

***It's grim up north?: A comparative study of  
the subjectivities of gay HIV positive men  
in an urban and rural area***

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## **ABSTRACT**

This comparative study of the experiences of gay HIV positive men living in urban and rural areas explores the dynamic interrelationship between lived experience and service provision. The literature in this field has drawn on a familiar stereotype – the urban, sexually active, gay man. This man – and his community – does not exist in a rural environment in the way it is assumed nor does it necessarily fit the experience of gay men in London. By creating a link between the questions of subjectivity and the question of how we improve services, I argue that a mechanistic construction of need may follow an assumed urban model which may not hold for all men in an urban setting, nor for men in rural areas.

Gay HIV positive men are faced with new psycho-social dilemmas in relation to the virus, including unpredictability of outcome, as well as the complexity and burden of the current treatment. They engage in a constant process of renegotiating their sense of themselves in space, time and relationships. Through the use of narrative methodology, my research builds a new perspective on the experience of these individuals which can help to shape the services and policies of the future.

The stories of 21 gay HIV positive men were gathered and analysed in relation to five areas of focus: community/space, relationships, identity, health and services.

Rural participants were less able to build and maintain a politically strong identity and rural services need to create strategies to enable gay men to draw on the strength of a collective voice. 'Doing for' services, prevalent in rural areas, may be appropriate for the very ill but can perpetuate a culture of helplessness. The healthist discourse adopted by London services promotes individualism and responsibility. Services for HIV positive men in all areas need to hold the dynamic between 'doing for' services for the sick and dying and a healthist discourse for those who can look to their future.

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## CHAPTER 1 - INTRODUCTION

Having worked with HIV positive gay men in London and in rural North Yorkshire, I was struck by the differences in the experiences of these groups of people. These differences were manifested in contrasts in service provision and in everyday life resulting from living in a rural area. I became interested in the dynamic interrelationship between service provision and the lived experience of the men with whom I was working. There is a body of literature on service provision and, distinct from that, a body of literature concerning HIV positive gay men and issues of subjectivity. What appeared to be lacking, however, is a link between these two and it is this gap which my research is intended to fill. The gap exists both in the literature, and in the reality of these men's lives. I aimed to sharpen our understanding of gay HIV positive men's subjectivity through a comparison between urban and rural experience and to clarify if and how services should be differently shaped in different areas. My principle questions were, how do gay HIV positive men live their sexuality and HIV status in urban and rural areas? What understandings do they create of themselves, their relationships and their lives? What is the interrelationship between these understandings and the services which exist for these groups?

I begin with a review of the existing literature. I critique the contemporary research on health care and service provision for HIV positive gay men and the ways in which concepts of need are constructed in and through this work. I then look at the literature relevant to the themes I explore in my research: community space and relationships, identity and subjectivity and concepts of health, in particular health/ill-health as HIV positive. In the methodology chapter I consider the four areas on which I have based my methodological choices: the epistemological assumptions which underpin the research; questions about which theoretical perspective lies behind my choice of methodology; the process or design which lies behind the choice of my particular method and, finally, in a separate chapter, my method i.e. what techniques or procedures I used to gather and analyse the data. The results

are the stories of the participants. Whilst the rest of the research is concerned with making links and contrasts across these stories and between the participants, this section retains the individual story. I have therefore retained many of the details of each participant's story and placed this section as a separately bound appendix. The data analysis chapter draws on the themes established in the literature review: community, space and identity; relationships; identity; health and individual's relationships with professionals, treatment and services.

The data demonstrates that the different ways in which gay space and gay community are constructed in urban and rural spaces has had a significant effect on the ways in which participants constructed themselves both as gay and as HIV positive. Participants' relationships with sexual partners, friends and family illustrate that the spectrum of relationship needs are differently constructed across urban and rural spaces. Differences in space, community and relationship give rise to differences in the participants' shifting understandings of themselves, both as gay and as HIV positive. Central to participants' identity was their self-understanding in relation to health and there are differences across the two groups of participants in terms of how they constructed meaning from their diagnosis. Finally I drew on each of these four preceding themes to explore how the participants across the two areas accessed medical and support services and what were their experiences of those services.

The final discussion chapter draws largely on the work of Ken Plummer (1995) in drawing together the literature, my theoretical perspective and the research data. I return to the five themes of the literature review and data analysis: community and space; relationships; identity; health and relationship with services and re-conceptualise them as narrative performances, caught in a particular space and time. I look at new ways of conceptualising need and responding to need, making concrete recommendations about services for gay HIV+ men living in both rural and urban areas. I conclude the research with a meta-analysis of these narratives. The research itself is a post-modern narrative performance; a celebration of the space between binary oppositions:

urban/rural; gay/straight; positive/negative; healthy/ill; community/individual; belonging/not belonging and so on. These spaces – whilst constructed and problematic ‘fictions’ – are core to our understandings of self and other.



## **CHAPTER 2 - LITERATURE REVIEW**

In this chapter I explore the existing body of literature and outline what I believe is the gap in research in this field. I review the service-focused research on health and social care provision for HIV positive gay men, arguing that it takes a limited definition of 'need' rather than considering broader quality of life issues. This affects the ways in which services are provided in different areas – they are not sufficiently flexible in terms of geography and community and concentrate on the service rather than the individuals for whom the service is provided. In my research I consider what it is like, as a holistic experience, to live in an urban or rural area as an HIV positive gay man. I argue that a mechanistic construction of need may follow an assumed urban model, which may not hold for all men in an urban setting, nor for men in rural areas.

I consider what has been written about gay geography and rural space – how sexuality is lived in and through space and community. I then review the research which considers HIV positive gay men and issues of subjectivity, arguing that although this body of work is significant in terms of drawing a rich picture of the lives of these men, it does not provide concrete ideas which can help HIV positive gay men to improve their situation, nor does it give specific guidance to service providers. I also review the body of literature on HIV and the anthropology of the body; the lived physical experience of HIV. Much of what has been written about gay sexuality and HIV has drawn on a familiar stereotype – the urban, sexually active, gay man. He is white, middle class, educated and active in the 'gay community'; itself another stereotype. Working with gay HIV positive men in Yorkshire, it was readily apparent to me that this man – and his community – did not exist in a rural environment in the way it is assumed in the literature and that the men with whom I was working were making sense of their sexuality and their status in correspondingly very different ways. In my work with HIV positive gay men in London, I have also been led to question the experience of gay men in an urban environment. How closely do they or their experience resemble the urban stereotype?

Through gathering men's stories about themselves and hearing how they understand what it means to be gay and HIV positive in terms of their own lives, my research aims to build a new perspective on the experience of these individuals which can help to shape the services and policies of the future.

## **2.1 - CONTEMPORARY RESEARCH ON HEALTH CARE AND SERVICE PROVISION FOR HIV POSITIVE GAY MEN: CONCEPTS OF NEED**

In this section, I review the research which looks specifically at service provision for HIV positive people in both London and in North Yorkshire and use this as a springboard to make links between questions about HIV, the body and subjectivity, and service provision for HIV positive gay men in London and Yorkshire.

### **2.11 - London-specific research**

There is no London-based research which looks specifically at the needs of HIV positive people. The London-based Sigma studies are based either on sexual behaviour or HIV prevention and health promotion. This in itself is significant. Given the number of positive people based in London, a nationwide study such as the Sigma research discussed below will largely reflect London experience and attitudes.

## **2.12 - North East specific research**

### **'The Sexual Health Needs of HIV positive gay and bisexual men': A report commissioned by the Northern & Yorkshire Regional Health Authority**

**Paul Court et al., 1995**

This is a report which pays particular reference to quality of life issues and current service provision for HIV positive gay and bisexual men in the area covered by this particular health authority. The participants were asked through questionnaires and semi-structured interviews to identify what was important to them in their lives and those areas they perceived to affect their sexual health. The research found that participants' sexual health was inextricably linked to their general sense of health and well-being. As this is a relatively focused study, the research data concentrates on sexual health issues, such as sexual activity, safer sex and disclosure and there is little or no consideration of how participants understand their HIV in terms of their identity and relationships. The report also includes a section about service provision which highlights the inherent dilemma for services in rural areas: balancing the need for a personal, human and local response with the requirements for standards of excellence and expertise: 'In addition to participants wanting specialist services, there was an equally important desire for a more personal approach to services.' They also advocated the need for 'regional centres of excellence' which would combine both voluntary and statutory sector services. The definition of need used in this research is very focused on service provision and in danger of giving rise to a narrow conception of what people require from services. Service users' lives are portrayed only in terms of their HIV and sexual health and only needs which can potentially be met through services are considered.

Many research participants were very aware that they were accessing services which were of a lower standard than those available in London and some chose to travel long distances to access services which they perceived

to be of higher quality. This demonstrates the basic assumption by service users in the pattern of service take-up that local and small means amateur, ad-hoc and inferior. Participants expressed concern that professionals working in a low prevalence area who were not specialised, necessarily would not be as expert in their field as those working in a high prevalence area. The research does not provide any basis for this in terms of the detail of service delivery, only an assumption by service users that if professionals only worked with small numbers of people, they had less opportunity to build up their expertise. Another need identified was for one-to-one peer support through voluntary organisations. The report did not, however, outline the very real difficulties for service providers in making such support viable and workable. The spread of the population, transport difficulties, fears around confidentiality and the small size of the gay scene in a rural area are but some of the obstacles which problematise peer support services and I develop this point later in considering the implications of my research data in the context of service development and delivery in rural areas.

What this report lacks is a holistic portrait of how HIV positive gay men living in a rural area conceive themselves and their world and how their illness fits within that life-understanding.

### **Services for people with HIV/AIDS in North Yorkshire: Review of current services and options for the way ahead (Land et al., 1996)**

This review was commissioned by the North Yorkshire Health Authority because of a concern about the reactive evolution of services, changes in funding for services, questions over the viability of non-statutory services and organisational changes within Health and Local Authorities. The report specifically looks at options for service organisation and delivery, and the balance of specialist to generic services. What is significant about this report is that it entailed a review of services drawn from interviews with a range of professionals, a review of different national patterns of service delivery and recommended options for the future. Service users were at no point directly involved in this piece of research about current or future services, although

existing needs assessment studies (e.g. Handyside, 1994) were summarised in a separate chapter. This report led to several recommendations which formed the basis for the development of HIV services in the area which were in place at the time of my research, particularly a 'hub and spoke' network where the aim was to have specialist workers in regional centres who would train, advise and inform more generic local staff.

One of the principle aims of the recommended 'hub and spoke' system was to set up a model which was specialist-led rather than one which is specialist-provided – bringing the benefits of specialisation to an otherwise generic service framework. Whilst in principle this might seem a rational response, there is no consideration in the report of the difficulties of this model for service users. Positive people, particularly in rural areas, have concerns about accessing generic services which include issues about confidentiality, perceived lack of expertise and a need for one-to-one consistent support (see Court et al., above). This report had as its focus the desire to create efficient, streamlined services from the point of view of commissioners and service providers, with a resultant loss of focus on the requirements of the group of people whom these organisations will serve. This focus is even more apparent in the suggestion that there should be one non-statutory service based in York and that the management/provision of non-statutory community services for the rest of the county should be put out to tender. The reason given for this proposal is that the two models of care provided can then be compared with a view to the future. This would lead to a competitive, closed method of working rather than a culture of collaboration and partnership between the different agencies. As I demonstrate through my research, a fundamental flaw in this report is the lack of understanding of the unique experience of people living with HIV and the particular requirements they may have of their services. This leads to the claim in the report that 'confidentiality is...the only characteristic which people with HIV disease require which is different from other groups' and that 'the health and social care needs are similar to other clients'. Ironically, given the above, one of the conclusions of the report is that care must start from the needs of the individual and their

circumstances and preferences, and that high standards of care will depend on the close involvement of individuals with HIV.

### **2.13 - National research**

**Proceeding with Care: Phase 3 of an on-going study of the impact of combination therapies on the needs of people with HIV**

**Will Anderson, Peter Weatherburn, Peter Keogh, Laurie Henderson  
Sigma Research, May 2000**

The significance of this document lies in the understanding of the authors of the holistic experience of living with HIV and the fact that the concept of 'need' is placed at the centre of this model:

'Although a clear distinction between the themes of need and service use was hard to sustain, participants were not asked specifically about their use of services until after they had reflected at length on their experience of living with HIV, their needs and how they had addressed their needs' (p5)

Anderson et al. point out that most health and social care research, including HIV research, defines need in terms of people's demands for services, and this is very much a limitation of the other reports in this review. There are problems with such an approach, as the authors point out: people with HIV may meet their needs in ways other than through services; people may use services to meet a wide range of different needs and a demand on existing services may fail to discover changes in the pattern of people's needs over time.

The starting point for this report is the fact that 'the impact of anti-HIV combination therapy on the needs of people with HIV has been shaped both by changes in health and changes in prospects' (p2). The focus is on people's unique and changing perceptions of their lives and there is a recognition that people meet their needs in different ways at different times. There is also a

recognition of the nature of service use – that ‘people with HIV do not rationally select services to fulfil identified needs’ (p2). On the contrary, people will use services in a piecemeal, exploratory way, possibly using a service to fulfil a need in a way different from that intended by the service provider. Also, people’s use of services will in some way contribute to the way they frame what they need.

This report starts from the standpoint of the individual and that is reflected in its recommendation that ‘responsiveness to individual need is more important than delivering the ‘right’ services to everyone’ (p3). There is also a crucial acknowledgement of the different and changing relationships individuals will have with anti-retroviral therapy and an understanding that access to treatment, increased health and a new future does not mean that people are in less need of emotional and psychological support; in fact dealing with uncertainty and change involve different mental health stresses. All the recommendations from this report start from the basis of individuals’ lives as they see them. Improvements in health are an important part of the picture, but they are not the whole picture:

‘This model of need, bringing together individual perceptions about life’s possibilities with the reality of current difficulties and losses, is both individualistic and dynamic. Every participant in this study had a unique perception of need and a unique story of need...Every participant had also found their own way of meeting their needs...Although services were important in meeting needs, this was not the only role they played in people’s lives’ (p10)

My research takes very much the same definition of need and the focus of my study is also people’s lived and felt experience. It is only from this starting point that we can build a clear picture of need as individuals themselves conceptualise it in their lives. One of the recommendations of the report is that ‘providers should respect the individuality of their users’ needs and be sensitive to their beliefs, interests and doubts. Responsiveness to individual need is more important than delivering the ‘right’ service to everyone’ (p3).

The principle concern of my research and one to which I return throughout this review of the literature is the extent to which individual need is shaped, or is felt to be shaped, by locality and the extent to which services need to be locally based. Another recommendation of the Sigma report is that 'Providers and commissioners should not focus on combination therapy as the key to understanding the needs of their users, but attend to all things that shape individual lives' (p3). It is vital to balance medical advances and success with a concern about people's lived experience in the context of anti-retroviral therapy.

One of the differences in my study is that I focus on the experience of gay men whereas this report also includes heterosexual men and women. My focus highlights the connections between a particular sexual, social and cultural identity and the experience of living with HIV. This report still focuses on 'need' albeit from a very holistic viewpoint, whereas my research looks more broadly at an individual's subjectivity and how a gay identity and an identity as HIV positive fits into that subjectivity. The main focus for my research is sharpening an understanding of gay positive men's subjectivity through a comparison between urban and rural experience, and through this process of comparison I clarify and build on the findings of this report in relation to service provision. It is interesting to note that some of the issues identified by the women in the Sigma report are ones which may be characteristic of gay men's experience in rural areas. For example, for many of the women in this study, self-help groups provided a safe space for them to disclose and discuss their status and to build informal support networks whereas the urban gay men were less reliant on these services because they had a wider range of alternatives.

The Sigma report highlights the importance of peripatetic workers for helping individuals who are concerned about confidentiality to access services, and this also may be of particular relevance for many gay men in rural areas. In terms of services, it is significant that this report finds that very few participants were in contact with their GP and most accessed a clinic directly for their health care, which undermines the recommendations in the North



East based reports about encouraging access to generic services. The authors note that individuals' use of services was often a rather haphazard process of exploration: 'trying things out, seeing what worked...and finding out what else might be worth trying' (p40). The researchers note that participants generally developed patterns of service use which worked well for them, but perhaps the success of such an endeavour largely depends on the range of services available to an individual. When one clinic and one voluntary organisation is all that is on offer, this process of trial, error and compromise is necessarily more confined.

The report also suggests that service use helps to define need. Individuals who discuss matters of concern with their peers and/or professionals will use this experience to articulate their needs in particular ways: 'Services provide a language for articulating need which is sustained by wider ideas of what it means to be healthy or fulfilled' (p6). Gay men in rural areas have particular peer and professional contact which will lead them to frame 'need' in ways which are different from their urban counterparts.

There is a general move by service providers to change the way in which services are provided to fit the changing face of HIV, but this report points out that this move exists alongside a corresponding move by service users to change the way in which they use existing services:

'At a time when service providers were trying to work out how they should be changing their services to meet the changing needs of their users, those same users were manipulating the existing opportunities of the services to address, for themselves, the changing needs' (p43)

The concluding words of this report are ones which lie very much also at the heart of my research:

'A service which respects the individuality and complexity of need will succeed and be cherished. A service which imposes

a view of need and how needs should be met will not. At a time of change, it is crucial that services do not assume that they must transform themselves and, in doing so, lose touch with the lives of the people they exist for' (pp44-5)

### **The National Strategy (DoH, 2001): A critical review of the strategy and the user-led response**

The national strategy for sexual health and HIV was brought out by the Department of Health in 2001 for consultation. Its claims are 'Better prevention, better services and better sexual health' and for the purposes of this review I am focusing on the implications of the strategy for gay men already diagnosed HIV positive.

#### Implications of the strategy for gay HIV positive men

Whilst there is a recognition that HIV remains a life-threatening condition and that combination therapies have not provided a total solution, there is no mention in the strategy of the complex mental health needs of many people living in a chronic state of uncertainty and change. It recognises the relationship between sexual ill-health, poverty and social exclusion (p3) but does not outline any concrete action in the areas of social exclusion and stigma. One of the given aims of the strategy is to improve the health and social care of people living with HIV and this is defined as:

- Helping patients adhere to drug regimes
- Helping access to education, employment and leisure facilities
- Ensuring people have their needs assessed and met for welfare benefits, housing, advocacy, interpretation, peer support and other practical support for life in the community
- Supporting carers and families
- Making sure that people living with HIV can benefit from wider initiatives that promote social inclusion (p33)

The National AIDS Trust (NAT) response is that this fails to recognise the increasing complexity and diversity of HIV social care needs and my research highlights this new complexity. As the NAT response points out, introducing service standards will not necessarily solve this problem. The UK Coalition and Terrence Higgins Trust Consultation exercise produced a slightly different list of what people felt that the social care needs were for people living with HIV which again differed significantly depending on HIV status, sexuality and ethnicity. When people were asked what would most improve the health of people living with HIV:

‘Whereas many people raised good sexual health education, gay men ...pointed to the need for the Government to tackle homophobic prejudice and discrimination. This issue was raised both by men who were diagnosed HIV positive and those who were not’ (p5).

Gay men also pointed to the need for more flexible clinic opening times for people who work. In terms of social care needs, the consultation exercise highlighted the need for:

- ❑ Better support groups
- ❑ More focused support for returning to work and education
- ❑ Information about how to find HIV and sexual health services (66%)
- ❑ Peer support; welfare, legal and housing advice; and treatment and adherence support (over 60%)
- ❑ Over 57% felt it was important to fight discrimination and prejudice
- ❑ Slightly less than half highlighted the need to provide support on employment and training

It is important to note that the social care needs as defined by the strategy, by the consultation process and those as defined by the Sigma research ‘Proceeding with Care’ which I have discussed above, are all different and all reflect the different ways in which the data was collected.

### How does the strategy outline service need in rural areas?

The strategy recognises that services across the country vary in quality and calls for better and more consistent standards. There is, however, little consideration of the balance to be struck between consistent standards and the need for services to be responsive to local need which will continue to differ significantly across different areas. Unless there are new protective measures put in place, the end to ring-fenced budgets for HIV services means that in low prevalence areas, commissioners could significantly reduce HIV-related spending. The strategy does specifically mention difficulties for HIV positive men in rural areas, noting that long journeys and patchy provision often restrict access to services and that information is often out of date or unavailable.

Part 4 of the strategy states that sexual health services should be developed around patients' needs and doing that successfully means providing a choice of easily available services; focusing services on local needs; giving staff education and training; giving providers clear descriptions of tasks, roles, skills and interrelationships; giving people better information about local services; reaching an understanding between commissioners and providers about the sexual health characteristics of the local community and setting local targets for service improvement. These again are laudable goals for developing improved services in rural areas. There is also a recognition in part 4 of the strategy of the difficulties individuals face in accessing services: embarrassment, previous bad experiences, worries about confidentiality, social exclusion and homophobia are amongst the problems stated. The strategy recognises that commissioners and providers need to understand and respond to local communities and build networks with others inside and outside the NHS who serve the target populations. This is particularly relevant for services working with gay positive men in rural areas where there can be serious barriers to accessing services. The National AIDS Trust response to the strategy specifically refers to people in geographically remote areas as a marginalised community experiencing barriers to treatment access. This is

implied but not specifically stated in the strategy itself. The NAT response goes on to detail barriers to treatment as including fear of stigma, discriminatory practices of health professionals and lack of access to treatment information (p16). The strategy states the importance of users becoming more involved at all levels of service planning and delivery but there is nothing in the document which specifically recognises the barriers to becoming involved, particularly in terms of confidentiality, and this may be of particular concern for gay positive men in rural areas.

There is specific reference in the strategy to a move to broaden the role of GPs in HIV-related health care. The UK Coalition and THT consultation exercise noted fundamental difficulties with this. Almost 80% of people with HIV had experienced some form of prejudice or discrimination since their diagnosis and health care staff were common sources of discrimination with dentists and GPs being the most frequently cited professionals. In the UK Coalition and THT Consultation, 70% of the gay men consulted said that they would not feel comfortable using their GP because of concerns about confidentiality, insurance implications and lack of training in HIV in a primary health setting.

'Partnership at all levels is central to the strategy's success' (p12). Whilst this a laudable aim, partnership in rural areas risks homogenising services and losing responsiveness to local need. This move to more working in partnership needs to be balanced with another principle in the strategy which is 'Responding to the different needs of different populations - ...services should meet the needs of local communities' (p13)

The next stage of the National Strategy was the publication in January 2003 by the Department of Health of: 'Effective Commissioning of sexual health and HIV services: A sexual health and HIV commissioning toolkit for primary care trusts and local authorities'. This explicitly states that it is not intended to be a blueprint, rather it should be used as recommended best practice; guidance which may help to make sense of local situations, whilst recognising local

diversity and difference. The toolkit draws on the priorities stated in the NHS Plan (2000) which are

- To ensure policy making is more joined up and strategic
- To ensure public service users, not providers are the focus by matching services more closely to people's lives
- To deliver high quality and efficient public services

Other national policy priorities drawn on in the toolkit are

- The development of multi-disciplinary and multi-agency partnerships
- Reduction in health inequalities
- Bridging the gap between health and social care provision
- Development of more patient-centred services
- Improved access to services

### Research implications

The strategy encompasses all groups of people in need of sexual health services, but the UK Coalition and Terrence Higgins Trust Consultation exercise noted distinct differences in the responses given by people depending on their HIV status, sexuality and ethnicity. Being a gay man, being HIV positive and living in a particular area will all give rise to a very particular set of experiences which will differ from the experiences of other groups. The strategy gives as a potential priority, research which looks at the barriers preventing access to services, and this is part of my enquiry into the experience of gay positive men in rural areas. The National AIDS Trust response states that the strategy needs to support a national programme of HIV social and behavioural research with a high priority accorded to a national study of the lives of people living with HIV and my study contributes to this body of research. As NAT points out, we lack knowledge and understanding about living with HIV; 'taking treatments, living on benefits, the experience of discrimination, coping with illness...sexual health and sexual behaviour, the effects of using drugs and alcohol, mental illness...isolation, work and identity' (p18). My research aims to address all of these areas. The NAT document states that such research needs to be sustained, national and closely linked to grass roots practice. The comparative aspect of my study will lead to

understandings which will be relevant across different areas and the qualitative nature of my methodology ensures that the data is 'bottom-up'.

