). HIV+ gay men did not have a 'face' within the bulk of the materials reviewed and furthermore, there was nothing to indicate that (to corrupt an old gay liberation phrase) HIV+ gay men are 'everywhere'.

This 'de-personalisation' is enhanced by health promotion materials which talk almost exclusively of protecting oneself from the virus whilst stopping short of saying exactly where the source of this possible infection will be (ie from another gay man's body). Health promotion specialists are clearly concerned not to be seen as demonising HIV+ gay men as 'infecting agents' or 'reservoirs of infection'. However, this approach can have the added effect of never encouraging an HIV- man to think of his own HIV prevention in personal terms, ie. that any of his sexual partners may be HIV+.

If 'contact with the epidemic' (that is, having a friend, partner or lover who is HIV+) relieves the fear of HIV and gives some gay men the impetus to maintain safer sexual practices, then this lack of representation or de-personalisation of HIV+ gay men may be detrimental to primary prevention.

There is a further consideration which illustrates the need for an increase in the representations of HIV+ men within general gay health promotion literature. This study has shown that many HIV+ gay men rely on their gay friends and gay social networks for much of their social support. However, many of the men in this study either fear or have experienced rejection from gay friends and especially sexual partners when they have been open about their HIV status. Increased representation of gay men with HIV could have the dual effect of providing 'role models' for recently diagnosed gay men and allay the fears of HIV- men around having HIV+ friends and partners.

Aside from the problem of representation, some HIV+ gay men in the focus groups found health promotion materials alienating as shown in this quote from one participant:

[Referring to the slogan 'positive or negative, it's the same for all']. "It's just not true, I mean, where does something like that leave me or anyone else in this room for that matter. It's certainly leaving all of us behind."

Others complained of complacency from the gay community about the difficulties of living with HIV and how it is not seen as a political or legal issue

"The most political gay men get today is to complain that the drugs they're taking in nightclubs aren't legal or they can't have sex where they want to or they might even get excited for a few days about the age of consent, but you never hear anything about discrimination against gay men with HIV. No-one gives a toss."

This lack of representation was taken by some as an indication that 'the gay community' is insufficiently politicised about or ignorant of the difficulties experienced by some HIV+ gay men.

Materials which did mention gay men with HIV/AIDS

A small sub-sample of materials did mention or represent gay men with HIV/AIDS. These can be broken down into two broad categories: those which concentrated on building a gay community response to HIV and those which sought to give the same sexual health advice to gay men regardless of their status. Materials which dealt exclusively with HIV/AIDS are discussed in the next section.

One series of posters depicted abstract representations of gay men. The human figures within the posters are inscribed with positive and negative symbols denoting the indeterminate HIV status of the participants. They each dealt with recreational drugs, injected drugs, sex within and outside of relationships and support for HIV+ men. The by-line for all four posters is designed both to reflect the diversity of gay experience and to highlight the using condoms for anal sex in all circumstances. For example, the poster for recreational drugs says:

"Some of us get out of it, some of us don't. All of us fuck with condoms - every time."

These posters go some of the way to representing HIV+ men within a larger gay context. However, they do so in a very abstract way. The fourth poster is of interest as it shows one figure inscribed with the letters "HIV-" holding another figure inscribed "HIV+". On both of their bodies are inscribed the word "Yes" and the two figures are surrounded by mens names. The by-line reads:

"HIV, discrimination and grief threaten our community. Build our strength, stay together and support each other."

Another, less abstract, series of posters again takes as its focus the diversity of gay men. The

text reads:

"Our community is diverse. Some of us are into frocks, some of us are into muscle [...] We all share being gay and we share the effects that HIV has on our community, our friends, our partners, ourselves. Our love - gay love - will help us survive. Our community is stronger than ever. Fight AIDS, always have safe sex..."

Another poster in the series reads:

"Habit or hot pants, lycra or leather, sequins, syringes, AZT or LSD. No matter what we're into, there are some accessories that we all use when we fuck. Condoms and lube. Always use condoms and water based lube for fucking..."

These posters use bonds of community to support gay men with HIV. However, they do not represent men who we can assume to be HIV+. They also highlight issues that are of common concern to both HIV+ and HIV- gay men, thus integrating positive mens concerns into a broader political approach. However, they share a characteristic in common with other materials which also mention HIV+ men. One leaflet reads:

"It doesn't matter if either of you has HIV, safer sex will protect you both".