## **2.1 Conclusion:**

### **Ways of conceptualising need and responding to need for HIV positive gay men: local diversity and future uncertainty**

The literature regarding HIV support services highlight a number of issues which are key to my research. An important question is about how need is constructed and the effect this has on service development and delivery. Is the definition of need service-centred or can a more diffuse concept of need be used in understanding the lives of HIV positive men? A more diffuse concept of need will take into account local difference and diversity across different urban and rural areas and it is these differences which I highlight in my research. Urban and rural differences are evident in an individual's experience of their spatial and community context; their network of relationships; their resulting sense of identity as HIV positive and gay; the way in which they reach an understanding of their health state and their pattern of service demand and service use.

To live with HIV is to live with uncertainty and paradox and this needs to be reflected in the services which respond to the needs of this group. In the last ten years of HIV services, new psycho-social dilemmas have been highlighted and old difficulties continue. Gay positive men now have to deal with unpredictability of outcome as well as the complexity and burden of the current treatment. There are clear differences between clinical and social change: two key findings of a piece of research into the impact of anti-retroviral therapy on the lives of people with HIV were:

- Starting anti-retroviral therapy typically produces marked improvements in both biological markers and physical health, *but these improvements do not always translate into similar changes in personal and social well-being*
- The success of treatments *should not be assumed to bring about anything other than physical health*. The uncertainties and obstacles of life,

especially life with HIV, are not easily overcome (Anderson & Weatherburn, 1999 *my italics*)

Mental health is jeopardised at times when the individual's felt and lived experience is at odds with the discourses available to them to frame that experience. HIV is not a stable entity and changes in personal experience, discourse and social framing is a constant source of uncertainty for individuals – to be constantly negotiated and renegotiated.

A crisis in one's sense of self may happen at different points and not necessarily at the point of testing and diagnosis. HIV is clearly more than a medical condition – it is an issue of identity and people living with HIV need to manage a changing understanding of who they are and will construct stories that will fit their experience of themselves, drawing on cultural stories which we have constructed to frame the experience of HIV in society. We create meaning for ourselves, both individually and socially through our stories of illness.

The HIV crisis is a crisis of constant change. Once a crisis of health, now it presents many people with a crisis of identity and a changed sense of one's place in the world. People tell an individual story and their story is a changing one over time. HIV is also a story which is told in society, constructed in and through particular cultural discourses which are both affected by and affect the way it is manifested. Again, perhaps one of the hardest things for some HIV positive people, particularly those who have been diagnosed for some time, is the way in which HIV is constructed has undergone such dramatic changes in the last twenty years. People who were diagnosed through the 1980s were diagnosed with a terminal illness with a short prognosis. To live positively with HIV during those times for many people was to come to terms with the loss of one's future, with dying. Since the advent of anti-retroviral therapy to die is almost considered rather 'bad form'. The 'story' of HIV in society creates a framework of meaning within which people may or may not be able to fit their experience.



HIV is a story constructed in space and communities. It is a changed and changing story in which we make sense of ourselves and our world, our past, present and future. People will describe themselves in a particular way according to whether they perceive themselves as having a strong sense of their own self-efficacy or regard themselves as the victim of circumstance. Individuals who have a strong sense of self efficacy may be quite conscious in the way that they create a sense of meaning around HIV for themselves. HIV becomes part of their life - sometimes peripheral, sometimes more central – to be integrated into other aspects of their lives. People who struggle more with their status may regard it as meaningless, pointless in terms of the rest of their lives and an adjunct rather than as something which could fit with other aspects of self.

My research picks up on key research priorities as identified by the Royal Society of Medicine in a conference held in December 2000. The aim of the conference was to find better ways of serving patients with an uncertain prognosis or from particular areas of social disadvantage. They identified, among others, two research priorities:

- 'a review of existing models of care and the evidence of success or failure among specific under-served populations in geographic areas (rural, inner city). How does access to care differ by setting? How does the quality of care differ by setting?'
- *Changes in the HIV disease trajectory* must be evaluated in relation to palliative care decision-making. This should also include reasons why people choose to stop curative or life-maintaining therapy'

Workgroup: Sept. 2001 Journal of the Royal Society of Medicine 94(9) p484-5 (Goodwin D., Marconi, K., Teno, J.)

HIV poses particular challenges in relation to uncertainty and stigma, both to the people living with the virus and to services supporting them. Anti-retroviral therapy has led to the redefinition of HIV as a chronic rather than terminal condition but loss, grief, crisis and uncertainty are all issues that face HIV positive people today. People living, or dying, as a result of HIV enter a constant process of renegotiating their sense of themselves in space, time

and relationships. In a context where the discourse is so much more about living healthily with HIV, there is a particular need for a sensitive response from services to those who are not able to define themselves within that discourse.

HIV is still a stigmatised condition and many people living with HIV encounter prejudice on several levels simultaneously. Gay and African communities, where prevalence of HIV is at its highest in this country, are minority communities which face a range of forms of discrimination. The difficulties faced by individuals through an HIV positive diagnosis will only fuel the exclusion they already encounter. In a socially excluded minority community, where family and/or friends may seem the only allies, revealing an HIV positive diagnosis risks exclusion from these and other forms of community support.

This first section of the literature review explores the service-focused research to suggest that the different ways in which the concept of need is constructed affects service development and delivery. A more diffuse concept of need would give a richer understanding of the lives of HIV positive men and would take into account local difference and diversity across different urban and rural areas, leading to more appropriate and responsive services. The following section explores the non service-focused literature in the field in relation to a number of themes which highlight the benefit of broadening our definition of need. In relation to this body of literature, urban and rural differences are analysed as they are evident in an individual's experience of their spatial and community context and their network of relationships; their resulting sense of identity as gay and HIV positive and the way in which they reach an understanding of their health state. All of these, I suggest, will influence their pattern of service demand and service use.

## 2.2 COMMUNITY, SPACE AND RELATIONSHIPS

This section examines the literature which explores what it is like to live as gay and as HIV positive, in a particular space and community. There is very little research which explores the subjective experience of HIV positive men in rural areas and I suggest that the way in which they are able to live their sexuality and status in a rural space will have a different impact from their urban counterparts on their sense of themselves (Brown 1994, 1995, 1997; Wilton, 1996, Butler & Parr, 1999). The formation of a 'gay community' is dynamically related to the existence and formation of 'gay spaces', be they bars, clubs, societies, cruising areas etc. Bell & Valentine's (1995) edited text *Mapping Desire* is particularly useful in a consideration of how sexuality and space constitute one another (see also Philo, 1992 below for a consideration of space in rural geographies).

The urban 'gay community' has come to represent community action and consumer hegemony (Nelkin, Willis & Parris, 1991). For gay men in urban areas, there is a diversity of choice in terms of where one can go, with whom one associates and what activities are available, providing gay men with a variety of different ways in which to construct themselves and provides outlets for those areas of expression in a collectively validating way. In urban areas there exist gay communities which can help to affirm a positive sense of oneself as gay by providing outlets for individual expression in a collective environment. One of the most affirming aspects of the gay 'community' within the HIV epidemic has been the growth and expression of 'family' relationships of love, friendship and support both through HIV voluntary organisations and informally through relationship and friendship networks (Levine et al., 1997) although it must also be acknowledged that HIV has also been instrumental in breaking bonds between gay men through death and burnout.

Knopp (in Bell and Valentine, 1995) points out that sexualised spaces are portrayed as a specifically urban phenomenon and that generally urban

culture is one of consumerism and surface; an archetypal space of modern sexuality. Urban spaces allow for anonymity and the possibility of escape from cultural and familial pressures but many of these gay spaces are commercial in character and can exclude those who do not 'fit'. The consumerist, marketplace expression of urban gay culture can be highly pressured, and gay 'norms' can be as oppressive as any heterosexist expression. Gay men who do not conform to the healthist materialist ideal of the bar and club culture, may find themselves excluded twice over, and those who aspire to be part of that culture may have to deny parts of themselves in order to fit. Binnie in the same volume points out that gay urban spaces are market mediated; that money is the major prerequisite and the greatest obstacle to the establishment of autonomous, independent, assertive gay male subjectivity. This combination of plurality of choice within a consumerist and potentially arid and disenfranchising medium is also played out in the growth of gay 'virtual space' in phantasy 'phone lines, the use of the internet etc. (although for some gay men the internet is an invaluable link to a sense of community). We have a paradox – urban space and community can be both liberating and oppressive, freeing men from the shackles of cultural normative pressures and recreating them in a different guise.

Rural spaces have been described as heteronormative, providing little or no opportunity for anonymity, affirmative collective gay action, open gay expression or alternatives to traditional frameworks. Again, however, we have to take into account a paradox; we need to consider the extent to which gay men in rural areas *are* able to create their own spaces within a heteronormative environment in cruising areas, pubs, each others' homes etc. (Philo, 1992).

It is clear that the term 'gay community' is problematic in both an urban and a rural context. People often feel themselves to be gay before they become part of the community; much of gay history is concerned with the lack of community (Warner, 1993); one's sense of community is very dependent on one's individual circumstances and many men who have sex with men do not define themselves as gay at all, let alone part of a gay community. Whilst

acknowledging that the 'gay community' is nebulous, shifting, fragmented and at times oppressive, much of the existing literature suggests that it is an important factor in many men's lives in terms of defining themselves within and/or against their particular concept and experience of what the gay community is (Le Vay, 1995, 1996). The gay community is a concept which cannot be absent from a gay positive man's identity, even if it is a concept from which he distances himself.

Philip Gatter (1995, 1999) has looked particularly at the influence of community on the development of identity – particularly social identity – and sexuality in relation to HIV/AIDS in an ethnographic study of an AIDS Service Organisation in London. He argues that we need to understand identity from a processual perspective, i.e. individual and collective identities as emerging from specific historical circumstances and struggles. He suggests a dialogic approach to appreciate how different forms of identity engage with an identity as HIV positive and how individual and collective identities are complex, shifting mosaics. Gatter draws on Foucault and Weeks to present identity as a site of conflict and contestation for both groups and individuals and as in a constant state of process and flux. He argues that the relationship of being gay to being HIV positive is a distinctive one in urban Britain because of the relation between HIV, identity and sexuality and involves issues such as involvement in AIDS Service Organisations as a user, volunteer or employee; involvement in activist groups and re-imagining of the body as a battleground against HIV. My research explores whether this activism and involvement is something that is *necessarily* experienced by urban gay HIV positive men and also whether this is the experience of positive gay men in rural areas. The setting of Gatter's research will have influenced the type of data he collected in this respect. Whilst Gatter's call for research which links the development of individual and collective subjectivities is justified from his ethnographic data, his research is based on work with men who to some degree were already 'activists' and so would have a particular relationship with collective identity construction. Gatter's analysis is very much related to HIV as an identity marker in relation to other HIV positive people which may simply not be applicable to most gay HIV positive men.

Gatter (1999) analyses how positive gay men have identified themselves, both collectively and individually, in response to the AIDS crisis. He conceives AIDS as a catalyst, changing the ways in which people identify themselves but also incorporating continuities from previous identities. He explores 'social identity', i.e. the ways in which people present themselves in relation to HIV in terms of the social process of identity formation, the significance of community and the role of illness and how it changes self perception in the context of social networks. The literature on HIV and identity is explored in more detail in the sections below.

Gatter draws on the theories of Bell and Valentine (see above) to articulate the geography of a sexual community but describes this in terms of interrelationships as opposed to my research which explores participants' understanding of their broader community and their sense of space and place. Like Gatter, I consider issues of identity; identity as HIV positive and how this draws on other and previous identities; identity as dialogic, as a site of contestation and in a continual process of becoming. Unlike Gatter's work, this research specifically compares urban and rural experience and suggests there are some fundamental differences in social identity construction in different geographical areas.

Weeks (1985) argues that politicised sexual identities need certain conditions for their emergence: large numbers of people in the same situation, a geographical concentration of such people, identifiable targets of opposition, sudden events or changes in social position and an intellectual leadership with readily understood goals. Part of my enquiry is into the effect (or not) of the absence of the first two factors for gay HIV positive men in rural areas on their sense of subjectivity. There has been a neglect, both of rural experience in research into the experience of gay men, and of the experience of gay men in the literature on rural geography (D'Augeli & Hart, 1987, Lockhart, 1989). Key questions for my research are to what extent does living in an area where there is no politically active gay 'community' – or maybe no sense of 'gay community' at all - impact on a person's sense of themselves as gay? If

identity is in large part relational, how does someone with little contact with other gay men construct a sense of themselves as gay? Importantly, to what extent does living in a low prevalence area affect one's sense of oneself as HIV positive and gay?

One notable contribution to this field is Paul Flowers who has undertaken a number of fieldwork studies in South Yorkshire and Scotland exploring sexual behaviour, concepts of the gay community and issues of subjectivity (Flowers et al., 2000). He argues that the community or solidarity of positive men is in danger of fracturing as a result of new health technologies relating to recency of diagnosis, treatment history, treatment failure or drug resistance which shape and define new types of HIV positive gay men with unique and differing responsibilities. It might be argued that the lived experience of the gay community has always encapsulated these contradictions even though changes in medical and social responses to HIV in the last decade have significantly changed many people's perceptions of the gay community and their place within it, in ways which may not always have been benign. Flowers looks at gay men's histories and uses their 'Coming Out' stories to explore the process of identity construction and how that might have impacted upon HIV risk-related behaviour. My study takes this a step further and explore how men's previous histories and senses of self impact on their construction of themselves as HIV positive in the present.

In a paper which explores gay men's accounts of growing up in a heterosexist society, Flowers (2000) points out that little research attention has been given to the spatial location of the social processes of stigmatisation, heterosexism and homophobia and he specifically explores the spatial aspects of social contexts and locale in relation to sexual health. Again this is taken a step further in this research and suggestion is made that little research attention has been given to the spatial location of the subjectivities of gay HIV positive men in general. Flowers' work is one of the few studies located in a rural and northern area and his research pinpoints some of the issues which persuaded me to make my research study specifically comparative between a rural and an urban location. For example, he illustrates that his subjects felt isolated

and excluded both from the straight culture which surrounded them and from an imagined gay community which was perceived as distant and inaccessible (cf. Gatter above), he also identifies the value the men in his research place on a gay identity which, although bringing severe costs, also brought significant benefits.

'Cottages' and 'Public Sex Environments' (see glossary) are often the only guaranteed sexual outlet for gay men in rural areas and Kramer (in Bell and Valentine, 1995) points out the difficulty of research in rural areas due to the fact that many men frequent cruising areas (see glossary) because they do not need to divulge much personal information. He suggests (although this is not based on empirical research) that rural gay men are more likely to form and to stay in incompatible relationships; rely on a social network which is based only on a common sexuality; experience loneliness and isolation and suffer from alcoholism, drug abuse and depression. The lack of empirical research evidence for these claims demands further investigation.

Apart from Paul Flowers' work, there has been little consideration of the experience of living with HIV in a rural area. The research which explores service provision takes a mechanistic definition of what 'need' is for this group of people and does not take into account their sense of themselves and particularly their sense of themselves within space, community and relationships. This gap in the research field affects the way in which services are provided in different areas. By comparing urban and rural experience for HIV positive men this study focuses specifically on the relationship between a person's sense of themselves in space; what they feel they require to live fully in that space and community and how this may be different across different spatial contexts. In rural areas particularly, the growth of HIV organisations have provided a forum for gay men to meet (O'Carroll & Collins 1995) but Altman (1994 in Nardi & Schneider 1998) carried out research which demonstrated that the growth of effective HIV organisations was more problematic in low prevalence areas and areas where there was little sense of gay collectivity. This research study explores the extent to which gay HIV positive men have a collective sense of themselves and what possible



channels exist for that expression, and how gay HIV positive men construct a sense of themselves within their particular social context. In rural areas in particular there may be a fear of an 'invasion' of foreign values and lifestyles into the community and HIV may represent the locus for this fear. This may lead to active homophobic sentiment or simply a sense that such things 'just don't happen here'. If masculinity and heterosexuality are the tropes that define membership of a closed rural community, then being gay may mean that you no longer 'belong' to Yorkshire – you are by definition an outsider.

This study is concerned with what it is like as a holistic experience to live in an urban or rural area as a gay man and as an HIV positive man. As I suggest above, a mechanistic construction of need may follow an assumed urban model which may not hold for all men in an urban setting, nor for men in rural areas because men will differently construct their identity as gay and as HIV positive across different spaces.

## **2.3 IDENTITY AND SUBJECTIVITY, GAY SEXUALITY, GAY SUBJECTIVITY**

### **2.31 - Constructing an identity as 'gay'**

There is a reasonably comprehensive body of literature which is concerned with questions of HIV positive gay men and subjectivity and clearly, the literature which looks at identity and sexuality is key to this research. How HIV positive gay men understand and conceptualise their experience is a question explored in the literature outlined below, but my concern with this body of work is that it fails to reach any concrete recommendations about how things could be made better. The following section considers what we can draw on from this literature to inform questions about service provision in the light of an understanding about gay HIV positive men's subjectivity. This literature demonstrates an ongoing tension between similarity and difference; between defining oneself in relation to others and experiencing oneself as unique.

Jeffrey Weeks (1995) articulates the space which we have created between sexuality as innate and as a social construction by conceiving the body as 'an ensemble of potentialities which are given meaning...in society' (p122). Our need to 'belong' with others is placed in tension with our need to articulate the unique nature of our individual experience. If our search for identity is the search for truth about ourselves, then we will always be struggling between constructing an identity from the categories available to us, into which we will never fully fit, or tread a lonely and vulnerable path of articulating for ourselves alone, which is impossible anyway because we cannot but be influenced by the categories available to us; we cannot think outside those categories altogether. At the same time as presenting a critique of identity politics, we need to be clear about the benefits, even necessity, of a sense of identity and belonging. Our sense of ourselves is constructed with and through our relationships with others and defining ourselves in opposition to others allows us to articulate our inner sense of who we are:

'Identity is about belonging, about what you have in common with some people and what differentiates you from others. At its most basic it gives you a sense of personal location, the stable core to your individuality. But it is also about your social relations, your complex involvement with others, and in the modern world these have become ever more complex and confusing. Each of us live with a variety of potentially contradictory identities, which battle within us for allegiance' (Weeks, 1991, p184)

Any claim to a particular identity is to some extent a limitation and a compromise, so we could argue that identity categories are, by their very definition, excluding (Lancaster, 1987, 1992, Leiner, 1994, Jacobs et al., 1997; Melhuus, 1998). For example, identity categories may exclude those who do not fit the category 'gay man' for whatever reason; those with AIDS who are not activists; those who do not feel a part of the 'gay community'; the insistence of definable and explicit categories doubly excludes large groups of people. The exclusions of the gay and AIDS activist communities can uncannily mirror the exclusions of the culture at large (Annetts and Thomson in Plummer, 1992, Edelman, 1994, Messner, 1997, Miller, 1998).

Paradoxically, it may be the very success of gay liberation that has allowed internal discord.

To keep the category 'homosexual', in this society is, to some degree at least, to retain the dichotomy between hetero and homosexual in a hierarchised relationship in which heterosexuality will be dominant and normalised. The paradox of gay liberation is that the idea of homosexuality is predicated on the very hierarchised positions to be attacked (Plummer, 1992, Seidman in Warner, 1993, MacKinnon in Harwood et al. 1993). Dollimore (1991) helps to explain some of the media and politically driven homophobia when he points out that a paradoxical consequence of creating homosexuality as a fictional other is that heterosexual hegemony has created an object of desire; an enduring fascination with 'other sexualities'. We can argue that the definitional boundaries with regard to sexuality are attempts to discipline and control whilst, on the other hand, we can argue that resistance to these disciplinary forces has taken place from within those categories themselves (Edelman, 1994). Whilst there may be a danger that gay men historically define themselves largely through and as a result of homophobic discourse, such as the trials of Oscar Wilde and the medical texts of sexologists (Weeks [1981] 1989, Mosse, 1985, Halberstam & Livingstone, 1995), if all resistance is linked to power relationships, rather than forming part of the originating oppressive forces, we can conceptualise an endless possibility of micro-resistances at all levels of society.

If homosexuality is born from within the category heterosexuality, to what extent is the concept 'gay' useful, relevant or liberating for gay men? Is this is a label which they ascribe themselves or is it ascribed to them by others? Jeffrey Weeks (1985, 1991) carefully steers a path between identity politics and queer theory, maintaining the efficacy and limits of both positions. He argues that sexuality is a historically produced phenomenon, that legal and medical discourses helped to shape the 'homosexual' as a distinct identity and this created 'the elements of resistance and self-definition that led to the growth of distinctive homosexual identities' (1991, p108). The idea of being gay forming a defining part of one's identity is comparatively recent and is

beset by many contradictions, confusions and potential exclusions. He argues that we need to construct sexual identities to protect ourselves from the chaos of limitless choice which would otherwise threaten to engulf us. He concedes that identity can become prescriptive but that it can also provide a point of choice, actualisation and resistance. Sexual identities are the media through which we negotiate our sexual selves in the world and as such they cannot be willed away. In order to explain oneself and negotiate relationships, one has to have words for one's subjectivity that others will be able to understand. In the end, Weeks' view is guided by pragmatism; that the 'necessary fictions' which are sexual identities are a matter of a continual process of choice, a narrative quest which spurs us into thinking again about what we value and what we want in the world.

'Identity may well be an historical fiction, a controlling myth, a limiting burden. But it is at the same time a necessary means of weaving our way through a hazard-strewn world and a complex web of social relations. Without it, it seems, the possibilities of sexual choice are not increased, but diminished (Weeks in Caplan, 1988, p49)

Each of us at different points in our lives will experience ourselves as sexual beings in a way that is unique for us at that moment. Within that infinite diversity there will be continuities and empathies which will enable us to make connections with others' experience across time and space. According to our situation and our needs, the continuities and discontinuities with others will play more or less important roles for us. I use Weeks' conclusions as a springboard in considering *how* positive gay men grapple with these issues – the extent to which they need and choose to define themselves, the extent to which they defy pre-fixed categories and what they need in order to find their own consensus. In addition, I explore how positive gay men will negotiate this process differently according to an urban or rural spatial context.

## **2.32 - Constructing an identity as HIV positive**

Our experience of HIV and our theorising of that experience take place in a particular historical and cultural context. Giddens (1991) argues that the modern Western world emphasises the role of the individual in creating their own subjectivity from a bewildering array of choices. Life has become far more contingent and uncertain; this can give rise to a sense of liberation but also a crippling existential anxiety. It is also important to acknowledge that people have a different range of choices and are differently able to take up those choices. This will also vary for people across the course of their lives. Giddens defines a crisis as a point when 'activities concerned with important goals in the life of an individual or a collectivity suddenly appear inadequate' (Giddens, 1991, p184). Living with HIV may place an individual in a fluctuating yet permanent state of crisis. Our society is characterised by a declining trust in certainty: law, medicine and religion no longer provide us with answers we can trust. Paradoxically, this does not stop us looking to those structures for certainty amidst our doubt. One of the particular anxieties for many people currently living with HIV is the lack of consensus about what risks attend particular choices; some 'experts' advocate early treatment, some late, some none at all, some alternative treatments etc. It becomes impossible to evaluate with any certainty the choices one is making. Positive gay men are living in an uncertain world with uncertain choices and my research explores how they manage that uncertainty to create a meaningful sense of themselves in the world. Giddens points out that there are moments in a person's life-span when the degree of choice is problematised and the extent of choice-making is conscious, and heightened, with attendant heightened anxiety. For positive gay men, the (continuous) process of 'Coming Out', receiving a positive diagnosis and the process of living with that diagnosis are all points at which someone's choices may be radically changed and the choice-making process become more conscious and more problematic. Not only are we faced with different choices and the responsibility for fashioning our lives out of those choices, but the world also provides us with an uncertain and contradictory set of moral and ethical frameworks on which to hang the

decisions that we make. To become aware of all the choices that we make and all the risks involved would be to collapse into existential angst; in order to live in the world we need to balance active choice making with a denial of some of the choices and attendant risks. That sense of basic trust with which we operate in the world may be undermined by a positive diagnosis. Such a moment Giddens calls 'Fateful' and is a time when life is perceived anew with attendant implications for one's perception of self.