Unfortunately, the leaflet doesn't go on to explain what the dangers are. Thus like the posters, it mentions HIV+ men, but nowhere are their health questions addressed. Another leaflet is more successful when it talks about the dangers of rimming saying:

"... hepatitis, salmonella and some other parasites. If you have HIV, these can be very serious."

but it still lacks detail. Another context in which HIV positive men were mentioned is in the case where they may be unaware of their serostatus. Two postcards and another leaflet approximate the following text:

"Anyone can have HIV without knowing it - safer sex protects us all".

This is very good advice. However, the fact that it is the only allusion to HIV+ gay men in a leaflet of several pages may be taken to imply that the only time an HIV+ man will have unprotected intercourse is if he is unaware of his status. Another postcard reads:

"The guidelines for safer sex are the same if you're HIV-positive, negative or don't know. Fucking is by far the biggest risk in sex"

without differentiating what the risks are for HIV+ and HIV- men.

There appears to be insufficient advice and information regarding sexual health targeted specifically at HIV+ men within a mainstream gay medium. The sketchy sexual health advice for HIV+ men in these resources would indicate that they are produced mainly for men who are assumed to be HIV-.

Although still clearly targeting men who assume themselves to be HIV-, a photo story series has been more successful because it represents men who consider the possibility that they might be HIV+. A character in one story uses this as a reason not to have unprotected anal intercourse with his partner:

"...either of us could be infected".

Another photo story in the same series examines the dilemma of a couple considering giving up condoms where both have to consider the possibility of being HIV+. It rightly considers the "trauma of the test" and touches on the issues of dealing with a sero-discordant relationship: "and what if we both get different results?". Unfortunately, this question is left hanging and the couple decide to stick to using condoms rather than address it. This is the choice they make and this particular leaflet has another issue as its central theme. However, there are no resources which answer questions which might arise for a couple who decide to test in order to stop using condoms. Indeed, there is no advice regarding what to do if one tests positive or one of them finds that he is infected at some later stage. This leaflet raises a question about sero-discordance, but there are no materials which answer the question it poses.

A third photo story portrays an inexperienced man meeting and having sex with an HIV+ man for the very first time. He realises that all of his other lovers might also have been HIV+. This story is successful in representing HIV+ gay men and may very well help to reduce anxieties about safer sex for young or inexperienced men. However, there is no accompanying leaflet which tells the story from the HIV+ characters' perspective. The focus groups raised many issues about disclosure of status to sexual partners, fear of rejection and entering into relationships etc. All of which could be included in such a resource (see Section 2). This resource might show an HIV+ man that he is not alone in his dilemmas and show an HIV- man that HIV+ gay men have equally complex, equally pressing but different concerns regarding sex and relationships.

Finally, we found one advertisement which both addressed HIV+ men as a distinct group and gave them some advice. The text reads:

"...If you test HIV positive, get support and advice from other positive guys. Gay or AIDS help lines can get you in touch with local groups. You can still have sex of course, using strong condoms to protect your partners.

If you are negative, remember that you are not immune to HIV. To stay uninfected, always have safer sex".

This text is significant because it gives HIV+ men and HIV- men different advice based on their status within the same advertisement. It also justifies the advice it gives. It does not assume that the issues are the same for all.

Materials which deal exclusively with Gay Men with HIV/AIDS

These materials cover a number of common themes. Those which merely illustrate the existence of HIV+ gay men as sexually active, sexually loving individuals; those which attempt to encourage a community based response to HIV/AIDS which includes HIV+ gay men; those which attempt to give similar advice regarding safer sex to both HIV+ and HIV- men; those which use the testimony of HIV+ men and finally those which try to describe the experience of HIV+ gay men.

Two sets of poster/postcards fall into the first category, these are the series headed "*My friend is positive / Mein Freund ist positiv*" and another set of postcards depicting HIV+ men in sexual acts. The first set personalises HIV+ gay men and encourages solidarity amongst and with HIV+ gay men. Within the latest series of advertisements however, there are only three which unequivocally depict gay men. One uses the personal pronoun, thus giving an HIV+ gay man a voice:

"Positive friends - We love each other".

The second set are three of a series of six postcards which depict HIV+ men embracing, fucking and sucking. Again, these simply depict HIV+ men as sexually active. A third postcard deserves a mention here. The card depicts Icarus, a gay German artist with AIDS. He is photographed in a tee-shirt depicting his T-cell count, his arms and face covered in KS lesions. Nevertheless, he is photographed in a standing position looking fit, strong and healthy. The text reads:

"AIDS hat ein Gesicht. Du bist herausgefordert."