To create a sense of identity is to create a framework of meaning around experience and Stephen Schwartzberg (1996) uses a psychological framework to explore how HIV positive gay men have, and have not, found meaning in HIV/AIDS as an individual journey. He takes as basic premises to his research that we need to find and maintain meaning in our lives, that the greatest psychological threat to any trauma is how it can destroy meaning and that individuals hold the potential to reach new understandings of themselves. His interviews with nineteen HIV positive gay men addressed three underlying questions:

- How, if at all, have gay HIV positive men found meaning in, or made sense of, AIDS?
- How do people, faced with such major adversity, maintain or recreate the belief in a meaningful world, even when external reality is radically altered?
- How has AIDS affected HIV positive gay men's beliefs about such issues as fate, religion, death, the meaning and purpose of life and the degree to which people control their own destiny?

He uses ten themes drawn from the data as building blocks of meaning to identify 4 styles of adaptation:

- Transformation – HIV as a catalyst for personal and spiritual growth
- Rupture – HIV as representing loss and despair
- Camouflage – a 'fine line of self deception'
- Impassivity – either a Zen-like acceptance or a depressed belief in one's own powerlessness

In his emphasis on the need for meaning he draws on evidence from concentration camp survivors to argue that an imprecise, imperfect or self harming framework is better in terms of survival than no framework at all (p26) and that more than one coping strategy may be relied upon. What Schwartzberg does not do, however, is to take this a step further to consider what these men in need in order to develop or maximise the coping strategies which are most functional for them. He does not look at what it is in these men's lives that have led them to develop particular styles of adaptation and whether, if they had different types of lives and influences, they would adapt differently.

Brian Heaphy (in Weeks & Holland 1996 & Barber & Huby, 1998) has carried out research specifically into issues of HIV and identity formation. He uses Giddens' (1991) concept of the 'fateful moment' to look at what resources people use to make sense of infection and diagnosis and to explore how people reach an understanding of what it means to be HIV positive. He regards identity formation in the context of HIV as a reflexive act in response to the need for ontological security in the face of uncertainty. He presents an HIV diagnosis as a 'fateful moment' which threatens our ontological security and leads us to construct a new sense of self. My research explores whether in fact HIV positive individuals may be faced with a number of 'fateful moments' in relation to their sense of self as positive, that these are different and happen at different times for each individual and are in part dependent on the individual's spatial context. Compared with other life threatening conditions, HIV causes wide fluctuations in health which can cause a person's sense of self as healthy or sick to 'see-saw'. For many gay men, there is also a community aspect to HIV which means that it might be part of their lives and identity before they were diagnosed. For this reason, it might be that some people do not experience HIV as a 'fateful moment'; their diagnosis and new identity as HIV positive may become more or less readily absorbed into the person's sense of self. In my research I consider people's reaction to HIV in the light of their sense of who they were prior to diagnosis – to what extent is their sense of themselves the same or different as that pre-diagnosis?

Again, Heaphy does not take his conclusions a step further to consider what would assist HIV positive men in a practical concrete sense in dealing with the potentially 'fateful moment' of diagnosis and the need to construct a new sense of self. He does not consider why some men seem more able to do this than others in a way which is meaningful for them and what internal and external resources have enabled them to make these changes in their sense of who they are.

Heaphy conducted his fieldwork in 1990-1 when perceptions of HIV as a terminal condition were very different for many people and conducting a similar study over ten years later will illustrate changes in the way in which a positive diagnosis might (or might not) be integrated into one's sense of self as a chronic and treatable, manageable condition. Like Crossley (below), Heaphy did not consider issues of space or place in his work.

Another important dimension within which identity is constructed and manifested is time. We create a sense of ourselves as located in time; our present in terms of both our past and our future. For HIV positive men, the changing face of HIV and living with a continuous sense of uncertainty about the future will have a particular impact on their understandings of themselves in time. Michele Crossley (née Davies) (Davies, 1997, Crossley & Crossley, 1998, Crossley 1997, 1998, 1999a & 1999b, 2000a, 2000b) has written several papers based on qualitative research carried out with long-term diagnosed individuals drawn from the National Long-Term Survivors Group. The field-work was conducted in 1995, i.e. before anti-retroviral therapy became routinely adopted and accepted which will have had a significant bearing on the type of data she collected. It was also based on interviews with men who had been diagnosed positive for some years and classed themselves as 'long-term survivors' which again will have had a significant bearing on the data. Crossley (Davies 1997) wrote a paper based on this research in which she looked at concepts of time, dividing people's stories according to whether they seemed to be living with a philosophy of the present, living in the future or living in an empty present. She identifies issues of temporality and disrupted and/or ambiguous temporality to be central in



someone's attempts to adjust to living with the virus and I suggest that this might be even more widespread in its application with the development of anti-retroviral treatment. People are now living with a more uncertain concept of time; for example they may have been diagnosed at a time when the long-term prognosis was poor, only later to be 'given back' their future as a result of new treatments, whilst at the same time the long term efficacy of those new treatments remains in doubt. Questions of time are also complicated for those who choose not to take treatment, who take alternative treatments or for whom the treatments have failed. In her early work Crossley (Davies, 1997, Crossley & Crossley, 1998, Crossley 1997, 1998, 1999a & 1999b), suggests that living in an empty present is a maladaptive response although in her later work she moves away from attempts to valorise one way of living over another. Although living in an empty present is perceived as harder for and by the individuals concerned, we need to look at these different temporal understandings themselves taking place in time and ask why different individuals conceive themselves as living in time in such different ways. People understand the virus as something which has occurred at a particular time in their lives and also as something which has occurred at a particular historical time in terms of our collective understanding. Philip Gatter (1995, 1999) also makes the point that an individual's understanding of their experience of the virus will be affected by and will affect the particular historical and cultural moment in which they place themselves.

Crossley (1997) uses the same data to look at how the process of constructing self in terms of 'Othering' takes place within HIV positive individuals, themselves made 'Other'. She argues that those people who have been able to build a 'robust' theory of the meaning of their diagnosis have done so by constructing oppositional images of self and other. These 'Others', identified as the 'weak-minded, negative, HIV+ individual', and the 'newly diagnosed' serve as negative prototypes of the 'healthy' self. Again using the same data, Crossley (1998) examines the way in which HIV positive individuals are caught between competing discourses in terms of constructing themselves for themselves and for others. People seem to sit more or less uneasily between sick role and healthist discourses. Crossley (1999) suggests

that her participants present themselves through one or more of three narratives: a 'normalising' story, a 'conversion/growth' story and a story of 'loss'. These correspond to the different perceptions of time she encountered (living in the future, living in the present, living in an empty present respectively). She also draws on Giddens' (1991) distinction between emancipatory and life politics to suggest that each of these stories afford both liberatory and repressive potential according to the person's life world at any one time.

I draw on Crossley's conceptions of discourse, time, self and other in relation to HIV positive gay men, but again I take her understanding a step further in order to consider what resources men need in order to understand themselves and their experience given the fact that they are living within constant change and a continued sense of future uncertainty. My research also addresses issues of space which are not addressed in Crossley's work and I draw on a more diverse group of people. Developments in treatments and in the field generally since 1995 will also yield a different set of data. A significant aspect of Crossley's work which lies at the heart of my research is the idea that a 'healthist' discourse can both liberate and repress according to the spatial and community context within which the individual is placed.

In his paper 'Illness Narratives, Time, Hope and HIV' (2000) Douglas Ezzy, like Crossley above, draws on the concept of narrative in a combined qualitative and quantitative study of people living with HIV in Australia to look at different constructions with which people make sense of their illness experience. Ezzy uses three narratives to explain how people reach different meanings of living with HIV. Linear-restitution narratives are goal- and future-orientated, materialistically focused and assume that life, both present and future, can be controlled by human action. Chaotic linear narratives are defined against a linear ideal resulting in depression, an empty present and despair for the future. Polyphonic or quest narratives involve living with a philosophy of the present, accepting future uncertainty, maintaining a communal rather than individual orientation and focusing hope on mystery, surprise and creativity rather than on concrete gains.

Each of these narratives hold different meanings for individuals in terms of hope, orientation, spirituality etc. Ezzy points out the precarious nature of linear restitution narratives (which are adopted by many of Crossley's participants) and the despair of linear chaos narratives. His 'polyphonic' narrative is able to embrace many of the contradictions and tensions inherent in living with the virus. Ezzy qualifies his narrative categories by stating that all these narrative forms are clusters on a continuum rather than closed categories. He does not assign narratives to particular individuals but rather argues that narratives by their very nature are always in process, inconsistent and unfinished and one individual can incorporate different narratives at the same time and over time. Apart from a brief consideration of the relationship between the type of narrative used and links with the gay community, he does not consider what might influence people in adopting different narrative articulations. He interestingly finds that new treatments tend to underline rather than radically to alter the type of narrative used by an individual and this is a question I explore further in my analysis.

Ezzy draws on Frank's (1995) analysis of narratives of illness: a restitution narrative which minimises the experience of illness; a chaos narrative which portrays the person as the passive victim of senseless suffering; and a quest narrative which presents illness as a journey. Ezzy suggests that these different analyses are associated with different kinds of hope: concrete hope in the future, loss of hope and transcendent hope. His analysis also corresponds to Crossley's (Davis, 1997) different forms of temporal orientation: living in the future, living in an empty present and living with a philosophy of the present. Ezzy presents a clear analysis of the different ways in which people construct an understanding of living with HIV but he does not fully consider why different people reach different articulations of themselves and what would help people to construct a subjectivity which would be functional for them. Once again Ezzy's analysis risks becoming merely academically 'interesting' rather than concretely helpful.

There are links to be made between Crossley's, Schwartzberg's and Ezzy's analyses: Crossley's normalising story, story of loss and growth story correspond to Schwartzberg's Camouflage, Rupture and Impassivity and Ezzy's linear restitution narrative, chaos narrative and quest narrative. Crossley's concept of living with a philosophy of the present and growth story, Frank's quest narrative and Ezzy's polyphonic narratives all correspond with a postmodern 'life politics' which incorporates fragmentation, discontinuity and contradiction. This is the cultural context in which we are placed at the beginning of the 21<sup>st</sup> century, the context in which the research participants are living, the political context in which organisations where they receive their services are surviving and the academic context in which I am writing.

Schwartzberg, Heaphy and Crossley all consider how being gay and HIV positive impacts on people's subjectivity; how they form an understanding of who they are. Their work takes a broad perspective on people's experience which was lacking in the research discussed earlier which focussed more specifically on service provision. The limitation on this more broadly based research, however, is that we are left with little sense of what concretely can be done to improve the quality of people's lives and we risk descending into purely academic 'interest'. Subjectivity is an individual narrative, a bodily experience, a social, cultural and historical construction held in a unique balance for different people at different times in their lives. We develop our sense of ourselves through our relationships in time and space with ourselves and with others. I suggest that this may be experienced as more or less liberating and/or oppressive according to individual circumstances. Gay men living with HIV may have a particularly problematic relationship with the world and this, as well as the extent to which they define themselves in relation to their bodies, sexuality, their place in time, space, community and relationships will have a significant effect on their sense of themselves. In my research I explore what has influenced different men to reach different understandings of themselves and what assists them in this process. By making this study specifically comparative between urban and rural experience I am suggesting that issues of space and community have a particular effect on gay positive men's subjectivity.

## 2.4 - HEALTH AND CONCEPTS OF HEALTH WITH HIV

In this final section I explore the physical experience of HIV in relation to the anthropology of the body. HIV inhabits a particular place between the individual and the individual in context; it is a physical condition which is individually experienced but at the same time is inextricably about relationships between people because of the way it can be transmitted. As well as being an individual and relational experience, HIV is a political and cultural phenomenon; understood and experienced at a community level. HIV is both object and product of different discourses each of which is historically constructed and placed (Weeks [1981](1989), 1985, 1991, 1995). HIV is very much a disease of this time. In 20<sup>th</sup> and 21<sup>st</sup> century Western society, sex, health, bodily fitness and well-being and the avoidance of death are principle elements of personal identity; an epidemic which associates sexuality with the disintegration of the body and death is therefore likely to have a profound existential impact (Murphy, 1994).

The way in which the virus infects the body and mutates is mirrored in the social and cultural meanings ascribed to it. HIV is potent symbol: 'it is an 'enemy' virus that threatens to destroy us not from the outside but from within...And this internalisation of the other can lead to our auto-destruction' (McGrath in Boffin & Gupta, 1990, p144); it infects through fluids associated with the transgression of boundaries; it feeds off the very system which serves to protect the body against it; it actually becomes part of the body, so that the body is literally destroying itself. Issues of homophobia, stigma, disclosure and risk police the borders we construct between self and other, individual and collective, public and private and HIV also treads those borders. Living as a gay man with HIV in this culture is, at least to some extent, to live in a world which is homophobic, heterosexist and stigmatising. An individual's relationship with themselves and with the world will be in part influenced by this oppression and the degree of resistance with which they counter it. Positive gay men have continuously to make decisions about risk (Douglas &

Wilavsky 1982), disclosure, 'Coming Out' (see glossary) (Goffman 1963 in Gerhardt 1989 & Garrick, 1997), their relationship with medical 'expertise' and treatment and so on. Each of these decisions will have an impact on that person's understanding of themselves and also impact on the way he is viewed in the world. Ronnie Frankenberg (1992) specifically looks at the social response to epidemics of sexually transmitted disease:

'Epidemics are *social* sicknesses in which the whole social relationship between nature and culture is put in question for many individuals at the same time...Epidemics are accompanied by an attempt simultaneously to maintain and to redefine the boundaries of the same and other and thereby to maintain and to replace modes of ritual and symbolic control. Sexually transmitted diseases which become epidemic, especially those with an expected fatal outcome within a relatively fixed period, represent for society as a whole...the ultimate in loss of control over nature and the individual. They demand social explanation and redressive action over and above clinical cure and prevention.' (p75)

HIV can be conceived as a somatisation of social and cultural trouble (Crimp, 1988, Sobo, 1996, Segar, 1997, Waitzkin & Magana, 1997) and, equally potently, as symbol of oppression and resistance. Whilst we can regard the AIDS epidemic as precipitating a 'sex panic' (or, alternatively, insufficient concern to change behaviour); for many people, both individually and collectively, HIV has also become a focus for an inner and/or political realisation; a turning point. Radley (1993) argues that metaphor plays an important role in allowing people to conceive their situation as viable and comprehensible and an HIV positive diagnosis can become the springboard for a radical re-orientation of the self; a catalyst for change. Many group and individual actions by gay men, as a result of AIDS, have been powerful acts of affirmation. One of the most well known is the AIDS Memorial Quilt (Meyer in Fuss 1991) which is intended to represent rootedness, participation and belonging. The symbolism of the Quilt is about connectedness and the effect is a sense of inclusivity and encouragement of unity in diversity. The Quilt's

intention is to draw people out of isolation into a collectivised experience and to construct gay identity as a source of pride.

Health and illness are not necessarily oppositional; one of the confusions of HIV is that diagnosis is an ascription of an illness label whilst the person may feel healthy, and/or they may feel ill whilst being labelled 'asymptomatic'. Also, being labelled at risk may in itself be detrimental to health. Armstrong's (1979, 1984, 1987, 1993, 1995) argument that illness is not only placed in the body but also in time and within the community has a particular resonance for all gay men, whether tested negative, positive or untested. The body, sick or healthy, is no longer simply a bio-medical physical entity but something placed at the dynamic between the individual and society. Health is not a description of a person's physical state but their own sense of their relationship with themselves, others and the world. It is within these paradoxes that the men in this research live their lives. HIV then can be experienced in many different, and often contradictory ways. Each individual will need to create their own understandings of what it means to them to be HIV positive, and this may differ radically for different people and for the same person at different times. One of the major components in understanding HIV, however, will be the person's broader understanding of what it means to be healthy and what it means to be ill.

If social and cultural trouble is inscribed on the body as illness, this does not necessarily make us the passive victims of collective misfortune. If our own stories are inscribed on and through our bodies, sometimes in the form of illness, this does not make the cause of illness our own personal deficiency. What I do suggest is that HIV is a representation of illness at a social and cultural level and the way in which people physically experience HIV will be consistent with and will form a part of their own individual biographies. The story of people's illness in their lives, how they formulate that story and how they choose to tell their story forms the core of my research. We can only fully consider the social and cultural construction of HIV through an analysis of the virus as an embodied experience. We experience HIV through the effect it has

on our own and/or others' bodies and the fact that these bodies form a collective experience in space and time.

## **CONCLUSION**

In the first section of the literature review, I have explored the service-focused research to suggest that the different ways in which the concept of need is constructed affects service development and delivery. A limited definition of 'need' has been used and broader quality of life issues have not been considered. As a result, services are not sufficiently flexible in terms of geography and community and can lose sight of the experience of the individuals for whom the service is provided. A more diffuse concept of need would give a richer understanding of the lives of HIV positive men and would take into account local difference and diversity across different urban and rural areas, leading to more appropriate and responsive services. In my research I consider what it is like, as a holistic experience, to live in an urban or rural area as an HIV positive gay man. My assumption is that a mechanistic construction of need may follow an assumed urban model, which may not hold for all men in an urban setting, nor for men in rural areas. I use this assumption as a springboard to make links between questions about HIV, the body and subjectivity, and service provision for HIV positive gay men in London and Yorkshire.

The literature which is reviewed in the second half of this chapter is clearly significant in terms of drawing a rich picture of the lives of gay and HIV positive men, but it does not provide concrete ideas which can help these men to improve their situation, nor does it give specific guidance to service providers. The literature on HIV and gay sexuality in relation to HIV has drawn on a familiar stereotype – the urban, sexually active, gay man and this study problematises that stereotype both in urban and rural locations. Urban and rural differences are evident in an individual's experience of their spatial and community context and their network of relationships. This will affect their resulting sense of identity as gay and HIV positive and the way in which they



reach an understanding of their health state. All of these, I suggest, will influence their pattern of service demand and service use.

We negotiate our sexuality and status through our understandings of who we are and gay HIV positive men will have a particular relationship with that process. We need to build on existing understandings of how people develop their sense of subjectivity to create new insight into what people need in their lives which will enable them to develop an identity as gay and HIV positive which is functional for them. Drawing on my experience as a practitioner in both an urban and a rural environment, I suggest that differences in experience for urban and rural positive gay men will lead them to have different needs in terms of improving the quality of their lives. By exploring service provision within a broader understanding of gay positive men's subjectivity, I have reached a more comprehensive understanding of how services can best meet the requirements of this group of people.

In this review of the literature I have looked at the service based literature which largely takes a narrowly-focused needs-based perspective on the experience of gay positive men and the academic literature which, whilst taking a broader perspective on the lived experience of individuals, does not consider what concretely can be done to improve men's lives. In my research I attempt to synthesise these two branches of literature by retaining a broad perspective whilst also considering actual service provision. In the section which follows I look at the theoretical and ethical basis of my methodological choices for the research.

## **CHAPTER 3 - METHODOLOGY**

### **3.1 - INTRODUCTION**

I used a qualitative approach and specifically a narrative methodology in order to gather the stories of the participants. The interview schedule was loosely structured around three pre-determined themes derived from the literature review – what did it mean to the participant to live in an urban or rural area; what did it mean to them to be gay and what did it mean to them to be HIV positive: ‘Narrative psychological approaches tend to be very much grounded in the attempt to understand the specific experiences undergone by individuals (Crossley, 2000, p40).

Crotty (1998) argues that we approach research with four initial questions and I use these to structure my thinking about my methodological choices.

- ❑ the epistemological assumptions which underpin the research (what theory of knowledge is embedded in my approach; how do I know what I know?)
- ❑ questions about which theoretical perspective lies behind my choice of methodology (what is the philosophical stance which supports the methodology, provides a context for the process?)
- ❑ This leads to the methodology – which strategy, plan of action, process or design lies behind the choice of my particular method?
- ❑ Finally, what is my method? i.e. what techniques or procedures have I used to gather and analyse the data?

### **3.2 – EPISTEMOLOGY**

An epistemology, according to Crotty, is a way of understanding and explaining how we know what we know. It deals with the nature of knowledge, its possibility, scope and general basis. In common with most qualitative research, a theory of knowledge which underpins my work is constructionism. My assumption is that truth, or meaning, comes into existence in and out of our engagement with the realities of our worlds. Different people may

construct meaning in different ways: it is the interplay between subject and object that generates meaning. To apply constructionism specifically to my research, I consider some of the advantages and disadvantages of this approach to thinking about the body, health and illness and sexuality.

### **3.21 - Constructionism, health and illness**

Social constructionist theory conceptualises reality as constructed by society; the body is no longer a biological given, it is a series of potentialities which we invest with reality and meaning (Weeks, 1985, p122).

In their book *The Social Construction of Reality* (1966), Berger and Luckmann argued that, unlike animals, humans are ontologically open; that is, at birth we are incomplete and socially we must construct our own reality and meanings to protect ourselves against anomie and chaos. According to this theory, we make the social reality in which we live (externalisation), this in turn shapes our experience of reality (objectification) and the social reality we have created becomes in turn an objective structure which defines us as social agents (internalisation). The way in which we construct our reality is born out of an attempt to find both meaning and security in a world of infinite possibility (Turner, 1992, p83).

An analysis of the discourse around health and illness is particularly useful in analysing power relations in medicine; we can use this to help us to understand the doctor-patient relationship, the space of the institution of the hospital, state control of medicine, 'patient power' and the growth of advocacy groups, and the role of preventive health and health promotion in terms of the discipline of the body both through exterior forces and their interiorisation.

A purely constructionist approach, however, permits no phenomenology of the lived body. Whilst our experience of our bodies is mediated through discourse, the essence of our embodied self is perhaps something beyond and irreducible to discourse. If disease is purely a social construct, how can I account for the physiological changes which take place within my body? There is clearly a much more problematic relationship between what we can

physically perceive and what meanings we construct around these perceptions:

'We can never hope for an unproblematic atheoretical correspondence between our knowledge and the natural world because each new experience of the world necessarily interacts with our prior beliefs about it' (Nicholson & McLaughlin, 1987, p111)

There is also the difficulty of reflexivity. If all knowledge is constructed, then the theories of social constructionists are just as socially and culturally determined as anyone else's. This is true, but confuses a point about how knowledge is caused with how it should be assessed (Nicholson & McLaughlin, 1987, p115). The fact that we are unable to think outside our social, cultural, historical frameworks, does not make what we say illegitimate. Social constructionists have been criticised for relativism. If truth and rationality are products of a particular time and space, how can we value one belief or way of thinking above another? Surely I am in no more privileged a position as the next person to pronounce that my standards of what is true are the only ones or the correct ones? A more productive way forward is to become more conscious of what criteria both myself as researcher and others use to make these judgements, thus I have a double endeavour; to reflect both on my subject matter and on my part in creating it (Bury, 1982a, 1982b).

Although illness is a social construction which serves a social purpose, illness can also serve an individual function. HIV is a socially constructed phenomenon in that it has particular resonances and meanings within society which will inscribe the experience of living with HIV. The experience of an HIV positive person, however, is also about themselves and their own relationship with their physical being. This has a symbiotic relationship with but is separate from the social construction of this particular pathology.

### **3.22 - Constructionism and the body. Sexuality**

In this section I shall look at the relationship between constructionism and essentialism in understanding sexuality. The idea that sexuality is not a biological pre-given, but something which is the product of a particular social, historical, cultural and political moment, shaped and determined by a multiplicity of forces (Weeks, 1989 p13) is the essence of the constructionist argument, which has been developed from ideas drawn from structuralist anthropology, Marx and Foucault. Sexual identity may be constructed in opposition to religious, medical and political pressures: 'We have the bodies we have because they have been inscribed by religion, philosophy, science and ideology, and these exist as they do because of our bodies' (O'Neill, 1989, p3). On the other hand, we can argue that we construct our own sexuality by creating boundaries and categories for ourselves out of a limitless pool of possibilities which might otherwise threaten to engulf us. Either way, sexuality as a construction can be conceived both as a rigid trap, an imposition and as a site of choice, actualisation, resistance, a precondition of personal stability.

Limitations of the constructionist argument include that it emphasises discontinuities across time and space at the expense of aspects of sexuality which seem universally to be existent such as same sex desire. Another difficulty with an exclusively constructionist ethic is that it threatens to deny the subjectivity of experience; Crimp (1988 in Frank, 1990, p136) argues that 'the body's nature has a stubborn reality which is not reducible to cultural practices'. Essentialism has had a bad press in recent academic debate, becoming a catch-all insult for anything which attempts to describe experience as *a priori* and unmediated. Whilst it is true that to construct sexuality only in terms of genitality is at best reductive and unhelpful, it is similarly reductive to argue that we have no sexuality beyond that with which we are provided or acquire through our context. We have an inherent, pre-given sense of who we

are sexually in relation to ourselves and to others which will always be greater than our sexual expression in the social world. It is this which makes sexuality so powerful, liberating and dangerous.

Social constructionism and essentialism can be appropriated both by homophobic and radical ideologies. Homophobic discourse can use the essentialist argument to portray gay men as sick, mad or deviant, and the constructionist argument to portray them as criminal, unnatural and dangerous to others. Gay liberatory debate can use the idea that sexuality is beyond culture to portray same sex desire as liberated from social and cultural fetters. It can use the constructionist argument to define 'gay' as a political and radical standpoint in resistance to oppressive structures. We need to conceive of nature and culture as mutually determining sexuality without losing the complexity and richness of either debate. We should not deny a pre-given sexual orientation in our consideration of how this is mediated in our particular context. The difficulty is how we categorise what is essentially uncategorisable:

'We become less sure of what the body is because the body is our criterion for certainty; what we know about our bodies is, as knowledge, already embodied...there is no opposition between objectivism and relativism. What there can only be is multivocality which reflects the diversity of embodiments of understanding'  
(Frank, 1990, p160)

It is this paradox which we come up against when we try to categorise sexuality (Epstein, 1996a, 1996b). First of all, we need to consider the question of whether sexuality can and should be categorised in the first place. The emergence of 'the homosexual' as a distinct category of person took place in the Western world during the 18<sup>th</sup> and 19<sup>th</sup> centuries and does not exist in other times and places in the same form. Perhaps it is more productive to conceive sexuality as a continuum, or as a web of polysexualities rather than as a series of fixed identities. Again, there are uses and limitations to both sides of the debate. The category 'homosexual' gives a false appearance of uniformity when in fact the reality is far more complex and

includes experience which evades categorisation such as men who have sex with men who do not identify as gay, situational homosexual activity and nonsexual relationships between men.

It is ironic that the structures and institutions which sought to control and regulate homosexuality contributed through its definitions to the self definition and points of resistance of those it sought to identify; the growth of the identity of the gay man as a personal affirmation, a complete life career and as a political choice has enormous liberatory potential. There is, however, a paradox within the very affirmation of a gay identity: 'the very fact of affirming a gay identity as a political act underlined its arbitrariness as a social description' (Weeks, 1989, p287). If sexuality is conceived as a continuum, this does not dissolve the categories of homo- and hereo-sexual; a continuum only exists because of the poles which define it at either end (MacKinnon in Harwood et al. 1993, p116). We are socialised to regard sexuality as a dichotomy, one pole naturalised and the other pole stigmatised. If this is the way in which we are socialised to perceive sexuality, this is how we will construct our own personal sexual identity. It may be that the image of a web of polysexualities is more effective at problematising categorisation and the very insistence by a heterosexist culture of the existence of a discrete category of homosexuals itself raises concerns about the categories themselves. On the other hand, it is difficult to conceive gay liberation and the politics of gay sexuality without some at least provisional attempt at forming and performing a personal and collective gay identity and the sense of one's own personal sexual identity within a collective group helps to make sense of ourselves in the world:

'Identity may well be an historical fiction, a controlling myth, a limiting burden. But it is at the same time a necessary means of weaving our way through a hazard-strewn world and a complex web of social relations' (Weeks in Caplan, 1987, p49).

It is possible to steer a middle ground between falsely restrictive and narrow sexual categories and the chaos of limitless possibility which holds no potential for collective political action. Each of us at different points in our lives

will experience ourselves as sexual beings in a way that is unique for us at that moment. Within that infinite diversity there will be continuities and empathies which will enable us to make connections with others' experience across time and space. According to our situation and our needs, the continuities and discontinuities with others will play more or less important roles for us.

What constructionism, according to Crotty, drives home, is that there is no true or valid interpretation. This does not mean that we have a moral vacuum; there are more or less useful interpretations but none of us can claim our particular construction as 'true' or 'valid'. This clearly has important repercussions in research. The fact that we can construct many different meanings in relation to a particular phenomenon means that we can approach our research in a radical spirit of openness to create/construct newer, richer meaning. Consciousness is directed towards the object and the object is shaped by consciousness, subject and object, distinguishable as they are, are always united; it is about humans engaging with their world and about the meaning generated from this engagement. 'Objectivity and subjectivity need to be brought together and held together indissolubly. Constructionism does precisely that' (Crotty, 1998, p44)

Crotty makes two key points about constructionism which are important in understanding why and how I argue that my approach is constructionist and help me to deal with some of the concerns which I outline above. First of all, to say that reality is socially constructed is not to say that it is not real. We are merely explaining that we assign particular meanings to our realities and these are constructed. Secondly, social constructionism is relativist:

'We need to recognise that different people may well inhabit quite different worlds. Their different worlds constitute for them diverse ways of knowing, distinguishable sets of meanings, separate realities...description and narration can no longer be seen as straightforwardly representational of reality' (Crotty, 1998, p64).



### 3.3 – THEORETICAL PERSPECTIVE: PHENOMENOLOGY

I now consider the theoretical perspective which underpins my research; the philosophical stance which provides a context for the process:

‘whenever one examines a particular methodology, one discovers a complexus of assumptions buried within it. It is these assumptions which constitute one’s theoretical perspective and they have largely to do with the world that the methodology envisages. Different ways of viewing the world shape different ways of researching the world’ (Crotty, p67)

A phenomenological perspective suggests that if we lay aside our preconceived understandings and revisit our immediate experience of phenomena, we admit the possibilities of new meaning. This approach assumes a relationship between subject and object, between us and our world; we, as beings in the world, cannot be described apart from the world, just as our human world cannot be described apart from us. Phenomenology invites us to engage in a direct, immediate way with the phenomena of our world and to make sense of them through that engagement; the emphasis, the focus, is on what we directly experience before we try to make sense of it. We are required to place our usual understandings in abeyance and look at things freshly. Whilst cultural understandings and assumptions are inevitable and in some ways liberating, they may also at times become limiting and oppressive. There is always and inevitably a slippage between any understandings that we have and the phenomena itself and phenomenology explores that slippage: ‘that innate chaos which by renewing our deliriums keeps us from sterility’ (Cioran, 1976 in Crotty, 1998, p81)

Not only is our symbol system limiting, argues Crotty, but it also tends to substitute itself for what we actually experience, i.e. we see the meanings we know rather than the thing itself. Phenomenology is about setting that meaning system aside. There is always going to be a reliance on symbolic

frameworks of meaning and we cannot experience things in their totality, let alone express them as such. Our phenomenological viewpoint will be as constructed as any other but it will be a new meaning, a fuller meaning or renewed meaning, some form of 'fresh take'. We are calling into question what is usually taken for granted. This, argues Crotty, is phenomenology as it has been traditionally understood, but recent changes of emphasis have focused more fully on the *subjective experience* of everyday life: 'What has emerged...is a quite single-minded effort to identify, understand, describe and maintain the subjective experiences of the respondents. It is self-professedly *subjectivist* in its approach...and expressly *uncritical* (Crotty, 1998, p83 italics in original). I use both strands of phenomenological thought to underpin my research. I use the 'fresh take' approach of traditional phenomenology and adopt the more subjectivist stance, the putting oneself in somebody's place, of more recent work in the field: 'an exploration, via personal experiences, of prevailing cultural understandings' (ibid, p83). The phenomenologist's world is not pre-determined; it is open to discovery, new directions and new significances and phenomenology is an attempt to break free from any fetters of cultural symbolism which might limit our world view.

Once again, I look at how a phenomenological perspective affects the way I perceive key areas of my research – the body, health and illness.

### **3.31 - Phenomenology and the body**

Illness from a phenomenological perspective attempts to reconcile the experience and the meaning given to that experience. Kleinman (1988) attempts to encapsulate illness as an embodied experience which the individual can formulate into a narrative; in fact the central task of therapy is to form such a narrative to be shared with others and to give coherency to the experience. Kleinman believes that through the sharing of such a narrative, the ill person's body can be communicative in new ways and that those around them can also experience their bodies differently in relation to that

person. Kleinman (1980 in Helman, 1984 & Tishelman and Sachs, 1988) developed the idea of an 'Explanatory Model' (EM) for illness. An EM is the individual's answers to the questions 'What has happened? Why? Why to me? Why now? What would happen if nothing were done? What should I do?' Kleinman argued that lay EMs were idiosyncratic and changeable, influenced by personality and culture and both conscious and unconscious. The physician's EM, on the other hand, is governed by scientific logic and clinical consultation is a transaction between two EMs of a particular illness. When we try to explain about our sense of ill health, most of us will draw on potential causative factors within ourselves, in the natural world, in the social world or in the supernatural world; usually a combination of some or all of the above, and if I become chronically ill, I may fundamentally have to rethink my sense of self at all of these levels (Bury, 1982).

The attempt to articulate embodiment is crucial to our understanding of ourselves and our world and gives weight to the discourse of the individual. If I can articulate my body and if that articulation has just as much credibility in the world as any other discourse, then I have some freedom in my sense of selfhood.

Whilst a sense of the bodily experience is crucial to our appreciation of what our bodies are, this cannot be divorced from the concept of the body as a product of social, cultural and political forces. There is a danger of losing what for most of us *is* in a theoretical quest for what are *abstractions* or *aspirations*. A phenomenological perspective is one way of problematising the divide between illness as social construction and embodied lived experience. Kleinman's Explanatory Model of illness shows how people attempt to create order and meaning in sickness situations, the effort to normalise and legitimise the sickness process is an attempt to avert chaos, although the means by which it is done may differ and the boundaries of what is deemed to be normal are fluid. So, rather than be faced with a situation which is not normal, we will alter our parameters of normality. So illness in part can be framed as a problem of meaning, we need to formulate an image of order to account for the inexplicable. We do this socially and also individually. For

example, socially we give illnesses names, we attribute them to particular causalities, e.g. genetic or lifestyle factors, we control them in particular ways, such as through drugs, and we frame them in particular behaviours and institutions.

To what extent all illness is somehow illustrative of our psychic and social lives, and can be more or less clearly 'read' as such is a matter of debate, certainly somatisation, i.e. symptoms of illness which do not have a physical manifestation, can be conceived as an attempt at 'storytelling' as a more or less coherent narrative of stress. More or less coherent dependent on how bearable it is to tell as a coherent whole. We feel stress within ourselves as individuals but it is mediated by cultural patterning to produce particular symptoms. Bakhtin (1973, 1981, 1986 in Waitzkin & Magana, 1997) identified 'speech genres' which are typical forms of utterances that occur within specific sociocultural circumstances: 'The transformation of terrible narrative into somatic symptoms may become the culturally sanctioned 'way of knowing' and of processing such stress.' (Waitzkin & Magana, 1997 pp818-9).

Clinicians also use narratives in an attempt to understand the illness experience, and this takes place beneath the objectifying clinical language of biomedicine. Thus the patient on the one hand will be described in terms of their clinical symptoms in the language of the expert, and will also be framed in terms of their personality and social, cultural and economic context. It is much less clear who has control of this second language which is more likely to predominate when diagnosis is uncertain (Mattingly, 1998):

'Narrative reasoning is not grounded on the logic of the necessary or probable, but on the logic of suspense, the logic of the plausible after all...Narrative is needed to contemplate the world in its complexities...for narrative is built on surprise, chance, contingency, the anomolous event' (Mattingly, 1998, p289)

### **3.32 - A phenomenological understanding of sexuality**

A phenomenological approach underpins my attempt to steer a middle course between postmodernism and queer theory on the one hand and identity politics on the other. Drawing on the literature reviewed above, I take as the foundation of my research the following premises:

- A gay identity is historically and geographically situated
- Queer politics and identity politics can be both liberating and oppressive, useful and seemingly irrelevant for different people at different times
- People will reach their own synthesis of these ideas in their construction and understanding of their own subjectivity
- None of these terms are fixed, people reach their own understandings of terms such as 'gay', 'identity' etc.
- Contradiction and paradox is central to thinking about subjectivity; opposites can co-exist; what we understand as binary oppositions may not be opposed but inhere within each other.

Husserl (1970 in Denzin & Lincoln, 2000) argues that the relation between perception and its objects is not passive. Human consciousness actively constructs objects of experience and is a constitutive part of that of which it is conscious. This is clearly useful in appreciating people's understandings of their sexuality which, albeit in a particular social, historical and cultural context, is actively constructed by the individual in their lives.

Schuz (1962, 1964, 1967, 1970 in Denzin & Lincoln, 2000) argues that we should focus on the ways we experience our life world; how we apprehend and act on the objects of our experience as if they are things separate and distinct from ourselves. The world is no longer 'out there' distinct from acts of perception and interpretation. We approach our life world with a stock of knowledge accumulated through social images, folk theories, beliefs, values and attitudes and apply these to our experience, thus making it meaningful

and familiar; familiar because the myriad phenomena of everyday life are collected into categories or 'types' organising the flux of life into everyday forms. This is all carried out through the ordinary language of everyday life. The words and categories we use to portray experience and make it meaningful constitutes our social world and gives us a sense that life is familiar, organised and substantial. Whilst we understand our sexuality through our relationship with and our understanding of the social world and this should be taken into account, a phenomenological approach will allow us to push back our cultural assumption about what sexuality and sexual identity are and enable us to have a 'fresh take'.

### **3.4 – METHODOLOGY: NARRATIVE METHODOLOGY**

The methodology, according to Crotty, is the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and methods to the desired outcomes.

Much of human endeavour is to create meaning out of experience. Through history and in different cultures, one of the ways in which we create both meaning and a sense of identity is through the construction of narrative (Vansina, 1985, Polkinghorne, 1988 in Ezzy, 2000, Marshall & O'Keefe, 1995, Plummer, 1995). My research is an attempt to construct a narrative through the hearing and recounting again of the individual narratives of gay men living with HIV.

Narrative constructions are particularly significant in a consideration of illness (Kleinman, 1988, Hammar & Kleinman, 1998, Frank, 1993, 1994, 1995, Bury 1981, 1992 in Hyden, 1997) and narrative forms are used both to make sense of illness and to express suffering. Illness is both individually and collectively a text or story with multiple interpretations all of which may be plausible (Turner, 1987, Kleinman, 1988); in constructing my research in terms of narratives I align my methodology with my subject matter. We find meaning in narratives

*and* in the act of reciting them (Lyotard, 1984:22 in Jackson, 1996, p38); they comment on experience without splitting off from it. By constructing my research narratively, I make it a performance in which the boundaries between the participants, researcher and reader will blur and control over meaning is not clearly held by any one person (Mattingly, 1988, p289).

Narrative is one of the main forms through which we perceive, experience and judge ourselves, our lives and our relationships and the form, presentation and organisation of the narrative all convey something of the self-image which the narrator wishes to communicate (Hyden, 1997). So the stories people tell are important not only because they offer a window into subjective experience, but also because they are part of the image people have of themselves. These narrative self-presentations shape how we conduct our lives, how we come to terms with pain, what we are able to interpret from our own experience and what we disown (Ochberg, 1988 in Hyden, 1997). Research creates rather than simply reflects social reality and the language of the interview will shape that reality. Narratives structure lived experience, and lived experience in turn structures narratives, which are therefore constantly subject to change (Mogensen, 1997, p432).

### **3.41 - What is narrative?**

For the purposes of my research I draw on Paul Ricoeur's description of narrative in terms of emplotment (Wood, 1993). Ricoeur described emplotment as consisting of the following elements:

- One story is made out of multiple incidents
- Heterogenous elements are organised into one story making a totality which is both concordant and discordant
- Two sorts of time are employed: an open and indefinite succession of events (and then?...and then?...) *and* integration, culmination and closure (a beginning, middle and end)

I perceive my research as a web of stories, all involving the features of emplotment Ricoeur describes:

- The participants' narrative as recorded in the interview
- The narrative of the research project as a whole
- My narrative which forms part of my role as listener, reader and writer
- The narrative of each reader (which will also include myself as the researcher and the participants)

I consider that there is an appropriate 'fit' between narrative research as a methodology, my area of enquiry, and my personal interests and approach. Narrative is a slippery term but for the purposes of this research I use the features outlined by Ricoeur above and use the framework of the interview situation to delineate the parameters of each participant's narrative.

### **3.42 - Relationship between participants, researcher and reader: a reflexive process**

This approach places emphasis on the importance of the interview as event, as a dialogic, social activity and allows for the interpretive process as part of the interaction. The information gathered goes beyond pre-constructed discourses, reveals the complexity and ambiguity of the relations between self and the world and allows people to express the detail and complexity of their experience. Narrative combines the way of collecting the data and a way of perceiving, shaping, creating and understanding it. It produces *and* creates meaning through the narrator, myself as researcher and the reader.

When we look at narratives we need to look at intention – why, how, when a story is told – and the background knowledge of the narrator and listener and how each interprets the other. The story is created by the negotiation between the speaker and the listener. Narrative is speech act: it initiates and guides a search for meaning among a spectrum of possible meanings. The possible meanings will very much depend both on the context of the person's life in



space and time and on the micro-context of the interview itself: 'Interviews are social processes of mutual accommodation during which transfers of information occur' (Vansina, 1985, p63). There is no unique meaning to any story; there are a range of meanings which the interviewer and reader can extract. We negotiate how the story will be heard *and*, of course, how it will be told.

The participants both tell their stories and create their own meaning constructions from their experiences. Through narrative we come in contact with participants as people engaged in the process of interpreting themselves and through this we can gain an understanding of how such accounts constitute rather than simply reflect the realities of the social world. Whilst the interviews were of course an account of concrete data, what is created is the participants' stories which they tell for themselves as adults through recovered memory. Kierkegaard's (Josselson, 1995) observation that we live our life forwards but understand it backwards is particularly relevant in a consideration of narrative methodology: 'Narratives are not records of facts...but of a meaning-making system that makes sense out of the chaotic mass of perceptions and experiences of a life' (ibid p33).

The participants are engaged in a process of restructuring their world views as a result both of remembering, disclosing and living through the reverberations of 'telling'. This is reflected by myself as researcher and you as reader. These echoes through the multiple layers of living, telling, writing, and reading our lives are an integral part of what it means to make meaning and they create a potential space where the boundaries between oneself as knower and the other as known are relaxed (Chase in Josselson & Lieblich, 1995). Bakhtin's (in Chase ibid p36) understanding of the dialogic self; that the self can only exist in relation to the other is also relevant here our lives are experienced interpersonally; told interpersonally and understood interpersonally. I suggest that the concept that we shape our reality through the telling of it creates the potential for new understanding.

Understanding is again located within the participants, myself as researcher and you as reader. These understandings are held by each of us as individuals but are also socially, historically and politically constructed. In turn, our individual understandings shape social, historical and political discourse. All research findings have political implications and 'qualitative research that frames its purpose in the context of critical theoretical concerns still produces...undeniably dangerous knowledge, the kind of information and insight that upsets institutions and threatens to overturn sovereign regimes of truth' (Kincheloe & McLaren in Denzin & Lincoln, 2000, p138). I suggest that we need to hold in mind the historical, cultural and political location and impact of this research in order more fully to understand the position from which the participants speak and live their experience; how I as researcher construct my understanding and how you as reader understand the research

### **Reading the narrative**

The act of reading the narrative is a crucial stage in the whole process; not only does the reader create the narrative in the act of reading, but they also read themselves into the narrative. The act of reading takes place at multiple levels in research: the participants become their own readers as they read their transcripts and the finished piece of work; I 'read' their narratives in the context of the interview; they read what I have heard and written and the reader reads themselves through all of us!

'[O]ne could not say that I thought of those who would read [my book], of my readers. Because they would not according to me be my readers, but the real readers of themselves...It was my book, and thanks to it I enabled them to read what they saw within themselves' (Proust cited by Ricoeur in Wood, 1993, p198).

### **3.43 - Relationship between self and society**

Narrative forestalls a split between individual and society (Fischer-Rosenthal in Chamberlayne et al., 2000) – it is a way of being within and without, of treading that space. Because narrative is situated in the spaces between self and world, change and continuity, the individual and collective, it is a useful way of articulating these spaces without imposing rigid divisions between within and without: 'a dialectic between social conventions and individual desire which leads to life stories that have a claim to uniqueness within an intelligible frame (Murray in Smith et al., 1995, p182).

### **3.44 - Narrative in the reflexive formation/creation of the self**

A narrative methodology is appropriate to research issues of subjectivity, as the whole purpose of the interview relationship is to allow people to express the subjective and personal meanings of their lived experience. This will give voice to the relationship between the person and their world. Identity is one's sense of self in relation to the world and our stories allow us to construct a narrative identity at a historically collective and thus also at an individual level. The necessity of a reader/listener in narrative gives us a sense of self in relation to others; one needs a story in order to take part in the conversation that defines identity (Murray in Smith et al., 1995). It is not only the teller but also the audience that defines the narrator's identity:

'If you want to know me then you must know my story, for my story defines who I am. And if I want to know *myself*, to gain insight into the meaning of my own life, then I too must come to know my own story' (McAdams, 1993:11 in Crossley, 2000, p67)

The self is actually created through the stories we tell about ourselves, these explain who we are both to others and to ourselves (Kelly & Dickinson, 1997, p276). To ask what I am in abstraction from self-interpretation makes no sense:

'The self only comes into being through the telling of the life story...self is narrative in which the narrating 'I' retells and restructures experience and the experience of the self...The narrating 'I' is both the self and provides simultaneously an account of self' (Ricoeur, 1986, p132 in Crossley, 2000, p50).

Our lives themselves can be assimilated into a story and are understood both to ourselves and others through the reflexive stories we tell about ourselves.

### **3.45 - Narrative in society**

Narrative is a relational concept, treading the space and articulating the individual in the world. Narrative serves a collective as well as an individual function, both the narratives we tell about ourselves and the collectives which feed and are fed by this process:

'The ceaseless nature of storytelling in all its forms in all societies has come to be increasingly recognised...Society itself may be seen as a textured but seamless web of stories emerging everywhere through interaction: holding people together, pulling people apart, making societies work...the metaphor of the story...has become recognised as one of the central roots we have into the continuing quest for understanding human meaning. Indeed, culture itself has been defined as 'an ensemble of stories we tell about ourselves' (Plummer, 1995:5 cited by Heaphy in Barbour & Huby, 1998, p23)

## **Cultural stories**

Narrative is also able to reveal to us the ways in which individuals internalise, appropriate, reflect and use cultural myths. For example, when participants tell me their stories, some of the ways in which these narratives are expressed will be influenced both by dominant cultural myths about gay men and the myths created by gay culture (Samuel & Thompson, 1990). Narratives play out the interrelationship between collective memory and myth on the one hand and individual experience on the other. They emphasise both the diversity of social experience and how each individual story builds on a common culture: 'a defiance of the rigid categorisation of private and public, just as of memory and reality' (Samuel & Thompson, 1990, p2).