(trans: "AIDS has a face. It's up to you to do something about this")

Although more shocking, the message is again simple and unequivocal. It personalises HIV+ gay men whilst calling for the support of a wider community. By depicting a very public gay man with HIV, it provides a role model for recently diagnosed gay men and by showing a very beautiful man with KS, it challenges the cult of beauty which can make life more difficult for HIV+ gay men.

Another card attempts to combine the need for support with recognising that HIV+ gay men are sexually active. The line on the front reads

"My friend is positive - fuck him."

on the back of the card are listed a number of activities which one might do with a sexual partner, with a friend, with a lover etc., the last of these being:

"Laugh with him, cry with him, get angry with him."

Again, this card appeals for a political gay-community response to HIV/AIDS. Another card states:

"Most gay men today have friends or lovers who are HIV-positive. Many of us are positive ourselves. Fighting AIDS isn't just about safer sex education to keep people negative. It's about..."

The card continues to list a number of ways in which members of the gay community both HIV+ and HIV- can support HIV+ gay men.

The materials reviewed so far are solely concerned with HIV+ gay men but do not address their sexual health needs. Their utility in terms of advice and information for HIV+ gay men is very limited. Those materials which seek to advise HIV+ gay men about sexual health are very small in number. Within this sub-sample, we found only six resources in total. Two posters are similar in the advice they give to HIV+ men. The first reads:

"Some of us have HIV, some of us don't. All of us fuck with condoms - every time!"

As a prescription, this statement is incomplete and too reductionist. There is nothing whatsoever within this advertisement to support this statement. The second poster gives the same advice, but justifies it:

"Some of us have HIV and some don't. We can't tell by looking. When both partners have HIV there are still reasons to have safe sex. Safe sex avoids other sexually transmitted diseases. Also, reinfection with different strains of HIV can further damage our immune system. Have safe sex with every man every time. Our love means that we care for ourselves, care for others."

This poster therefore goes a lot further in that it tacitly recognises that HIV+ gay men consider the option of unprotected anal intercourse. It prescribes rather than proscribes and advises against it, referring to re-infection and other STD's (although still not backing this up with more detailed information). It also reminds the reader of his responsibility to "care for others" in being careful not to infect them.

The photo story series has two leaflets which deal with issues of concern to HIV+ men. In the first, three HIV+ men discuss whether or not to disclose their serostatus to sexual partners. One character is asking advice from the other two. One man tells his sexual partners, the other doesn't. This leaflet is successful in representing HIV+ gay men as sexually active. It also helps in preparing HIV- men for the first time a sexual partner tells them that he is HIV+. Although, this leaflet does not have the space to do so and recognising that this medium is unsuitable, the focus groups have revealed the questions raised in this story as highly complex for many HIV+ men, but nowhere else are these questions sufficiently explored. Again, we found no materials which talked about the fear of rejection or about starting a relationship with a partner of a different sero-status, or accidental infection. This leaflet represents HIV+ men but does not address their needs as outlined in this report.

A more recent photo story is more effective in allaying the fears that some HIV+ gay men might have about infecting others. Again, it represents HIV+ men as sexually active. The couple in the story may be sero-discordant or they may be concordant. This is never revealed. However, it is clear that the couple use a condom when they have anal intercourse. Again, the message is, as long as sex is safe, there is no risk to an HIV- partner. The text at the end of the leaflet expands upon this, reminding the HIV+ reader of his responsibility to protect others and to protect himself from reinfection and other STD's. It also says:

"Looking after your health also means carrying on doing the things you enjoy, which naturally means having sex."

This leaflet is more successful than its predecessor in addressing the needs of its HIV+ reader. However, like all of the other materials included in this review, it does not go far enough.

The final two resources are magazine advertisements which are interesting because of their testimonial style. The first reads:

"5 years ago I learnt that I was HIV positive. I felt angry, deserted and victimised - Today I'm back in control."

The other reads:

"HIV testing scared the hell out of me - But now I know I can do so much more for myself."

Both of these by-lines are accompanied by approximately 12 lines of smaller text which talks about taking control, a good diet, moderate exercise and early medical treatment. Both advertisements are unremittingly upbeat and 'American' in their style. However, both convey large amounts of detailed information about coping with HIV disease in a very personal way. The issues raised in this study are equally complex and perhaps best addressed in a testimonial or dramatic form.