One of the aspects of a narrative methodology which is crucial to include is a grounding of the personal narrative in the material and social context of the teller. This is particularly important in carrying out a comparative study. In this way, individual experience can form part of a cultural narrative which is placed in a context of social, political and personal relationships.

### **3.46 - The function of narrative for the individual**

Our stories help us to overcome life crises by giving them meaning and this is particularly apparent in narratives which incorporate illness. Hyden (1997, p55) has outlined five principle functions of an illness narrative which are particularly pertinent in a consideration of HIV:

- To transform illness events and construct a world of illness – the illness is articulated and positioned in time and space and in terms of a personal biography

- To reconstruct one's life history in the face of chronic illness – to re-establish the relationship between self, world, the body and one's personal biography which incorporates the illness experience
- To explain and understand the illness in terms of one's own life and as part of a shared culture
- As a form of strategic interaction to assert or project one's identity or to explain one's behaviour
- To transform illness from an individual to a collective phenomenon – this is particularly clear in the context of HIV – the illness becomes part of a political and social narrative and context

Hyden (ibid) also argues that illness narratives are built around three central tensions:

- To gain a public voice in order to relate a private experience – the place of oneself in the world
- To sustain the primacy of one's own voice in relation to the voice of medicine and, I would argue, other discourses – the individual voice amongst other voices
- To balance the illness experience against the scheme of one's own life – the 'fit' of different parts of a person's life

### **3.47 Cultural Stories and HIV: Illness narratives**

HIV is the site of bitter contestation over the meaning of the self. HIV potentially can destabilise all aspects of life because it is located at the cusp of the boundaries we draw between self and other, self and world, public and private etc. It is this which makes HIV the focus of so much fear. HIV is very clearly a phenomenon around which we have collected a whole range of cultural stories as we collectively have attempted to make sense of the virus and it is from within these stories that the research takes place; we conceive, articulate and understand the virus within a particular cultural frame. Metaphors can be told and retold until they become myths by which people

construct their reality. Myths are created as stories are told, retold and refined until the reality becomes figurative (Foster in Barbour & Huby, 1998).

### **Coherency and chaos in illness narratives**

The primary threat with which we grapple as a day-to-day physical reality is the threat of meaninglessness. This is crucial in considering the body, health and illness, not only because how we are in our bodies is a question of how we make meaning, but also because any theory is but an attempt to construct meaning out of that which will always remain elusive. Such a quest is in itself a way of responding to the virus. We create meanings around experience to shore ourselves up against chaos. As we attempt to create a sense of meaning in our lives, illness disrupts that and forces us both to recognise that our sense of meaning is contingent and to try to create a new meaning for ourselves incorporating illness (Taylor 1989 in Crossley, 1997). The meanings we construct will not necessarily be consistent with other people's and are unique for us in space and time (Geertz, 1973 in McGrath, 1998). Our concepts of illness are not necessarily theoretically rigorous or scientifically sound; they may draw on a number of disparate factors which may seem to contradict one another (Fitzpatrick et al., 1984). One of the difficult debates is the extent to which narrative can incorporate chaos and to what extent this is bearable. Is there a point where narrative breaks down altogether or do 'polyphonic' and 'chaos' narratives somehow contain chaos within manageable parameters? I suggest that it is possible to steer a middle ground between falsely restrictive and narrow categories and the chaos of limitless possibility which holds no potential for expression. According to our situation and our needs, the continuities and discontinuities with others will play more or less important roles for us. It is the nature of the bonds of our groupings which is key. They need to be firm enough to provide safety against existential chaos but contingent enough to allow movement in and out of the collective.

'We may not know who we are and what is happening to us, but if we are able to narrate how we became who we are, then we can integrate ourselves because we can present ourselves as both consistent *and* contingent. Even if I have gone through many

contradictory phases in my life, the story I can tell presents me as myself' (Fischer-Rosenthal in Chamberlayne et al. 2000, p115)

### **Illness narratives in time**

Illness as narrative is historically located in terms of our collective history and each person's narrative needs to be looked at in terms of their past and future selves. Our sense of being in time is crucial to our sense of self and others and this is expressed through narrative; narrative is the way we have of describing lived time; i.e. time as we experience it as we ascribe meaning to our life events: 'time becomes human to the extent that it is articulated through a narrative mode, and the narrative attains its full meaning when it becomes a condition of temporal existence' (Ricoeur, 1984:52 in Hyden, 1997, p53).

Ricoeur describes narrative as the guardian of time and suggests that it conceptualises time in two ways (see features of emplotment above):

- A discrete succession of events that is open and indefinite
- A particular configuration of the story

The second is complicated in the telling of our life story as we do not know how it will end.

Narratives allow people to make sense of their past and to frame their future in the light of that past. As people tell their past, they select memories and recount them in the light of their present – how they see themselves now, how their present self sees their past self, what sense of themselves they want to bring to the interview and how their past and present move forward to an anticipated future (Temple, 1995). Gathering narratives allows those changing concepts of time and sense of self to be played out. Bruner (1987, 1991) suggests that the temporal dictates of narrative dictate how we experience time itself:

'I believe that the ways of telling and the ways of conceptualising that go with them become so habitual that they finally become recipes for structuring experience itself, for laying down routes into memory, for



not only guiding the life narrative up to the present, but directing it into the future (Bruner, 1987, p31).

### **Temporal experience of HIV**

Crossley's (Davies, 1997) research with long term survivors of HIV looks at concepts of time, dividing people's stories according to whether they seemed to be living with a philosophy of the present, living in the future or living in an empty present. She identifies issues of temporality and disrupted and/or ambiguous temporality to be central to someone's attempts to adjust to living with the virus and I suggest that this would be even more widespread in its application with further developments in anti-retroviral treatment. Individuals will also have an understanding of the collective experience of HIV as occurring at a particular time in history and as being experienced in time on a collective level.

Important aspects of time in relation to HIV include:

- Sense of shortened time which might be lengthened by improved health but will still remain in question
- Time punctuated by medication, medication regimes, success or failure of medication, time between blood tests and clinic appointments
- Time lost through illness, depression, time off work etc.
- Value of time, i.e. time may become more valuable, not to be 'wasted'
- Changing attitude to time - living more/less in the present/past/future
- Sense of self in time, both individual and collective histories, e.g. re-evaluating past self in the light of the present, sense of where one belongs in the history of HIV, gay consciousness, queer politics etc.

### **Speech and silence in illness narratives**

A narrative methodology places an explicit emphasis on the discourse used by participants. It is through the language that people use that the relationship between personal experience and the wider social and cultural forces that shape the experience is played out. People may adopt, to a greater or lesser extent, public narratives to give expression to their personal experience.

It is clearly important to consider the language that individuals use to describe themselves; the extent to which they place themselves within a recognisable, pre-existing discourse, place themselves outside this discourse or present competing or contradictory discourses. For example, an individual might place themselves within a medical discourse or a political activist discourse, but when describing some aspects of their life, maybe their sexual behaviour, they might place themselves outside this discourse or present themselves in another way, as a victim or a hedonist or something of that kind. Clearly silence is also of crucial importance here. It is important to consider the extent to which people are choosing to exercise silence in relation to the interviews; what people choose not to tell me as researcher, themselves, the tape recorder, their imagined reader. There are also limitations in the structure of language itself which can never directly describe experience; the ability of the narrator to tell their story and the ability of the listener to hear. We need to remain aware of the meta-narrative which may be told through silence, tone, internal inconsistency etc. This will also include a consideration of the issues over which people remain silent, why people might wish to withdraw or refrain from participating altogether.

We appropriate existing discourses to describe ourselves but we do not do this passively or non creatively. There are a number of dominant, competing, conflicting and shifting discourses of HIV and participants will position themselves in unique ways in relation to these.

### **Change and continuity in illness narratives**

Narrative has a forward momentum; something happens, there is a shift or change of some kind in awareness, action or setting. Narrative also incorporates continuity in order to create a whole: a narrative voice, setting, author – something to make it hang together. Different narratives hold these in a different balance.

Change in illness narratives can be divided into the following categories (Frank, 1993):

- 'what I have always been' in which the illness taps into or crystallises aspects of the personality that were already there; for example someone's identity as positive may provide continuity with their identity as gay. Someone's identity as HIV symptomatic may provide continuity with their identity as sick with another condition
- 'Who I might become' where the self emerging from the illness is wholly new
- 'Cumulative epiphanies' where the process of changing through the illness is gradual and cumulative

### **3.48 - Limitations of a narrative approach**

Any methodology has its limitations. People who participated in the study are those who already are interested in portraying their experience and can envisage doing so as a coherent account, also people will be selective about how they choose to portray themselves. This is not necessarily a limitation but it is a factor inherent in this type of research.

Researching across difference will entail a process of translation and it is inevitable that some of the story will be lost or at least altered. My methodology, however, incorporates translation and interpretation as part of the overall research process; messages have a double subjectivity – that of the sender and the receiver (Vansina, 1985). There are also positive advantages to researching across difference; if there is no assumption of common experience or understanding a participant may be encouraged to be more explicit in how they tell their story. To explore people's emotional, psychological and spiritual lives is to place oneself at the heart of the dilemma of never being fully able to articulate the experience of another (Parkinson, 1998). When there is no independently existing universal psychological reality, how we conceive emotions both reflect and affect our emotional reality and these are both affected by and affect other cultural processes. Emotions bridge meaning and feeling, mind and body, public and private and it is their

bridging character which makes them hard to articulate (Leavitt, 1996). Nevertheless, I suggest that the exploration is in itself part of the articulation.

### **Are narratives inevitable?**

Opinion seems divided on this point and I suggest that the issue is more to do with how loose a definition of narrative is used. There is certainly a need both individually and collectively for us to make sense of and articulate our experience through narrative:

‘whether we tell stories to each other of what happened, rehearse what will happen or invent what we wish had happened, the pervasiveness of story emphasises our need to tell ‘Once upon a time’ versions of experience’ (Ely et al., 1997, p63)

Spicer (1998) in his study of Native North American drinking patterns suggests that one’s situation may make it impossible narratively to construct one’s experience. He argues that narratives are neither necessary nor inevitable and we should beware of treating them as a privileged discourse without also looking at their limitations and omissions. It is certainly important to remember that fragmentation and incoherence are a fundamental part of people’s experience of suffering. If a person’s experience of the world has prevented them from developing a clear sense of who they are, they will struggle to develop and maintain a narrative which enables them to make sense of their experiences. There is certainly an important link between a person’s experiences in the world and the way they are able to present themselves but that interpretation, albeit always partial, is a fundamental aspect of being in the world. Narrative is one of the main forms through which we perceive, experience and judge our actions and the course and value of our lives (Hyden, 1997, p49). Stories do not necessarily have to have an easy ending but by making plight interpretable it becomes bearable (Bruner, 1991).

### **Does narrative repress or liberate?**

Researchers tread a fine line between liberating experience and suppressing or controlling it (Huby, 1997). We miss the point if we assume that to tell one’s

story is necessarily an act of liberation and narrative methodologies, like any other can liberate or repress. In her early work Crossley is critical of therapeutic narratives as a way of adjusting dissatisfied individuals to a flawed social environment. In her subsequent work she recognises the value of a 'redemption' narrative as enabling individuals 'to respond reflexively and creatively to the changes going on around them' (Crossley, 1999, p1687). She uses Giddens' (1991) distinction between 'emancipatory' and 'life' politics to suggest that the three stories she identified as used by HIV positive individuals – the 'normalising' story, the 'conversion/growth' story and the story of 'loss' afford both liberating *and* repressive potential. Taking the argument a step further, she questions the cultural assumption that liberation is something good, to be aspired to and, conversely, repression is something bad to be avoided. It is not sufficient to judge the potential of an individual story in isolation from the person's life world. Her analysis reminds us that adopting a narrative ethic – encouraging people to tell their stories – is not necessarily inherently liberating and we should not in any case adopt unquestioningly the desirability of liberatory potential without a consideration of the fit between the story and the conditions which form the basis of that individual's life.

It is clear that the question of the liberatory potential of narratives is itself historically situated; life politics is a politics of life decisions and can only come about if we have a wide range of choices available to us (Crossley, 2000):

'no longer freedom from want but the freedom *to* want; no longer a struggle for equality but a struggle for difference; no longer a freedom to act but a freedom to be...It is the reflexive concern with life, self and the body...characteristic of contemporary culture that...is resulting in a wide resurgence of interest in moral, political and ethical issues' (pp82-83).

Like many dilemmas in our world, it is the dilemma of choice, of plenty and of relative freedom and prosperity. This means that it is not a possibility for many individuals because of their social, economic or personal circumstances.

The expectation that we should live self-consciously is perhaps yet another burden: 'the necessity to narrativise our lives in a vocabulary of interiority. The self that is liberated is obliged to live its life tied to the project of its own identity' (Rose, 1990, p254). An increasing portion of our lives is open to our own construction but, in conjunction with this increased freedom has come what Beck (1992, p135) terms 'construction kits of biographical combination' which place pressure on individuals to construct themselves according to pre-given expectations. At the same time there is a 'moral imperative' inherent in polyphonic narratives which require a commitment to shaping oneself as a human being and Ricoeur makes this responsibility central to his concept of narrative identity.

The degree of reflexivity of the quest or polyphonic narrative is linked to the degree to which we are expected to become ethical beings. It might be that the expectation to take personal responsibility for the meaning of illness is experienced as an extra burden and the shade of differentiation between personal choice as liberation and personal responsibility as oppression is nebulous. The individual taking of responsibility and power is very close to the apportioning of individual blame. Similarly, a focus on the political, social, economic and cultural factors in health and illness threaten to assign the ill person a powerless victim status. Frank's (1998) evaluation of stories of illness in relation to the care of the self moves towards a synthesis of these different possibilities. He asks if personal narratives liberate the speech of the ill from social resistance or if they are simply a gentle form of compelling this speech. He suggests that reflection of what sort of stories we want our lives to be and what sort of stories we want to avoid are the core of any personal ethics. The ethical is animated by power *and* power is imposed through ethics. He resists imposing a divide between technologies of the self and the practices used in the care of the self.

### **3.4 Conclusion – the method arising from a narrative methodological choice**

Crotty's fourth question with which he argues we approach research is that of the method; the techniques and procedures used to gather and analyse the data. In the next section I describe how I concretely put into effect the theoretical perspective I have outlined above in order to collect the stories of HIV positive gay men. If narrative is our way of making sense of experience and articulating the space between self and not-self, then a narrative methodology is an appropriate one to adopt for an enquiry into the relationships of HIV positive gay men with themselves, with others, with their world. We tell stories, we do research, we read, on our journey towards an understanding, a 'truth' we will never attain but maybe the journey itself is sufficient.

## **CHAPTER 4 - METHOD**

Drawing on the theoretical ideas which I have explored in the preceding chapter, I drew up a research design which would allow me to explore the experience of gay positive men in urban and rural areas, using a narrative methodology. My aim was to collect men's stories using a loosely semi-structured interview schedule and analyse the data using a combination of pre-set and emergent themes. My decision to compare urban and rural experience was based on my interest in issues of space, community and identity. The decision to base the research in London and Yorkshire was in many ways a pragmatic one; I was living in London and had worked and therefore had contacts in Yorkshire. These two areas also seemed representative of urban and rural areas in the country as a whole and useful comparisons could also be made between them. At the time of the start of my research The Terrence Higgins Trust had just set up THT Yorkshire in Leeds, a merger with the former organisation Bridgeside which at the time was an extremely controversial move. My aim was to tap into the opinion of gay HIV positive men in the chosen areas to find out about their lives in the context of their sexuality and their HIV status and to find out what services they felt would benefit them. My research was committed to exploring everyday experience for these men and the meanings they create around those experiences. This qualitative data can enrich our understanding of the epidemiology of HIV in the UK and our clinical understanding of its treatment. My underlying premise was the 'subtle realism' described by Mays and Pope(2000); that whilst all research involves subjective perception and different methods produce different perspectives, there is an underlying reality which can be studied and research attempts to represent that reality rather than obtain access to some objective and verifiable 'truth'.



## 4.1 RESEARCH DESIGN AND CHANGES TO THE ORIGINAL DESIGN

After having established a framework of what I wanted to do, I drew up an information pack, posters and flyers for organisations and participants (see Appendix 3) which outlined the basis of the study. Organisations were my primary link with participants so I contacted a range in both areas: social services departments, clinics and voluntary organisations. I also advertised in the gay press in both areas.

In contacting and meeting with professionals in the field, my attempt was to take into account their particular agendas and concerns as they related to my research interest but the research clearly struck a chord with some professionals and not others.

I had chosen North Yorkshire as this was an area where I had worked and already had links. Unfortunately, my successor at the organisation where I had been based was not co-operative and there were concerns expressed by the management committee of the organisation which seemed to be based on an anxiety that service users would not appreciate a change in my role and this would undermine the current work done by the organisation. As this was the only voluntary organisation which worked with HIV positive individuals in the county, I decided to broaden my remit to include rural areas of West Yorkshire.

Neither the contact with clinics nor the social services departments led to any interested participants: all my links were made through voluntary organisations, the internet and press links. I believe that this was due to a number of factors. Clinics may tend to prioritise quantitative, medically focused research and in some organisations staff may have been simply too busy to give the research any priority in their day. On the other hand, voluntary organisations may have been more co-operative because the staff

were personally interested in the issue and because there was an interest in research and its link to service development. The subject matter of the research was also one which would more concern the work of voluntary organisations.

One of the primary difficulties in contacting interested participants was that I was dependent on the goodwill of the gatekeepers who might have many reasons for not co-operating: lack of interest, feelings of protectiveness towards clients, lack of time. I contacted the organisations first by letter, then followed up with a 'phone call and offer of a visit. Once I had identified a link person or link people and had visited them, I was far more likely to secure the co-operation of that organisation and contact participants through them. In two organisations – London Lighthouse and Calderdale and Kirklees HIV/AIDS Link, I was given the opportunity to talk to a group of service users which was extremely beneficial as the service users were able to meet me directly and to ask questions in a less exposed group environment before committing themselves to participating in the research.

The decision to expand the project to include parts of rural West Yorkshire gave me fruitful links but, as parts of West Yorkshire are highly urbanised, I then had actually to define what I meant by the terms 'urban' and 'rural'. I chose a pragmatic definition: that I would be happy to interview anyone who lived outside a five mile radius of the centres of Leeds and Bradford and/or participants who 'felt' that they lived in a rural environment. My justification for this rather loose definition was that I was more interested in participants' understanding and experience than on imposing pre-set definitions.

#### **4.11 - Organisations contacted:**

London:

Gay Men Fighting AIDS, Kobler Clinic, Body Positive (which then closed but some relevant services transferred to London Lighthouse), River House, St Mary's Hospital GUM Clinic, Hammersmith & Fulham Social Services, Chelsea & Westminster Social Services Department

North Yorkshire:

North Yorkshire AIDS Action, York GUM Clinic, Mesmac, York Social Services Department

West Yorkshire:

Calderdale & Kirklees HIV/AIDS Link, Seacroft Hospital, Bradford GUM, Mesmac, THT Yorkshire, Leeds General Infirmary

#### **4.12 - Organisations which acted as links for participants:**

London:

Gay Men Fighting AIDS, London Lighthouse

North Yorkshire:

None

West Yorkshire:

Begin, Mesmac, Calderdale and Kirklees HIV/AIDS Link

#### **4.13 - Sampling**

My sampling was purposive but, as described above, my attempts to reach a comprehensive range of men in the chosen areas were not altogether successful. This may have influenced the data. Self-selection in any case may have been part of the sampling process. My aim was to contact gay HIV positive men in London, North and rural West Yorkshire through contact with various organisations and through the media. I was aware that different men would access various organisations so I was careful to make contact with clinics, social service departments and voluntary organisations in each area as well as advertising in the local gay press through which I might make contact with men who did not access any formal organisation. I was also open to the potential of snowballing although in practice I only made one contact through this method. In this way I hoped to access a range of men who would be representative of the gay HIV positive population in terms of age, ethnicity, social class, health state and service history.

I had stated in my publicity material that I was interested in interviewing gay HIV positive men who lived in London, North Yorkshire or rural parts of West Yorkshire. Nevertheless I agreed to interview three participants who, although they did not strictly meet these criteria, were particularly interested in the research. One was a man who at the time lived in South Yorkshire, one lived in Brighton but had lived in London and was using London-based services, and one identified as bisexual rather than gay.

#### **4.14 - Research instrument:**

##### **The interviews**

After having contacted the organisations which were to take part in the research, I built up an interview schedule based on my reading and on what I had decided would be the focus of my research (see appendix 4 for a copy of the interview schedule and documentation kept on the participants). Whilst I wanted the schedule to remain reasonably loose (Brenner et al., 1985, Howarth, 1998, Hollway & Jefferson, 2000), the questions I asked were grouped around the following three themes:

- what does it mean, to you, to be gay
- what does it mean, to you, to be HIV positive
- what does it mean, to you, to live in an urban/rural area

The questions were framed with the aim of eliciting the person's story. I agreed to meet at a time and place which was convenient to the participant; either at their home or at the premises of one of the link organisations. The length of the interviews varied between one and one and a half hours; if the participant still had more to say at the end of that time we agreed to meet on another occasion and I met with several participants two or even three times. I spent some time at the beginning and the end of the interview to explain the process and to give the participant the opportunity to voice any questions or concerns. Although I kept to the three principle areas I wanted to explore, as the interviews progressed I used the schedule less and allowed the

conversation to flow more freely, using the schedule at the end of the interview as a checklist to ensure that the main areas had been covered.

I had hoped to use photographs to help to give the reader a sense of the space in which the participants lived, and to this end I gave each participant a disposable camera and asked them to take photographs of whatever was important to them (with due regard to confidentiality issues) so that their story could be supplemented by image. Only two participants, however, sent me photographs.

#### **4.15 - Ethics and access**

In order to carry out any research through a hospital clinic, I had to put my proposal before an ethics committee. This process was different for each clinic I contacted and took an enormous amount of time. Unfortunately, particularly given the time investment, I did not contact any participants through the clinics.

Confidentiality is clearly an important issue, particularly with regard to HIV status. I kept information about participants on a link file system which meant that the participant's contact details and their transcription would be stored separately. I informed participants that the tape of their interview would be erased once the research was concluded and participants had the choice not to have a tape recording made if they preferred, although in fact all participants agreed to be taped. Each participant was asked to choose a pseudonym by which they would be known in the research, although several specifically chose to be referred to by their own names. Transcripts were sent to each participant after the interview partly to ensure that their confidentiality had been protected sufficiently in terms of altering any identifying information.

#### **4.16 - Validity and relevance**

I aimed to maximise participants' control both over the interview process and over how the data was handled once it was collected. During the interview they could refuse to discuss a particular issue, they could stop the recording, and they could stop the interview and withdraw from the research at any point. As soon as possible after the interview I made a loose transcript and sent a copy both of the tape and the transcript to the participant for checking and altering. They could contact me either via a mobile number or by post at a PO box with corrections or revisions to the transcript or if they were concerned about any issues of confidentiality. This use of respondent validation ensured that individual participants were satisfied with their contribution to the research. Contrary to my original intentions, I decided not to send drafts of the completed thesis to participants for comments because my aim was to give an overview rather than incorporate individual voices except at the level of the raw data.

#### **4.17 - Reflexivity**

I was in a position of difference in relation to the research participants: I was a heterosexual woman, from a social work background, HIV untested, engaging in research. All this will have affected the way in which the participants told me their story, although it is difficult to be exact about what effect this will have had on the data.

The generalisability of the data is conceptual rather than numerical. A different sample of men might produce different data, as might a different researcher but the broad emergent themes and findings I suggest would be consistent across a different sample within the chosen areas or in different urban and rural communities. Further research would clearly be needed to build on this project.

#### **4.18 - After the interviews**

I made a transcription of the taped interview which was a detailed summary rather than an accurate transcription. Unlike many narrative researchers (Chamberlayne et al., 2000) I decided not to make a strict transcription. I suggest that strict transcriptions in their laborious attention to the minutiae of each communication lose the essence, or 'spirit' of the story and it was this which I wished to capture. Stories are meant to be read or to be heard as a whole and a full summary of the interview I hoped would capture the 'music' of the story as I heard it. As an extra check, I sent my transcription to each participant asking for them to check and review the data. I then grouped the data according to the pre-set themes, sub-groups within those themes and themes emergent from the data itself. It is also for this reason that I have kept each participant's' individual story as a separately bound appendix (appendix 5).

#### **4.19 - Thematic analysis**

I used Interpretative Phenomenological Analysis (IPA) as a method of drawing on the data to try to understand how participants themselves made sense of their experiences. The underlying focus of the research was to explore the participants' personal perceptions and accounts of their lives as HIV positive gay men in particular spatial contexts whilst appreciating the impact of my own conceptual field and the context of the research on the way their stories were told.

Kvale (1996 in Ritchie & Lewis 2003) identifies three different contexts of interpretation in qualitative analysis. First, a process of self-understanding where the researcher attempts to formulate in condensed form what the participants mean and understand: this I did by retaining in condensed form the stories themselves (Appendix 5). Secondly, critical common sense understanding where the researcher uses general knowledge about the context of statements to place them in a wider arena: this was done by

incorporating an analysis of current policy and government guidelines in relation to HIV services (see literature review). Finally there is theoretical understanding where the interpretation is placed in a broader theoretical perspective and I created this as a dynamic between pre-set and emergent themes.

As with all qualitative research, the raw data of this study was 'an attractive nuisance' (Miles 1979 in Ritchie & Lewis, 2003 p284) in both volume and breadth. The essential process of data reduction was carried out by grouping the data according to pre-set themes. This offered a systemic overview of the scope of the data and enabled me to identify subthemes and to make comparisons and connections across the whole data set. This analytic process was not linear: as I refined the themes and developed fuller explanations, I needed to revisit the raw data to check my developing assumptions and to search for new connections. This movement between the data and analysis helped to refine the analysis and to ensure it remained rooted in the data itself.

In order to move from the descriptive accounts of the participants' stories to a set of explanatory accounts, I looked both for patterns of associations in the data and for reasons why these patterns might occur, particularly in relation to the interrelationships between the pre-set themes. The sub-themes were ways in which I could group and code the data so that conceptual comparisons could be made. Breaking up and reconstituting the data according to themes and sub-themes and looking for connections between the themes enabled me to deepen my analysis, but integral to this process was returning to the raw data to re-root the analysis in the participants' stories.

An important part of my analysis was associative – searching for patterns of connection and contrast across the rural and urban cohorts, particularly in relation to the other themes. This involved identifying patterns, and exceptions to those patterns, and moving backwards and forwards between the data and any emergent explanations, interrogating the data to further my understanding



of spatial and community differences. Some of this was generated by explicit comparison made by participants themselves but most was generated by looking at patterns of connection and contrast across the data set.

My pre-set themes were those covered in my interview schedule: what does it mean to the participant to be a gay man, to be HIV positive and to live in a particular area. I wanted to explore issues of space, community and relationships, issues of identity, issues of health and resultant service use. Sub-themes emerged from the data itself, both as I was collecting it through the interview process and in the analysis. Thus the data analysis started deductively from the pre-set aims and objectives but was sufficiently fluid to incorporate emergent themes within these broader categories. This draws on the framework outlined by Pope, Ziebland and Mays (2000) and incorporated the following stages in the data analysis:

- Familiarisation:

I immersed myself in the raw data by listening to the tapes, writing and reading the transcripts in order to list the key ideas and recurrent themes

- Identifying a thematic framework

I then identified a thematic framework by drawing on pre-set issues and questions derived from my original aims and objectives as well as issues raised by the respondents themselves and themes recurring in the data. This process yielded a detailed index of the data; this reduced the data into manageable chunks which were then indexed, thus applying the thematic framework to all the collected data

- Charting

The data was then arranged according to the appropriate part of the thematic framework to which it related, thus producing a chart for each theme with entries from various participants

- Mapping and interpretation

I then used the charts to explore the range and nature of the identified themes and finding new associations between them. This process was influenced by

the original research objectives as well as by the themes that emerged from the data itself.

This process gave rise to a number of areas of interest:

- Being gay and HIV positive in an urban space and community, living within or without gay urban space and communities
- Being gay and HIV positive in a rural space and community and living within or without gay rural space and communities
- What does it mean to grow up and Come Out as gay?
- Critical or turning points in an individual's life
- Role of the family
- Role of friends
- Health concerns
- Use of and access to services
- Effect of grief and bereavement
- Meaning of home
- Life trajectory – sense of the future
- Need – or not – to be politicised as gay and/or HIV positive
- Role of long-term relationships
- Sex and sexual relationships
- Meaning and importance of spiritual beliefs
- Daily life – the pattern of a typical day
- Meaning of work

These areas had several common points. I conflated these and matched them to my original research aims and objectives to produce the following principle themes which I then went on to analyse in depth:

- The gay community – what is it and how do individuals place themselves in relation to it?
- Relationships – what role do different relationships have in an individual's life?

- Identity – what does it mean to an individual to be an HIV positive gay man?
- Health – how do individuals understand their health state as HIV positive?
- Services – what role do services have in an individual's life?

## **CHAPTER 5 - RESULTS**

I decided to reproduce the men's stories individually and in detail and these are included in appendix 1. The data needs to be understood across individuals as outlined in the analysis below but it was also important to the individual participants that their individual stories were reproduced as separate entities.

### **PARTICIPANT STATISTICS**

- 1 - Jake Yorkshire
- 2 - Shaun Yorkshire
- 3 - Robert Yorkshire
- 4 - Nick Yorkshire
- 5 - Tony Yorkshire
- 6 - \_\_\_\_\_
- 7 - Gordon London
- 8 - Stefan London
- 9 - Paolo London
- 10 - Jon London
- 11 - Joe London
- 12 - \_\_\_\_\_
- 13 - James Yorkshire
- 14 - Swaile Yorkshire
- 15 - \_\_\_\_\_
- 16 - Gareth London
- 17 - David London
- 18 - Tom London
- 19 - Peter London
- 20 - Graham London
- 21 - Paul Brighton
- 22 - Nicholas London
- 23 - Michael London
- 24 - John P. S. Yorkshire

NB: Participants 6, 12 and 15 denote files which were opened as the result of initial enquiries but the person decided not to participate in the study, no reason was given.

**Total: 21 participants**

7 – West Yorkshire

1 – South Yorkshire

1 – Brighton (using London services and gay scene)

12 – London

**Age range: 30-52**

**Date of diagnosis: 1985-1999**

**Work:**

6 not in work

2 substantial amount of voluntary work

1 full-time student

12 in employment

**Housing:**

11 live alone

7 live with partner

1 living in a Nursing Home

2 living in a flat share/with lodgers

**Source of access:**

Yorkshire participants:

Begin: 4

CKHAL: 2

Mesmac: 1

Snowballing 1

London participants:

Lighthouse 5

GMFA 3

Press 3

Snowballing 1

## **CHAPTER 6 - DATA ANALYSIS**

I used grouping and coding methods to order the data as it appeared in the transcripts and analysed it using a combination of the five pre-set overarching themes which I outline above in the literature review and allowing areas of interest to emerge from the data. The pre-set overarching themes are:

**SECTION 6.1 - COMMUNITY AND SPACE**

**SECTION 6.2 - RELATIONSHIPS**

**SECTION 6.3 - IDENTITY**

**SECTION 6.4 - HEALTH**

**SECTION 6.5 - RELATIONSHIP WITH PROFESSIONALS,  
TREATMENT AND SERVICES**

### **6.1 – COMMUNITY AND SPACE**

Gay men living with HIV, whether in an urban or rural environment, have to tread the space between individual and community identity; a process of identification which can be described as 'the detour through the other that defines the self' (Diana Fuss, 1995, p6). The research participants constructed gay community and gay space in terms of in/out, collective experience and individuation, sameness and otherness. They held a tension between the need to belong and the need to be different; the sense that they were the same as others together with a sense of the unique nature of their experience.

In this section I look at the experience of men living in an urban and a rural space and analysed their sense of what it means to be a gay man living in a particular environment and the communities created through that environment. There are important implications for gay men in terms of the space and communities in which they are able to define themselves, both in terms of their present living circumstances and in terms of their past

experience. I begin with the experience of the London participants and then explore the differences in the experience of the men in rural areas.

### **6.11 - Negotiating gay community and gay space in the city**

#### **Coming to London and Coming Out on the scene**

A substantial number of the participants, including several who had subsequently returned to rural areas, equated moving to London with Coming Out as gay. Many needed the anonymity, freedom from constraint, choice, diversity, and sense of collectivity that they saw an urban environment affording. The participants' stories demonstrated that even if they did not remain in the city or remain part of that scene, the process of establishing an identity as a gay man, both as an external identity but also as an internalised sense of self, seemed to require an urban space with specifically gay spaces and specifically gay communities.

Nicholas says that in the country there were no examples of quite what a gay person was, 'gay was something that people were in the cities, the country is strange...nothing is ever said.' He 'escaped' from the country by going to university but he believes it took him until he was about 25 to come out because of his rural background.

For these men, identity is socially constructed and socially maintained. We define ourselves 'in relation to' and it is through others that we find a language to conceptualise ourselves.

#### **Urban gay community outside London**

Not every participant had spent time in London; some had spent time either visiting or living in other urban centres such as Manchester. In fact, Manchester seemed to be the only other urban space that was in any way comparable to London; other cities were described as provincial or even rural in their closed nature, lack of diversity and mentality.



Paul would call the small gay community in the town he lives a gay 'population' rather than 'community': 'It's got similar small town qualities of incestuousness. Everyone knowing everyone else's business, or everyone knowing your sexual preferences...you still get that up here in London but numerically the chances are less likely that you'll bump into somebody who knows your sexual business.'

This suggests a gay identity is a phenomenon which is derived and maintained principally through large cities. Paradoxically, large cities provide the numbers, diversity and anonymity for a sense of community of gay men. It seems to be in a context of blending in, of not being noticeable or noticed that a gay community can be established and maintained. The data suggests that, if someone lives in a rural area, he will need at some point to spend some time in an urban space, with self-identified gay men, in order to develop a sense of being gay himself. Whilst it may be possible to construct an identity as a gay man through books, television and the internet, that certainly had not been the experience of the rural participants in this research. They all had spent some time in an urban space and identified that time as a period of self discovery and Coming Out as a gay man, at least in some measure.

### **Size of the scene**

London, and to a lesser extent Manchester, has an extensive gay 'scene'. Different participants held different understandings of what exactly the 'scene' is, although there was a general consensus that it exists. The scene consists of both a space and a community which inhabits that space. It consists of a wide diversity of bars, clubs, cafés, shops, gyms etc. some of which are clustered around Soho and others scattered across London. These spaces were made 'gay' through a combination of factors: unstated dress 'codes'; the sexual orientation of the owners, workers and clientele; music and décor etc. Different London pubs and clubs have different and changing histories, their flavour shifts over time and reputations wax and wane. Participants made decisions about allegiance to particular bars or clubs on the basis of music, size, type of clientele, sexual preferences and geography. Interestingly, almost everyone placed themselves *outside* the scene although many of the

participants used the scene, and so would be viewed by others as part of it and even constituting it.

Gordon describes the urban gay community as 'a series of communities bound together by friendship and common interest' which might be bars, the church, lesbian motherhood, geographical proximity etc. 'In the city there are lots and lots of groups and each of us is in lots of groups and our relationship to each group is very different'.

Tom sees the gay community as the Compton Street Café people, dressed in black and whatever is fashionable and he doesn't want to be in that group. To him the gay community also involves drug taking which he does not do: 'I'm not very pro gay community - whatever that might mean'.

To create an identity is to define oneself 'in relation to', not necessarily to define oneself as 'within'. The data suggests that participants held nebulous concepts of 'gay man' and 'gay community' which may not exist as concrete realities but in terms of which individuals and communities define themselves. For the participants, the concept 'gay' is an invisible point around which are clustered different identities and communities. 'Gay community', 'gay man' and 'gay scene' were terms used as short cuts to evoke something complex and in some measure indefinable. There was an acceptance by participants of the limitations of these terms but they were still used in the absence of any other convenient way to refer to these phenomena.

### **Different areas of the city have different characteristics**

A city is not a uniform thing and different areas of a city will have different atmospheres and will hold a different appeal. Some people had had comparatively little choice about where they lived; for example it might have been dictated by where they could get housing, but participants talked about their immediate neighbourhood as having a particular atmosphere that would distinguish it from other areas. For example, an area might be quite gay-focused with a number of bars close by; it might be rough, poor, well-heeled, well connected. It was generally understood that this might also change over time, that an area that was once thought of as unpleasant could improve.

Gordon has lived in Tower Hamlets all his life. The area has pockets which are safe and areas which are not. Gordon describes it as 'an area of extreme alienation which manifests itself as homophobia and racism and sexism. It's more to do with disempowerment and alienation and people feeling like they don't have any kind of control in their lives so they blame the Bangladeshis or the Poofs in an attempt to get some kind of control...It's where I've always lived, it's where my roots are, walking through...the Park and visiting where my aunt's shop used to be and my grandmother's flat's over there...I feel safe and comfortable.'

### **Some areas of London have more of a 'community' feel**

Some participants felt that their particular urban neighbourhood had a feel of community. This seemed more prevalent in the east end of London and those participants seemed more likely to have a sense of belonging there. They would be more likely to have grown up in that area and to have every intention of staying in that area - there was a sense of rootedness in the immediate neighbourhood. Those living in other areas of the city might intend to stay in London but there was less of a sense that it had to be in that particular community. Some were living in the city because it suited them for the time being; they might have every intention of moving to a more rural environment in the future or they might remain undecided. Others had a very definite sense of permanency about living in an urban space.

Gareth really appreciates the diversity of London which feels so 'normal' compared with where he grew up; 'London's normal - normal people doing normal things'

Graham's partner, Chris, is keen to move out of London when he retires in three years which makes Graham very apprehensive...Graham thinks that living outside London would entail changes in lifestyle which he would be reluctant to do. He would no longer be able to access the Positive Gay Men's Group he goes to or go to the opera so regularly. He would not like to be regarded as the only gay couple, in an area where they would stand out. He also thinks that he would not be able to be as open about his status outside London.

### **Communities – diversity**

There was a definite consensus among participants that London gay space and community is diverse and evades any simple definition. There are

communities of interest, people define and forge their own communities, these change over time and mean different things to different people at different times in their lives.

Joe does not see himself as part of an exclusive community but when he first moved to London 'I had all these hopes of being part of a huge group of friends who would be in and out of each other's homes all the time and partying...if I think about it now I'm older the whole thought of it is actually quite horrifying!'

### **Problems on the scene - materialism, exclusivity, unhealthiness, emphasis on surface**

Very few participants had an uncritical position in relation to the scene, which is perhaps why they chose to place themselves in attitude outside it although physically they often placed themselves within it. It was described as overemphasising surface, being critical, backbiting, intolerant, uncaring. The 'gay lifestyle', it was felt, is unhealthy in its emphasis on sex, late nights, drug use etc. It was described in terms of an exclusive club where one has to conform to a certain image, be a certain age and behave in a certain way to gain entry. Its emphasis on sex can be hard for those who do not wish to or who cannot be sexually active.

Stefan describes the scene as 'very superficial' full of young people with model attributes; if you don't fit in you are completely ignored. He prefers to spend his time at home with Gareth - 'a boring couple's house life, the sofa, tele, tea'. When he was single he went out more often but preferred more local pubs to Soho; 'people are more likely to take you for what you are, rather than your bank balance, looks, age...you're not fitting my profile, bugger off.'

Tom describes gay culture as very ageist: 'The optimum age is 37. If you look through the adverts in Boyz, nobody's over 37 in Boyz magazine.'

### **Benefits of the scene - excitement, energy, sex, affirmation, a sense of collectivity**

The scene, however, held an irresistible urge for many participants. It is an exciting environment, affirming of one's sexuality, it gives a sense of

collectivity, of community, it is full of energy and life affirming, it is a sexually charged atmosphere and provides manifold opportunities for sex.

David says: 'I decide where to go by what's available on the night...I go to the extremes, I go to G.A.Y....most gay people would describe it as a fluffy pub. Disco type place. I also go to the Block which is a dress code type place. They have an underwear night. And anywhere in the middle!...It depends what mood I'm in, what I'm looking for. In a nutshell, if I go to The Block you basically get sex but you might not like the people you have it with, if you go to G.A.Y. you're not guaranteed to but you're more likely to have more of what you like.'

### **The changing face of the London gay scene**

Most of the urban participants agreed that the London gay scene had changed. It is more diverse, bigger, less political than it used to be. HIV is still very much a present factor but its location has changed; now embedded in the scene it may at times be in danger of being submerged.

### **The changing face of Pride**

The urban participants stressed the solidarity of Pride as affirming the aim to reduce violence, to recognise equality and interdependence; the achievements which Pride represents implied for them the inclusiveness of the gay community. Such achievements, it was felt, have not been made without an enormous and ongoing personal and collective struggle – coming out of the closet, both individually and collectively, is an ongoing political statement which makes personal identity a matter of collective endeavour. It is significant that there was no equivalent of Pride in the accounts given by the rural participants; no politically charged demonstration for gay men and no public celebration of their sexuality.

In many ways Pride encapsulates the different facets of the London gay scene. Outrageous, alive, energetic, sexualised, it is a colourful spectacle. Yet its many critics object that it is affected, oversexualised and endorsing excess in consumerism, sex and drugs. It is a celebration of surface. On the other hand, Pride was born out of deeply political roots; one of the controversies

surrounding Pride, and the gay scene and communities it represents, is to what extent does it and should it continue to be a politically charged space? Is it, in its colourful carnivalesque, a political gesture or not?

'...I've lived through really exciting times in terms of gay rights, identity and liberation. [Section 28] ...was when we became a community, more so than we had been before, because we had something to fight against...Homophobia...is like old toryism...it's really becoming a non issue. The only sad thing is that...in a way it does break down the community...now at Pride there are hundreds of thousands of people and you are not going to get that sense of single purpose...When we were a bit more oppressed, when there was a bit more bigotry and prejudice around us, we all pulled together, and as we became more accepted, there's less need for that and so we do become a community based more on commercial tastes and sex, not necessarily a bad thing but it's a bit sad' (Jon)

This suggests that if there is nothing against which to define oneself, no heteronormative 'same' against which the 'other' is defined, then the concept of a gay identity is destabilised. If we argue that heterosexuals need homosexuals to shore up their own identity, homosexuals will continue to need heterosexuals to shore up theirs. Participants suggested that the gay community, by reinforcing a strong identity pitted against heterosexuals, is in danger of perpetuating its own oppression. If group boundaries are overly rigid, there is a danger of transgression becoming an end in itself; to cross a boundary is merely to set up another boundary further off. It is, however, possible to have groups and communities which allow people to enter, leave, or be partially affiliated to them. They do not feel as safe but neither do they exclude people, nor are they overly rigid or claustrophobic to their members.

Most of the participants talked about prejudice, whether it was anti-HIV prejudice or homophobia - in a rural context. When instances of homophobia in the city were cited, they were isolated events rather than a general trend. There might be also a sense that one's neighbours might know and might disapprove but generally participants felt secure that, if they did, they would not dare do anything very much about it. Even a grumbling undercurrent of homophobia did not present any sort of threat. Participants believed that such

a level of acceptance was a comparatively recent thing and was on the whole an urban phenomenon.

'They [the neighbours] must know. I don't really speak to them that much...There are certainly one or two who'd like to say something but won't - they don't really have the grounds to, nothing they can say. ...Probably they think it's totally disgusting and I'd say it's none of your business. I don't really care, as long as it doesn't affect me or the people who live in my house. I'm quite happy to ignore them when we walk down the street if they ignore me.'  
(David)

### **Effect of HIV on the gay scene - support on the scene around HIV**

HIV is an individual and individualising condition *and* a reminder that our lives are played out through our relationships with others. It is an individual, community and global phenomenon of uncertain and shifting meanings which need to be individually constructed whilst at the same time demanding a collective response.

The strong initial collective response to AIDS by the urban gay community has also been marked by conflict. The gay men who do not wish to be activists, and/or who do not affiliate themselves with the gay community have been heavily criticised by activist groups which, of course, largely consist of middle class, articulate, white gay men, to the felt exclusion of other groups affected by the virus.

Participants differed in their opinions about the extent to which HIV inhabits the contemporary urban gay scene. It is most definitely still present but perhaps in a way which is more integrated rather than placed on top as it had felt to some participants during the 1980's and 1990's . Most people on the London gay scene will have been personally affected by HIV in some way, although older gay men raise concerns that new generations of young men consider HIV as belonging to a bygone era and generation. Men on the London scene expressed a more resolved position than their rural counterparts on whether and when to disclose their status. This seemed to be

based on an assumption that it would only rarely be that they would encounter a problematic response from a partner.

A few people experienced gay space as actually supportive around their HIV status and nobody considered it an unsupportive space:

Paul derived support from one of the London nightclubs called 'Warriors', which he describes as 'genuinely fully welcoming for people with AIDS...I would go to this club, declare my status and be given members' privileges. Everything was turned around in a positive helpful way, an empowering way.'

### **Difference in prevalence and understanding around HIV**

There was certainly a difference in participants' perceptions about their community's understanding around HIV. Most believed that in a city environment they could expect a certain minimum standard of knowledge and understanding about and acceptance of HIV. In an area of high prevalence there is an expectation that most people will have had their lives affected by HIV in some way so that it is less of an alien thing. This tended to make people feel safer in an urban environment - a sense that they would not be the only ones around with HIV and that this meant that they did not have to be so anxious about confidentiality because most people would have a reasoned response to any disclosure.

David started a relationship with someone from a rural community. Up until this point, in London, David had decided to be open about his diagnosis. Then it came up in conversation with one of his partner's friends and it was clearly a major issue: 'It made me realise the difference between what was normal in London and was normal, or what wasn't normal, outside. In London it's 'Oh, sorry to hear that, do you want another drink?' whereas outside it's 'Oh shit - he's got AIDS!' It makes you realise how different it is...I was quite shocked'

### **In/out of the scene**

It is significant when and why participants placed themselves in or outside the scene. Many participants placed themselves within the scene as part of the process of Coming Out, to themselves and to others. They then might stay on



the scene or they may retain their sense of themselves as gay but remove themselves from that context. This might be because they have a partner. According to the participants, once people develop a private space at home as a gay couple, they are less likely to go out on the scene. This is partly the simple reason that at that point they are not looking for a partner but also they are less likely to need the affirmation of themselves as gay if they are in a relationship. Other participants removed themselves from the scene or experienced themselves as excluded from it because its nature, even with its diversity, does not provide a space for them in which they feel comfortable. The very need to assert a particular identity demonstrates that it is not a clear cut, uniform thing, yet in that very assertion, there is the risk of fixing something which is in flux, limiting one's understanding of past, present choices and future possibilities. The problem with liberation politics is that, in challenging heteronormativity, new categorisations have been set up which can be just as exclusive and hierarchical as the ones being challenged, for example, categories based on age and appearance.

One of the difficulties of the urban gay scene for many men is its emphasis on youth, looks and sexual performance. Several participants were in their late 30s, 40s and 50s which they reported as too old in such a youth dominated environment. They found the emphasis on looks and beauty can be highly pressurising and excluding, and men who are experiencing any sexual dysfunction or who simply do not want to have a lot of sex find the 'copping off' environment irrelevant at best and highly undermining at worst.