4.4 Discussion

Many of the materials reviewed above do serve an important purpose. However, the absence or incomplete treatment of HIV+ gay men neglects the following issues:

- **Primary prevention**

HIV+ men have a clear role to play in primary prevention. They are the ones who will know about the personal circumstances of becoming infected. Their testimony in this respect is invaluable. This knowledge did not seem to be utilised in the materials reviewed. There is also evidence which strongly suggests that some men (including those that know themselves to be HIV+) make assessments regarding the possible serostatus of their partner when they have (unprotected) anal intercourse. These assessments will sometimes be incorrect. Both HIV+ and HIV- men not only need to be sensitively warned of the dangers of such assessments but

also informed about how to make them more successfully. The experiences of HIV+ men could be used to much greater effect in this process.

The decision of whether or not to take an HIV test and the process of HIV testing for gay men has not been addressed. Many materials shy away from this issue or recommend testing but do not give advice, support or information about what to expect or how to prepare for a positive test result. Again, HIV+ gay men have a specialist knowledge of this area which should be utilised.

■ Resource needs of HIV+ gay men

HIV+ men are not visible in gay media or health promotion messages for gay men. There is a need to improve community support networks for HIV+ gay men. There is also a need to minimise the harmful effects of rejection both from friends and from sexual partners. This study suggests that being 'out' about one's serostatus can ease the process of coming to terms with an HIV diagnosis and help in setting up vital support networks amongst other gay men. Increased visibility within mainstream gay culture and within health promotion messages will facilitate this openness.

Although there are some resources about disclosing one's HIV status to loved ones, there are issues concerning disclosure of status to one's sexual partners, one's friends and one's family which are unique to gay men with HIV. There do not seem to be resources which address these issues within an entirely gay context. Present resources either represent HIV+ gay men in an unnecessarily one-dimensional manner or do not mention them at all. There is a clear need for resources which address these issues at length. There are further issues about setting up care networks and negotiating a balance between biological family and partners or friends.

There are also questions regarding starting relationships, disclosure of HIV status to one's casual partners, fear of rejection etc. which none of the resources reviewed come close to addressing adequately. Again, many of these difficulties are particularly pertinent for gay men. What this study shows, however, is that there is a great expertise about dealing with these difficulties amongst gay men who have been living with HIV for some time. This knowledge can only come with experience. It is vital that any new resources developed makes use of this expertise. However, it is not enough to simply provide a group of HIV+ men with the space and money to come up with their own resources. They must also be backed up and constrained by real health promotion expertise.

None of the materials in this review addressed the issue of unprotected anal intercourse adequately. Although this is clearly a very difficult issue, there is a constituency of HIV+ gay men who are treating this as an option. It is vital that they are provided with the knowledge and skills to make the best possible personal choice. There is therefore a pressing need for more detailed information about the harmful affects of re-infection with HIV and infection with other

STD's.

Finally, the issues raised in this study are indeed complicated and difficult to address. To identify these issues within a printed resource is hard enough, but to do so in a way that will aid their resolution for the reader is even harder. The testimonial or photo story format might be better suited to this function than posters or cards. The interactive and narrative form where one character gives advice to another might also be more useful in this respect.

SECTION 5: CONCLUSION AND RECOMMENDATIONS

The purpose of this final section is to highlight conclusions drawn in the previous four sections and to make concrete recommendations based on these conclusions.

6.1 Social Support - Conclusions

The building of social support networks for many gay men was problematic. Those who went to their families for support often had difficulty integrating their own lifestyles and values with that of their families. This was often complicated by the presence of a partner. Likewise many men did not receive sufficient support from their gay social networks as did their partners. What follows is a synopsis of the conclusions regarding social support:

Men were used to making complex assessments about the utility of disclosing important events such as a positive HIV diagnosis to their families. Families reacted in a number of ways when told of the diagnosis. Sometimes, a parent or sibling acted as go-between. This process usually had a detrimental affect on that person. Where families were supportive, this support was sometimes experienced as burdensome. Both family members and PWHIV agreed that it is better to disclose earlier rather than later in order to deal with interpersonal problems which may arise. However, the support and care offered by families often came into conflict with the lifestyle of the gay family member, especially if he had a close network of gay friends, a partner or was sexually active.