### **Different worlds - gay and straight worlds**

Participants agreed that one of the advantages of being a gay man in London is the ease with which someone can move between the gay and straight worlds. A gay man can work in his straight job in the city, be in a bar in Soho by 5.30, move from one bar to another depending on his needs for that evening and feel safe in the knowledge that people from one world will not cross into the other.

Stefan feels that being gay gives him access to another world: 'I'm living in the straight world anyway to start with, what's close around me, or what's outside the front door, but on the other side there's also the gay world which has also got things to offer'.

### **Choice and diversity - opportunities**

Whether or not they were used, there was an appreciation of the choice and diversity of opportunities that an urban environment affords - shopping, gyms, adult education, music, bars, clubs, healthcare, friendships, sex. Part of the diversity also was the ease of transport to each of these things. Participants often talked about their homes in terms of the tube, train and buses - how easy was it to access the things that they wanted to do, the people they wanted to see - how easy was it to move to and from the different spaces they wanted to access. In a city a gay man can move from one space to a radically different one very smoothly - different spaces which, because of the overall spatial context of the city, can remain easily accessible by tube and night bus and which can remain clearly delineated one from the others. This ease of movement has implications for identity; urban participants were able to fulfil different aspects of themselves in distinct spatial locations.

### **Managing risk and danger in the city**

Embedded in the urban men's stories was a sense that the city could be a dangerous place in which to live and that one had to be on one's guard. None of the participants saw this risk as posing a particular danger to themselves as long as they were aware of it. There was a belief that there are ways to behave, ways to carry oneself, knowledge one has to have about where to go and where not to go, what to look out for and what to do if something or someone feels 'dodgy'. There was almost a sense of pride felt by some people who lived in more notorious areas of London that they could manage themselves safely in this risky space.

'That's the area I come from, born and brought up in ... I know the things that go on - OK, people get killed, people get beaten up, it's not something new...If you're walking down the

road and there's a group on the other side of the road, it's picking up whether there's a danger or not, sometimes you might cross over or turn down a street to get away.' (David, who lives in the East End)

### **Life going on**

Whether or not one chooses to access it, there is a sense of life going on in the city - a continuous current of energy that someone can dip in and out of or just sit, as in a pavement cafe, and witness. There was a sense of the city having its own vital pulse, or life force

'I think people in London have more drive than people in other parts of the country... I think London attracts a more dynamic kind of person who's going to be more dynamic about all levels of their life, whether it's health wise or social wise, personal development....I think...it's almost a death-wish to live somewhere...isolated.' (Michael)

### **Blending in - anonymity**

The diversity of the city means that you can do whatever you like and it will not be judged unacceptable. You can blend in and live in your neighbourhood completely unremarkably or you can be outrageous in terms of clothes, sexual behaviour etc.- in an urban space it is all absorbed. Urban participants were also generally unconcerned about different aspects of their lives meeting if they chose to keep them separate. So if you choose not to be out about your status or sexuality, there is not a continual fear that people will see you in a gay bar or at the Clinic .

### **The difficulties - expense, pollution, people are cold, lack of space, poor housing**

There are definite difficulties living in an urban space. The anonymity can be liberating but some participants experienced it as intensely isolating. If you do not work, or even if you do, it can be extremely difficult to build a community around yourself. Your neighbours may not care that you're gay and HIV positive but they also may not care about you at all, there may not be gossip

about you but that may be because no one talks to each other, including you. People in a city do live in a dangerous, risky place and people tend to be on their guard - this can be experienced as very alienating, cold and unfeeling. People do not talk in the streets, at bus stops; it is a standing joke that to make eye contact on the tube is just not done, so the micro day to day contacts with the people around you are stripped to the bare bones. London is also a dirty space, the housing is poor and scarce, there is not enough space to go around and the cost of living is very high.

### **6.11 - Conclusion**

The data demonstrates that, in order to create an identity for oneself as gay, an individual needs to create some contact with other men who also identify as gay at the same time as experiencing themselves as anonymous and absorbed. There was an acceptance by participants that these concepts did not in fact in themselves exist but in spite of that there was a felt need to create connections with those perceived to be similar; even if the individual later pulled away from those connections. Furthermore, these connections occurred in particular urban spaces; once again the gay 'scene' is not easily defined or identified but the participants nevertheless had a clear sense of what it was. This has important implications for the experience of those participants who did not have connections with other gay men or with identified gay spaces. I explore the experience of these men in the following section. It is important to bear in mind that the lives of the participants were not static and, although some urban participants had always lived in an urban area, all the rural participants had spent some time in an urban space and within at least some kind of community of gay men.

### **6.12 - Negotiating gay communities and gay space in a rural area**

If the formation of a gay 'community' is dynamically related to the existence and formation of gay 'spaces', be they bars, clubs, societies, cruising areas and so on, how possible was it for the rural participants to create and maintain a sense of themselves as gay men? As with the urban participants, the rural

participants constructed gay community and gay space in terms of in/out, collective experience and individuation, sameness and otherness, holding a tension between the need to belong and the need to be different. Flowers (2000) in his research into rural gay spaces, illustrates that his subjects felt isolated and excluded both from the straight culture which surrounded them *and* from an imagined gay community which was perceived as distant and inaccessible. It seems from the data that men in rural areas experience a similar dynamic but in qualitatively different ways.

There were three general patterns in the ways in which rural participants lived their gay identity. Some rural participants established and maintained a gay identity in spite of and in contrast to the prevailing norms around them and they believed that to retain a strong identity as a gay man was important to their sense of self. On the other hand, some participants defined themselves in relation to the people around them and incorporated same sex eroticism into those prevailing norms. Alternatively, rural participants described a small but tightly knit community of gay men within a rural setting, in which group norms and group identity are particularly important in terms of defining the group against the prevailing rural norms.

### **Rural gay communities**

From the data it is clear that the concept of a rural gay community, although generally accepted to exist, consists largely of small 'groupings' which are geographically diverse and may be 'hidden' from the public eye either because of integration within a straight pub scene or because it is hidden from heterosexuals in public sex environments. There is little or no choice either of space or grouping which can present a significant challenge in terms of access.

The rural gay community is primarily based around pubs and public sex environments. The pubs are in the towns and cities so someone living in a rural area needs to be able to travel. The public sex environments are located both in the towns and in rural roadside lay-bys and toilets. Because of the size

of the community, the pubs tend to have a particular 'night' and people will travel to that pub on that night, so on a Monday they may go to Wakefield, Tuesday to York, Wednesday to Huddersfield etc. This pub scene is far more integrated into the heterosexual pub scene than in a larger urban environment. In order to access gay and gay friendly clubs you have to be prepared to travel a significant distance - to Manchester, Sheffield or Leeds.

It is a small scene, so there is a sense that everyone knows everybody else. The gay scene in many ways replicates the village community - there is not the isolation that one might experience in an urban environment but there is a sense that everyone knows everybody else's business and if you have told one person you might as well have told everyone. If you wish to avoid someone or for some reason you do not want to go into a particular pub, your choice is severely curtailed and your options are to travel a long distance or not to access the community at all, so participants described easily feeling excluded from a whole community because of one incident or one relationship gone wrong.

In rural areas, both the spatial and the experiential boundaries between in and out and between straight and gay are far less differentiated than in an urban context. This fluidity can present difficulties in creating a clearly differentiated sense of oneself as a gay man. Significantly, not one of the rural participants placed themselves within the rural gay scene although most accessed it in some form which implies that, although there are definite difficulties with a rural gay scene, it is still necessary in terms of maintaining an identity as a gay man.

The data also illustrates that public sex environments (PSEs) play a particular role in a rural culture. In an environment which can seem closed and cliquy, PSEs provide the anonymity which an urban bar culture can afford but which is impossible in a rural space. In an urban bar culture there is a pressure to be highly sexually active and sexual prowess is measured by numbers of partners; in a rural bar culture you would be labelled promiscuous, so people who wish to have many partners and/or engage in anonymous sex can only

do so in PSEs and preserve their 'reputation'. This clearly has important implications for safer sex practices. Many of the same people will go the bars *and* PSEs but there is an unwritten rule that PSEs are a separate space and activity there should not be discussed in other spaces. It is important to bear in mind that I interviewed men who identified as gay and there are users of PSEs – men who have sex with men but who do not identify as gay - who I would not have accessed through my research so I will not have gathered a full picture of the function and role of PSEs.

Robert says that there is one club and one pub for a large catchment area, and these and PSE's are your only choice for meeting other gay men. People go to PSE's to avoid the gossip which occurs on the scene; he says that if you have more than three partners 'you're a slapper' and if you are positive it is almost impossible to keep it private; at PSE's there is little or no discussion and no-one talks about what goes on.

It is interesting to note that the language used to describe gay men in this context is the same as that used to describe sexually active women. There is no new language so a patriarchal discourse is adopted as the default discourse. In rural environments there is little availability to different languages and lifestyles, in the absence of which gay men will adopt the more traditional discourses around them.

### **Integration with the straight scene**

The reality of rural life for these participants is that if they draw solely on other gay men for their friendship group their choice is severely limited! Although urban participants did have straight friends, particularly women friends, this seemed to be more a pattern with the rural participants, and this may be linked also with the fact that the gay bar scene is more integrated with the straight bar scene. There is a lack of choice of any pubs, few pubs could solely sustain a gay clientele and different friendships encourage further integration. Once again that may make it less likely that someone who moves largely with heterosexuals in heterosexual spaces will create a strongly differentiated sense of themselves as gay.

## **Position of HIV**

Whilst the rural participants accepted that there was a general awareness in the gay community about HIV, it was described in similar terms as the position of HIV in the London gay community several years ago; placed 'on top' rather than an integrated awareness. Rural participants were more uncertain and more wary about disclosure of their HIV status as it carried more risk for several reasons. First of all there was a sense of risk of losing control of information; if you told one person you potentially had told everyone. Secondly, there was less certainty about the response of a potential sexual partner; several rural participants gave accounts of distressingly negative responses. There is less guarantee that people, even within the gay community, will be aware of the issues around HIV and people's knowledge base may be faulty, out of date and their attitudes embedded in fear and revulsion. In a rural space, gay and straight worlds intersect to a greater extent, so any disclosure in a gay space has the potential to leak through into the straight spaces you also inhabit.

James says that if people got talking about his sexuality, 'it would only take one person who had a thing against it...you never know what the reaction's going to be so you end up always having to live this sort of second life'. James said it is very difficult for him to make any contact with other HIV+ people locally because the community is so close knit and people are anxious about confidentiality so many of them travel out of their area to access support services, 'here people want to be so damn private'.

This clearly has significant implications for HIV positive gay men in rural areas in terms of both how they construct and live with their HIV status and might involve different decisions around self-construct, disclosure and behaviour than if they lived in an urban space.

## **Travel and accessibility**

Accessing a gay space and community in a rural area is key. Many of the participants who grew up in a rural area were not able to develop any solid



sense of themselves as gay until they were able to drive a car. Sex in public lay-bys hinges on having a car, and buses into nearby towns and cities stop early in the evening.

James said he was late in Coming Out, not until he was in his 20s. Until he learnt to drive he wasn't really able to get around. 'I knew it was all out there but I couldn't get to it' The nearest gay scene at all was over 20 miles away, 'and I didn't know anybody else...if you live in a village and it's got one bus a day or something ridiculous and you know on a Monday you can go to Darlington and back...I remember driving from the house and...parking outside one of the gay pubs in Newcastle, and watching people go in, and plucking up the courage to go in, and eventually I went in and it was...awful, horrible, but I persevered and went back and went back and I eventually got to know people'.

In spite of this experience being 'awful' and 'horrible', James went back. Participants who moved from a rural to an urban culture in order to Come Out often experienced this transition as extremely ambivalent and they might judge themselves in the same terms as the homophobic culture against which they are trying to define themselves, yet at the same time they experienced a need to define themselves within a gay space.

### **Forming and maintaining a gay identity in a rural area**

The data from the urban participants affirms the idea that identity is socially constructed and socially maintained. We define ourselves in relation to others and it is through these relationships that we find a language to conceptualise ourselves. In the absence of strong community bonds between gay men in a rural area and in the absence of choice of spaces in which to create those bonds, rural participants had to use past experience in an urban context; travel to urban spaces on an occasional basis, and/or to utilise as best they could the spaces and relationships which were available to them. They were drawing their identity as gay from experience which was distanced in space and/or time rather than from their immediate context.

As was clear from the stories of the urban participants, a gay identity is a phenomenon which is derived and maintained principally through large cities

and the gay 'others' with whom one comes into contact in urban gay spaces. The rural participants needed at some point to spend some time in an urban space, with self-identified gay men, in order to develop a sense of being gay themselves. They could then translate that identity back into a rural context.

### **Homophobia in a rural area**

The rural participants may not have cited any more specific instances of homophobic prejudice than the urban participants, but they did report a general lack of diversity and a resulting sense that the community was not tolerant of difference in general and homosexuality in particular. As with disclosure about their HIV status (see below) the rural participants needed to take care about disclosure of their sexuality or, if they were open, cope with the negative consequences of some people's opinions. Whilst in an urban space there might be isolated instances of homophobia, in a rural context it was accepted as a generally held position.

### **Managing different spaces in a rural area**

The urban participants agreed that one of the advantages of being a gay man in London is the ease with which one can move between the gay and straight worlds, keeping those different worlds clearly delineated. This is clearly not the case in a rural setting. The rural participants expressed strong anxieties about different parts of their world meeting and information leaking from one set of people to another. Within the gay community itself there seemed to be an unwritten code of behaviour to manage this – actions in a PSE were not, for example, to be discussed in the pub, but rural participants had to adopt other strategies to cope with the fluidity of the boundaries between the gay and straight worlds they inhabited. This was an important aspect of many of their lives as most of the rural participants had chosen not to disclose either their sexuality or their status in all areas of their lives.

## **6.12 - Conclusion**

The research participants negotiated the space between differentiation and merging, separateness and community according to their perceived available choices and changing needs. The process of identity formation, both as a gay man and as HIV positive, was significantly more problematic in a rural area because although contacts and spaces were available, there was less choice of available ways to be and to describe oneself. As with the men in an urban area, the rural participants reached their own synthesis of available ways to be in their construction and understanding of their own subjectivity but this took place within a context of less diversity in the choices available to them. Rural participants reached their own understandings of terms such as 'gay' and 'HIV+' in terms of their own lives but this also took place within the general context of a more traditional community which is regarded as suspicious of difference in any form. For some rural participants this was a frustrating, difficult and isolating process; others did not experience it as problematic.

### **6.1 - Community and space. Conclusion**

Identity is experienced as both personal and social but, significantly in both an urban and a rural area the gay scene is constituted in a particular space and by people who, although within it, regard themselves as outside it. Identity formation is a process of defining oneself 'in relation to' as well as 'within'. In both contexts, there is a general understanding that, although a useful form of short-hand, and although they describe something real, the terms 'gay' and 'community' are terms around which one can position oneself but are invisible at their centre. Self-definition reflected spatial distribution; the rural participants, some by choice and some by necessity, integrated their lives both spatially and experientially along more traditionally heteronormative lines than their urban counterparts.

HIV is now more integrated – part of the urban gay scene – and that scene is largely a supportive space in relation to HIV. This contrasts with the rural scene where HIV is not yet integrated and positive men do not always experience this scene as a supportive space. The difference between urban and rural space in terms of HIV prevalence leads to differences in self-understanding and identity as an HIV positive man as well as differences in behaviour around disclosure. I explore this in more detail in the later section on health.

There are urban and rural differences regarding the relationship between gay space and heterosexual space and the possibilities of moving between the two. In a rural context, gay spaces are either more integrated into straight spaces, such as in pubs which do not have an exclusively gay clientele; or they are 'hidden' from the heterosexual eye, such as in PSE's. This contrasts with urban gay spaces such as Soho which are identified as gay and yet also known to and accessed by the straight community. Participants established and maintained a gay identity differently in an urban and rural area partly because of the different ways gay space is constituted in the different areas. Rural gay men may experience exclusion from straight culture *and* from a gay community perceived as distant and inaccessible whereas it is more likely for an urban gay man to be able to inhabit both worlds and move between the two without anxiety about those spaces intersecting. Public sex environments in a rural space provide the same anonymity as an urban bar culture but rural participants were far more anxious about the possible consequences about being open both about their HIV status and their sexuality in all areas of their lives.

Gay HIV positive men tread a balance between differentiation and merging, separateness and community according to their perceived available choices and changing needs. This process of identity formation is very closely related to the spaces they inhabit. In the next section, I look at some of the ways in which the relationships men form affect their identity as gay and HIV positive and how these relationships differ across urban and rural contexts.

## 6.2 - RELATIONSHIPS

We look to our relationships – intimate, friendship and familial – to reflect and reinforce our understandings of who we are. Whilst all participants had similar relationship needs, the data shows that the way in which those needs were met across the spectrum of different possible relationships differed according to their urban or rural context.

### 6.21 - Sexual relationships and partnerships

One of the features of relationships which are outside the heterosexual 'norm' is that people have the freedom – or confusion – of constructing them away from a culturally approved blueprint. Gay relationships are formed against a backdrop of a myriad of expectations - in terms of heterosexual 'norms', different 'norms' which have been established since the time of gay liberation and changed again in a post-AIDS generation, and other ways in which people relate – friendship, family etc. All these affect decisions such as whether a relationship is open or closed, whether people live together or not, sleep together or not, and so forth. In a world where there are many different ways of relating and the concepts of traditional family, friendship and community networks are being challenged, we are faced with the need to construct different ways of interrelating. My research data suggests that there are significant differences between the ways in which rural HIV positive men negotiate their relationships as compared with their urban counterparts.

#### **Sexual dysfunction**

A number of participants experienced or had experienced sexual dysfunction as a result of HIV itself, the medication and/or social/emotional factors. The London participants were more likely to give lack of interest in sex the label sexual dysfunction and to regard it as a problem than the rural participants who expressed it in terms of simply not being interested in sex. Participants managed sexual dysfunction either by not having sex, or using viagra.

psycho-sexual counselling or a combination of these. One London participant instigated peer support around this issue at his local HIV agency. According to the urban participants, if you are on the London gay scene, to be unable to perform sexually can cut at the very heart of your identity and your ability to function in an environment which is so sexually charged. The rural participants' stories suggest that the rural gay scene, apart from PSEs, is less sexually charged so it is less potentially threatening to be sexually inactive in that environment.

Sexual dysfunction is a complex issue given that the participants were infected as a result of sex, and the nature of HIV and of a gay identity are very much influenced by sex, sexual activity and people's understanding of their sexuality. If you cannot have sex or do not have sex, your understanding of yourself as a gay man will be affected and your sense of your body as infected and infectious may also be affected – and, of course, vice versa.

### **Sexual vs. emotional relationships**

Some participants made a clear distinction between their sexual and their emotional relationships. Sex with someone did not necessarily involve emotional intimacy although over time that might develop. If someone was looking for a long-term partner with whom they could be emotionally intimate, sex was usually regarded as the necessary first step in getting to know someone.

David would like a relationship if the right person came along but the biggest difficulty is finding someone who's on the same wavelength; 'I'm not going to waste my time. If someone comes up to me and says they want a relationship, they're in love, I'll say 'sorry, I want a shag 'cos I'm in lust!'

Both rural and urban participants had relationships which were purely sexual but the pragmatics of this was easier in an urban area where there are more cruising areas, more bars and clubs, a more anonymous community generally and a more anonymous gay scene. Rural participants were more likely to be

in exclusive, long-term relationships which mirrored a heterosexual marriage-type partnership. Some participants had a strong sense that they wanted a correspondence between their sexual and emotional relationships whereas others felt that they fulfilled different needs and could therefore be fulfilled by different people. In an urban setting there is a wider spectrum of available possibilities for negotiating intimacy, whereas in a rural area the available blueprint is largely heterosexual marriage.

### **Safer sex & disclosure**

The urban participants on the whole were much clearer about the circumstances of disclosure - when, whether and how they might disclose their status in a sexual encounter. They found a position with which they felt personally comfortable which involved consideration of the risk to themselves and to their partner. Participants also tended to make personal decisions about what constituted safer sex for them although their behaviour did not always accord with the decisions they had made around this.

Jon says: 'If they really want me to fuck them without a condom, and they're positive and I'm positive, and that's discussed and that's what they want, I'll do that, but I don't want to be fucked without a condom because it's not safe enough for me, and I would happily tell them that before I had sex so they didn't think it was a reciprocal arrangement. I think you've got to choose your own level of safety and if you talk about it, then that's fine, it's an adult decision...It doesn't seem to me to be an outrageous thing to say that positive men should try not to infect other men with the virus'.

Jon believes that the vast majority of positive men really don't want to transmit the virus but that the issues are not as simple as a lot of people think. He describes a couple of times when he has had unprotected anal intercourse with someone who did not know his status: 'I think part of my self-justification process is that they are very unlikely to have become infected. And all the other justification processes you use; why aren't they using a condom, maybe they're positive too; they should be taking responsibility...bad, bad, bad, bad reasonings, not morally bad, just faulty logic.'

Rural participants might also have made similar decisions and taken similar positions regarding safer sex and disclosure. It was harder, however, to

disclose in a rural area because the attendant risks are greater. The stories of very negative responses about disclosure were more frequent in rural areas and people carried more risk of rejection, misunderstanding and gossip.

A while ago James went to one gay pub and had a wonderful night, going 'back to being who I was before I was diagnosed'. He met a nice guy, gave him a lift home and was asked in for a coffee. This man was James' age and James thought he would be OK about telling him his diagnosis, 'I told him and he just went ballistic, hit the roof. I thought I was going to be punched...I quickly made a major exit and got home to find snotty messages on my answer machine...I was quite happy for it to be a friendship and he just went beserk...it's a different sort of rejection when they turn round and make you feel like you're dirty...like saying you've got nits when you're a kid at school'.

What was clear from all the participants was that it was not easy to take a position in relation to disclosure and safer sex and to stick with it. The dynamics of the individual encounter and the risks of rejection and humiliation needed to be balanced against the risks of viral transmission. The fact that the risks of viral transmission are not totally clear further muddied the waters. Participants had to balance decisions and fears about disclosure with difficult decisions about safer sex against a backdrop of uncertainty about risk, for example in relation to oral sex, insertive versus receptive anal intercourse, infectivity when your viral load is undetectable and so on. Health promotion messages in relation to this have also changed over the years; in the 1980s the messages about condom use were unambiguous, whereas in the last few years, the literature from organisations such as Gay Men Fighting AIDS have taken into account new information about infectivity and qualitative research into gay men's sexual behaviour to incorporate a more complex picture.

### **Serodiscordant vs. seroconcordant relationships**

The categories used to describe AIDS implies that the virus exists within individuals whereas in the lived reality of participants' relationships, HIV existed within the relationship in a way which had to be negotiated and managed by both partners whatever their status. Some participants were clear that they would rather be in a sero-concordant (where both partners are



positive) relationship because only someone who was living with HIV themselves could understand and appreciate the practical and emotional issues. Also the sexual risks were less loaded. Others would prefer to be in a relationship with someone negative (a sero-discordant relationship) because they had already experienced the pressures of being a carer and possibly losing a partner to HIV. There were no clear differences between the urban and rural participants regarding this. What was clear from the data across both areas, however, is that what was important was where the couple 'positioned' HIV within the relationship; not necessarily in terms of who was infected but in terms of how central they made it in the relationship, what weight it was given, whether it was a shared concern or one individual's burden, and whether it was given similar meanings by both partners.

Paul says he used to be adamant that any boyfriend would have to be negative but then on the other hand positive people can provide each other with peer support and mutual understanding. Now he feels he takes a more balanced view. He thinks that the issues that come up either way 'can be dealt with, accommodated, got round, understood, as long as you talk, as long as there's this thing called dialogue in the relationship, it's something I'm very keen on anyway, openness and honesty within relationships.'