There was very little support for the partners of HIV+ gay men. In addition, partners sometimes experienced difficulty accessing support because their partner was secretive about his diagnosis and illness. Partners also neglected their own support needs and experienced the same rejection from friends as the PWHIV. Attitudes of families becoming involved in care or attitudes of some health care workers put a strain on a relationship. Recognising these difficulties, many men with HIV felt inhibited about starting a relationship. This had the effect however of denying these men the support which a successful partnership can bring.

On the broader gay scene, many men felt inhibited about being open about their HIV status. There were related concerns raised about the lack of visibility and lack of representation of HIV+ men on the scene. There was also concern about the level of ignorance amongst HIV-men about the realities of living with HIV disease. Consequently, many men saw ASO's as vital to their social support. Many men saw the support and company of other HIV+ gay men as vital also, both in terms of advice about how to deal with their diagnosis and for day to day support. There was a definite perception that these needs were not being met in any other way. There was consequently concern for those men who did not have a support network which included other HIV+ gay men. Finally, the establishment of a strong HIV+ identity was seen as extremely helpful by many gay men in dealing with and living through HIV disease.

5.2 Health Promotion Materials - Conclusions

There is a distinct lack of visibility of HIV+ gay men in health promotion materials generally. This may have the effect of maintaining ignorance and fear regarding HIV+ gay men amongst gay men who assume themselves to be HIV-. It also deprives HIV+ gay men of essential role models and a sense of community. Within this context of invisibility, there are practically no health promotion materials which represent the reality of living with HIV disease for gay men (in both it's positive and negative aspects). Whilst many resources advise gay men to test for HIV, there is no provision or advice for gay men regarding living with an HIV diagnosis should they test HIV+. Furthermore, other areas are unconsidered such as: advice on starting and maintaining social support networks; disclosure of status to friends and family; development of care networks; negotiating relationships and maintaining a sero-discordant relationship; options regarding disclosure of HIV status to sexual partners and to gay scene acquaintances. Health promotion materials fail to consider options around unprotected anal intercourse adequately. There is no information which facilitates an HIV+ gay man to make the best and most informed choices regarding his sexual practice. Finally, this and other studies have shown that HIV+ gay men have amassed a wealth of personal experience about all of the areas mentioned above none of which is being used in present resource production.

5.3 Recommendations.

We recommend three main methods for meeting the needs identified in this report. These are resource production, community / service development and further research.

Production of the following resources are recommended:

- A resource which uses the experiences of the men in this study to advise gay men on central areas that arise for them as they begin to deal with a positive HIV diagnosis: friends, family and partnerships. This resource should also encourage gay men to investigate their current support network, and assess it's suitability for becoming a care network if they should become ill.
- A resource which explores the option of 'coming out' with HIV and it's role in establishing a strong gay identity. This resource would necessarily need to include positive role models and testimonial regarding this process, perhaps backed-up with a series of mainstream gay advertisements / features.
- A series of resources designed to increase the visibility of HIV+ gay men within the mainstream gay media / on the gay scene. This could also serve to educate HIV- men about the realities of living with the disease.
- A resource which guides gay men through the experience of taking the HIV test. This resource should include a detailed examination of the issues should one test HIV+.
- A resource which deals with the emotional and sexual problems inherent in maintaining a long-term sero-discordant relationship.
- Finally we recommend primary prevention resources which utilise in a direct way the experiences of HIV+ men.

Community Development

- We recommend that ASO's critically assess the function of their organisations as safe spaces for gay men. Many do serve this function already, however there is a need to target diverse constituencies of gay men in a more proactive way. If possible, more diverse social activities could be organised, perhaps focussing on gay men with HIV, but being attractive to gay community networks generally.
- There is also a need to increase the availability of self-help support groups for HIV+ gay men as well as support groups for partners and carers.

It must be emphasised that these changes should only be in addition to and not instead of present service provision.

Further Research

- In addition, we recommend further research into the suitability of present care services for gay men. This is in reference to the following questions:
What is the most appropriate way to deliver generic health services to gay men with HIV? What are the benefits (if any) to both physical and mental health of delivering this type of service in a more appropriate manner? Do the needs of gay men in this respect differ from other groups infected with HIV? What are the needs of health care professionals regarding training on homophobia and knowledge of gay mens lifestyles? What benefits could be gained from this training for care personnel, medical and mental health personnel?

The research outlined above must to start with a description of the service use of a large sample of gay men. Therefore, service use needs to be mapped not only across different service providers and different service areas (for example incorporating different ASO's and GP's), but also across time (for example, the patterns of service use of an individual throughout the course of his HIV disease). Qualitative methods can be use to explain patterns identified.

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