Tom was in a relationship with Tony for 18 years but Tony was diagnosed after he and Tony split up. Tom describes Tony as refusing to face the reality of his diagnosis – he did not go for a test until his health was severely compromised and he refuses to speak to other HIV positive people. After Tom was diagnosed Tony would never ask him about his hospital appointments 'because by asking me it challenged his situation'.

The different ways in which Tony and Nick live with HIV can cause difficulty within their relationship, 'to me it's not there...to Tony it's a third member.' Tony thinks and talks about HIV much more than Nick, finding out as much information as he can. 'I shut it out and forget about it whereas Tony will look it up and research it'. Tony's anxieties about his lypodystrophy has also caused difficulties between them.

### **How important is it to be in a long-term relationship?**

Participants felt more or less need to be in a long-term relationship. For some people that was one of their principle desires for the future and any encounter

was charged with the possibility that this could be 'the one'. Other people had been hurt in the past by rejection or bereavement or valued their space too much and were quite happy with more casual relationships. This was far easier to achieve in an urban environment because of the anonymity, availability of potential partners and the general acceptance of having multiple sexual encounters.

### **When relationships end**

Loss of a relationship through bereavement or rejection was often one of the principle life traumas for the participants and it might take years to regain desire for and confidence in physical and emotional intimacy. Several participants had cared for their partner and may have lost them in all but body well before they actually died.

When Tony's partner Peter became progressively ill and confused Tony was tempted to leave but he had made a pledge to Peter in his heart. He thinks his upbringing and his own father's illness made him believe that you should stay through thick and thin, in sickness and in health. He had nightmares in which he would try to get away but was physically unable to. He wished that Peter would die. When Peter eventually slipped into a coma and died, Peter's family took all the money and possessions from Tony's and Peter's home.

The experience of bereavement was similarly traumatic for men in both urban and rural areas but a significant difference was that the urban participants experienced their loss in the context of a community. The urban gay community in the 1980s and early 1990s experienced massive collective losses and the urban participants were able to derive some support from a sense of experience shared. The rural participants on the other hand often experienced their loss in a context of isolation and secrecy. (See section on bereavement below)

### **6.22 - Friendships**

Gay friendship groups make a political statement and are central to the maintenance of a sense of oneself as gay. This has an impact both on social

attitudes to gay men and on gay men's perceptions of themselves in areas where there is no clearly defined gay community. HIV has also had an affect on perceptions of friendship networks, both in terms of strengthening the emotional bonds between men and also by breaking bonds through death and burnout. The urban and rural participants met their friendship needs in different ways according to the different social context in which those links were made.

### **Re-evaluating friendships, expectations of friendships**

The majority of the participants had gone through some process of re-evaluating friendships. Friends would fall by the wayside when the going got tough or there were friends who never gave but always took, and there needed to be a certain ruthlessness in terms of one's own needs. Some interpreted this behaviour as selfish but nevertheless felt the need to maintain their own self interest.

'You know when you have a piece of wood and you whittle away the bits that you don't need, you end up cutting away an awful lot of stuff that is painful to have to do... but then you cut away so many people and situations that you become quite isolated. I think I have to see it as a positive thing to do, because I think I have to avoid being in positions of stress and not being comfortable.' (Michael)

'I suppose I started to think about other people around me and if I enjoyed having them around me or if I found them overall to be a drain or a pain...I was actually quite harsh about it...I only held on to friendships with people where I was quite clear that things were heading both ways between us...So...HIV certainly had an impact on my social interactions...and it was an aspect that was quite important from a personal point of view...I'm pretty sure that it's helped me avoid feeling stressed' (Joe)

Rural participants were more likely to have heterosexual friends, particularly women. Urban participants had a larger pool of other gay men to draw on to form friendship groups. Several rural participants strongly expressed the need to have more friends who were gay and HIV positive. Friendships affirm and reinforce one's sense of self. In a world in which we have more scope and

freedom to create ourselves and where our relationships are no longer limited to blood ties and our immediate neighbours, friendship networks provide a self-created community. Participants would search for friendships which would reinforce their pre-existing sense of self and provide a network of shared experience. This was much easier for urban participants, and for rural participants the difficulty in finding like-minded people could reinforce a sense of isolation and difference.

### **Friendships vs. sexual relationships**

Participants tended to make a distinction between friendships and sexual relationships; it was best not to have sex with your friends because it 'muddied the waters'. This distinction perhaps was easier for the urban participants to maintain because of the larger pool of gay men on which they could draw both for friends and sexual partners. On a small scene, you have to cope with constantly bumping into 'ex-es' - both ex-friends and ex-partners - things have to be resolved in some way between people because it is harder simply to walk away from someone.

'The friends I have are just people who've become friends, rather than have sex with somebody and then become friends, the sex wasn't all that good so we become friends. The real friends I have, we're just friends, none of them I've had sex with. You're not thinking there's anything else there; when they ring up you're not thinking does he want a repeat of the one night stand we once had two years ago, there's nothing there. I've realised that friends are better based on a non-sexual basis. It makes things clearer' (Tom)

Once again, decisions about relationships are affected by one's environment – gay men in rural areas have a smaller pool of people on whom to draw for all their friendship and relationship needs – contacts cannot be squandered and rifts have to be repaired.

## **Friends as replacement family**

A number of both urban and rural participants described their friendship group as a 'replacement family', particularly those who were estranged from their family of origin.

Gordon has made new and different friends but he had a 'chosen family' of friends and those relationships cannot be replaced. He makes an analogy with war and with his grandmother who will 'drag out photographs of going hop-picking and all the people in her photos are now dead.'

## **Bereavement**

Urban participants who had a large pool of gay friends had had to deal with the virus affecting their friends as well as themselves. Some would have experienced multiple bereavement as a result of HIV and would know a number of other people who were positive. This might have a number of different influences. It might 'normalise' HIV and in some ways be quite helpful because your friends are able to provide day-to-day support from a position of awareness and if a number of you are living with the virus it ceases to be such a big deal - it does not mark you out in any way within your immediate circle. On the other hand, particularly for participants who were active on the scene in the early days of HIV, the affect of the virus could be devastating. People lost not only their entire friendship group but also the social context in which it operated. Participants would talk about meeting friends in particular bars on certain nights - now not only have all their friends died, but the familiar background faces in the bar have also disappeared.

Michael has lost most of his long-term friendships and finds it difficult to form new ones so his daily life is reasonably solitary. He particularly feels the loss of one friend to AIDS who 'knew all about what was going on and he and I were always a support to each other, it was always he and I and we didn't need anybody else. He was as close to being a lover as a best friend could be, almost like a soul mate. I think a lot of people have soul mates who are not their

partner, whether they're straight or gay or whatever...We were very close on all levels, plus the HIV.'

Rural participants were far less likely to have a large number of friends who were HIV positive and/or who had been bereaved through HIV. Whilst this meant that rural participants were less likely to have experienced the devastating impact of multiple loss, it also meant that they might be the only person in their friendship group to be affected by HIV. From this position of stark difference from others it was qualitatively more difficult to normalise and integrate HIV into one's life.

### **Telling friends**

Participants would exercise caution when divulging their status to friends. There was a strong sense that news once told could not be untold and friends could not always be relied on. For some there was also an anxiety of losing control of information - once you told one friend you potentially had told everyone. This seemed to be more of a concern for the rural participants for whom the virus was not already a very present factor in their social circle. There is also a sense in which telling your friends involves telling yourself and some participants spent a time post-diagnosis when they did not tell their friends during a time when they were not ready themselves to consider their status.

## **6.23 – Family**

### **Rejection & acceptance**

There was a wide spectrum of experience in terms of family. All the participants described some measure of anxiety about telling family that they were gay and telling them their status. Some families managed this information in a straightforward manner and were felt to be very supportive. Some families had already guessed so hardly needed to be told. Some participants on the other hand had experienced either partial or total rejection

by their families, either for a time or permanently, others had walked away themselves either emotionally or physically from a family situation they found to be intolerable. Some participants were prepared to live with some measure of at least tacit disapproval and some families changed their attitudes when faced with the choice of accepting their son/brother as gay or losing him altogether.

David hasn't spoken to his parents for 10 years. 'I don't really know why, but I didn't want to and despite many people trying to persuade me otherwise, if I got back in touch with them, I would just want to do the same thing again...They wouldn't understand half the things I say anyway.'

Both John's parents are dead, but his other family have written him letters to say that they don't want anything to do with him because of his status.

Rural participants needed their families more. They were more likely to live near their family, see them on a regular basis, and regard them as a significant part of their support structure and of their social group. Family acceptance was therefore more important for rural participants because they played a more significant part in their lives. Several of the rural participants had moved to an urban environment during a period of Coming Out and establishing a sense of themselves as gay. They then returned to the area where they grew up post-diagnosis in order to be nearer their families and in what they experienced as a more supported and safe environment. Participants' current level of contact with their families ranged from none at all to daily contact.

The participant's sexuality and HIV status might become a 'family secret' and parents/siblings might express anxiety about the extended family finding out, or the neighbours. Participants were much more likely to tell their mother first and then the mother or the mother and son together would decide if and how to tell the father. Complicated strategies were adopted in telling fathers to get the desired reaction. Several participants had chosen not to tell their families at all and there were different levels of 'they know but it's never been discussed/they must know' which operated within the family.

The way Michael's father was told was that Michael's mother stayed at home with Michael, his father was sent to the vicarage, the vicar told his father that Michael was gay whereupon his father returned to the house.

The families of the rural participants were more likely to experience similar anxieties as the participants themselves in relation to disclosure and secrecy. Families who may be homophobic themselves might choose not to disclose in a wider context of perceived homophobia. It was also harder for family members in an area of low prevalence to make positive links with others affected by HIV.

A number of participants had had to deal with the death of family members which had affected them in different ways from bereavement through HIV. Some had come to an understanding that they would die before their parents, only to find that they were living quite healthily and that their parents did die before them. These deaths which would normally be understood to be in the normal course of life were experienced as out of kilter because the participant regarded themselves as the one facing mortality.

## **6.2 – Relationships. Conclusion**

People have relationship needs but they might not be fulfilled through traditional roles; different participants had different understandings and experience of family and friendship networks and these were lived out differently across urban and rural space. Sex, emotional intimacy and HIV are experienced in a complex inter-relationship. Participants found themselves having to negotiate different ways of framing their relationships or conforming to a heteronormative blueprint. Intimate relationships in a rural space seemed to correspond more closely to that blueprint than their urban counterparts. HIV played a significant role in negotiating sexual and emotional intimacy and this was perceived as more problematic for the rural participants who were negotiating disclosure in a more closed culture and with partners who would not necessarily react favourably. Disclosure is an act of identity formation;



telling others one's sexuality and/or HIV status changes one's perception of oneself. When participants framed their experience in words in order to tell, it changed their understanding of themselves. Rural participants were less likely to disclose either their HIV status or their sexuality and would make strategic decisions based on their judgement about someone's potential reaction.

Participants re-evaluated friendships and relationships in the context of crisis or of a changed and changing identity. There was a felt need for one's relationships to shore up one's identity of choice. This was harder for rural participants who did not necessarily have a friendship group of people who were perceived to be similar. There was also an urban and rural difference in the experience of bereavement and loss. In urban areas, personal losses were lived against a backdrop of multiple loss whereas in rural areas there was less of a sense of mass loss. Whilst rural participants may not have had to cope with multiple losses, there was a stronger sense of isolation and alienation from the rest of the community. Rural participants were more likely than urban participants to have more contact with their families and rely on them more for emotional and practical support.

The participants' sense of identity was experienced within a dynamic inter-relationship with their experience of community and space and their relationships with others. In the following section I explore specifically issues of identity in the context of HIV, sexuality, space and relationship.

## **6.3 - IDENTITY**

### **6.31 - Fateful moments**

Brian Heaphy (in Weeks & Holland, 1996 in Barbour & Huby, 1998) uses Giddens' (1991) concept of the 'fateful moment' to look at what resources people use to make sense of infection and diagnosis and to explore how people reach an understanding of what it means to be HIV positive. He regards identity formation in the context of HIV as a reflexive act in response

to the need for ontological security in the face of uncertainty. He presents an HIV positive diagnosis as a 'fateful moment' which threatens our ontological security and leads us to construct a new sense of self. The participants were faced with a number of 'fateful moments' in relation to themselves as positive and, as with any illness (see Kelly 1991, 1992, 1994, 1996, Kelly & Field 1998, Kelly & Dickinson 1997, Moss 1996, 1997 Williams, 1996) these were different and happened at different times for each individual. Some participants did not seem to experience HIV itself as a 'fateful moment'; their diagnosis and new identity as HIV positive seemed to be absorbed into the person's life concept.

### **Testing and diagnosis**

This was not always a fateful moment in a participant's sense of themselves nor in their life trajectory. If they already thought they were probably positive and if they already knew other people who were positive, there was a sense of continuity through diagnosis. If the person was living in an urban area at this point in their lives, they were more likely to believe that they were positive and to know other positive people. Those living in rural areas where HIV did not form such a significant part of their lives already, experienced testing and diagnosis as a significant shift in their sense of themselves and their relationship with their world.

'The friend that came with me (to be tested) was my best friend at the time... He was HIV positive so I had lived with him being HIV positive without symptoms for the previous 5 or 6 years...The doctor thought it was some big emotional thing but I already knew.' (Michael - tested in London)

'It was a process of hooking the pieces up...well there is a chance...it wasn't something I particularly freaked out about or got anxious or hysterical about. I went in there with a fairly clear head, half expecting that I would be all right and half expecting that I would hear dreadful things...but I actually handled it reasonably all right because I think I half expected it.' (Joe – tested in London)

In hindsight, Tony believes he was infected shortly before he met Peter, but at the time he was 'HIV naïve, gay naïve' and didn't really think that much about it...Then he developed thrush and visited a consultant but didn't suspect it could be HIV. He was tested and Tony was told the result and also advised to be tested. Neither of them received any pre-or post-test counselling. Tony had never been to a GUM clinic before and was 'absolutely devastated'...Tony tried hard to get information but there was little available and what there was was negative so they just cut themselves off and got on with it as best they could. (Tony – tested in Yorkshire)

If HIV was a significant part of external identity pre-diagnosis, it was more easily incorporated into a person's personal identity. In the first two cases above, the participants thought they might well be positive before testing, so in fact a positive result was confirming rather than challenging a person's sense of themselves. HIV is incorporated into urban gay culture and generally there is a reasonable level of awareness in an urban environment about the virus. In a rural context, however, there is less awareness about HIV, either within the gay community or within the community in general.

## **Coming Out**

This represented a shift in identity at whatever point in life this took place and however it was managed. For all participants, Coming Out involved some sort of contact with urban life, whether it was being able to visit a city, moving to a city, being able to move freely around a city. So for rural participants Coming Out was associated with some access to movement around a city (see also section on urban gay community and gay space above). Coming Out is, therefore, both an intra-personal shift of identity *and* a physical, geographical action.

Peter went to London, quite purposely 'to find out about gays, sex and stuff'... At first he was shocked at seeing men 'dancing, kissing and stuff' - his religious upbringing had taught him this was wrong. But as he sat and watched he thought 'Why is it wrong? People are happy enjoying the company, being together...I think it was at that club at that time on that night that I decided that yes, what other people had accused me of being I actually was - gay - I think I had a nervous excitement about it'.

## Death

The death of others as a result of HIV and loved ones often represented a fateful moment in a person's understanding of themselves. Many of the participants had cared for partners who had died as a result of the virus and this had resulted a significant shift in their sense of themselves - or a sense of everything falling apart to be put painfully back together again, in a different way, over a period of years. As discussed above, urban participants had also to deal with the cumulative death of large numbers of friends, acquaintances and loved ones as a result of the virus as whole communities were wiped out in the 1980s.

Peter's protracted death left Tony a physical and mental wreck. He went home and could feel himself 'sinking and sinking and sinking'. He began, now he had time, to focus on what he had gone through and the fact of his own HIV diagnosis.

After Rob's death, Paul describes himself as 'utterly distraught, desolate, this central person in my life was physically not there any more.'

As Peter experienced more and more bereavement, he became almost immune to the sadness of death; 'I didn't allow myself time to grieve'. He went to some funerals but in the end he decided he could better honour the dead by getting on with his voluntary work and carrying on living. 'You can't cope with such multiple deaths, 3 or 4 a week.'

Although urban participants had to deal with the devastation of multiple bereavement, this experience also gave them a sense of living through something collectively, as a community, whereas rural participants often had to cope with the death of partners and friends without contact with anyone who had experienced something similar. The rural participants therefore may have had a bereavement experience which was disenfranchised in that there was no community or collective validation of their loss. This may also have been the urban participants' experience in terms of the wider community but in terms of the gay community there was a sense of recognition and collective experience.

## **Starting treatment**

For many people this represented a fateful moment in their HIV trajectory and usually followed a symptomatic illness or blood results which indicated deteriorating health. Again people were more likely to be able to manage this shift in identity if it fitted into their world, for example if they knew other people on treatment.

Sean began to panic as it came to the time of his first dose of anti-retrovirals, then he decided 'You've set this time, now just get on with it, just do it'. He could certainly feel them going in to his system but he is looking forward to the increased energy which he hopes they will give him: 'I eat well, I look after myself well, and I think the medication will work well with me'.

Once again there was a difference between the urban and rural participants regarding treatment. Urban participants were easily able to discuss aspects of treatment and the experience of being on treatment with others in their network, which both provided information and normalised the experience. Rural participants were less likely to have such networks available which meant that for some the only information about treatment was what they could gather from their clinic, the internet or written information. Starting treatment or having difficulty with treatment was therefore more likely to be experienced as a 'Fateful moment' as it was less normalised within the person's network.

## **Illness**

Many participants adjusted to their diagnosis by constructing HIV as something you live with healthily; a condition one can manage. It then had a place in their lives and they could feel in control of the space it took up. Illness jeopardised this identity and once again could throw a person into a state of crisis as they re-established an identity which incorporated uncertain health.

For two years David's health was very good, his Viral Load undetectable and he had one change of anti-retroviral therapy when his Viral Load went up. He was on prophylactic septrin and stopped it a year ago. However, this was 'a nightmare'; in the next three months he had 2-3 chest infections; he had an anti-pneumonia vaccination but got common pneumonia (not

pcp). The doctors had no idea why he got this. He's now gone back onto septrin even though his CD4 count is over the level where pcp is a risk. The pneumonia has been the only major health problem David has experienced and it was 'quite a kick in the teeth...'

It was not sufficient simply to construct an identity as ill or healthy only on the basis of blood results because health does not always follow the medical discourse. Participants had simultaneously to tread several different discourses to incorporate fluctuations in their health into their sense of themselves. Once again this process was harder for rural participants who did not necessarily have access to a network of others who also experienced periods of ill-health. Incorporating illness within a context of isolation and secrecy is far more problematic and causes more anxiety. I explore this further in the section below on health.

### **Break-up of relationship**

The end of a relationship, through break-up or death might also be a fateful moment. People would then have to re-create themselves as a single person, maybe looking for another partner and have to deal with the issues of managing the whole process of finding a new partner as an HIV positive person. This seemed in all cases to be an easier process in London rather than in rural areas. There are simply more places to go to meet new people and disclosure carries less risk.

For some participants who had been bereaved through death or the end of a relationship, a positive diagnosis aligned mental and physical state – the mental anguish had some physical mark on the body in the form of the virus.

### **Contact with people who become formative**

Several participants described meeting people who then became formative in their lives as a fateful moment. This might have been a group of gay men when they Came Out or other gay men dealing positively with their diagnosis, or one significant friend or partner who helped them to create their sense of

who they were. For some it was a professional, usually a therapist or a psychologist, who had helped them regain a sense of themselves after a period of chaos.

John and Gordon were sent to see a psychologist and Gordon describes the resulting change in their perspective as 'amazing': 'We went in to see him thinking that we were going to die, we came out thinking what are we going to do with our lives...John did his accountancy qualifications, I got on with a life in theatre...we got on with our lives rather than feeling sorry for ourselves and that's actually stayed with me.'

It was at a particularly low point that Michael decided to join a positive Gay Men's Group 'and that was really quite a life saver. I was really very low. Michael has found the group enormously beneficial; he appreciates being able to talk with people who have been through the same experiences and are dealing with the same difficulties.

Tom says that his counsellor 'has been the most influential person in my life. One of the ways in which counselling has challenged Tom is around his own self-image: 'she gave me back my self worth, my purpose in life...it made me think about my role and what I want'.

This reinforces the extent to which other people are formative in terms of a person's identity; one person or a chance comment can alter the course of a person's life. It is significant that formative relationships with friends and groups were created in an urban setting whereas formative relationships in a rural area tended to be formed with professionals.

## **6.32 – Social stories**

### **Politicisation**

Several participants created a sense of themselves as gay and as HIV positive by constructing their identity as a political issue. For these people it was important to be open about one's sexuality and status, to meet with other gay men and other HIV positive men and to combat prejudice and bigotry in the rest of society. To manage a political identity was much easier in London than in rural areas where one is less likely to meet large numbers of other gay HIV positive men with a political sense of themselves.

Jon places starting university within a political context. It was 1986 when there was the first Government Campaign about AIDS and the start of Section 28 which 'was the thing which pushed me out of the closet and made me affirm my sexuality...as we were being actively attacked I felt I had to declare my colours'.

Gordon quotes Engels who said 'Don't mourn, organise!' and 'Living is the best revenge'...'organisation - I believe in. I'm a joiner - I get involved and do things...I believe in communities.' As a direct result of his experiences, Gordon spearheaded a campaign to raise awareness amongst lesbians and gay men over the importance of writing wills, 'I always find a way of channelling my anger and doing something constructive with it'

Rural culture is generally less political and this is reflected in the rural gay community as described by the participants. This is partly a result of the very concrete difficulty of political activism in an area of low prevalence.

### **The changed and changing story of HIV**

HIV is a story which is told in society. It is constructed in and through particular cultural discourses which are both affected by and affect the way it is manifested. Perhaps one of the hardest things for some of the participants to deal with, particularly those who had been diagnosed for some time, was the fact that the construction of HIV has undergone some dramatic changes in the last twenty years. People who were diagnosed through the 1980s were diagnosed with a terminal illness with a short prognosis. They were expected to die in painful and unpleasant circumstances with medical input only treating the symptoms. To live positively with HIV during those times for many people was to come to terms with the loss of one's future, with dying, and involved giving up work, going on benefit and living as well as you could with the time you had left. Since the advent of anti-retroviral therapy HIV is increasingly constructed as a chronic rather than a terminal condition. The 'story' of HIV in society, the way it is constructed by medical personnel, other professional groups such as social workers, voluntary organisations, the press, the Benefits Agency - all these not only have a tangible effect on those living with



the virus but also create a framework of meaning within which people may or may not be able to fit their experience.

The advent of anti-retroviral therapy meant that Robert 'wasn't dying any more...I couldn't get away with not having responsibility for my life...it got harder and harder and harder...to not be doing anything with my life...I couldn't believe I'd spent all that time...fighting benefit...guilt...only to be told by some silly arse, it's fine, you're going to live...that was almost as hard...that realisation that this therapy worked was as hard or harder...because the living's almost as painful as the dying.'

Gordon remembers a Far Side cartoon of a dinosaur in a cave settlement with the sign 'Sorry, extinct' and he has felt like that. In the mid '90s there was a backlash against the gay men from an 'earlier' generation and although he does not think there is much to be gained by dwelling too much on the past, there is a sense of a generation gone. He has one positive close friend now whereas in 1985 he had probably 10 or 15.

It is significant that the urban story of HIV has changed more than the story in a rural area. In London the discourse of HIV is increasingly one of 'living well' with the virus. In rural areas, the process of changing the story from one of illness and death to one of living well is slower and less certain. This is reflected in the ways in which the different participants continue to describe their experience. This has important implications for the understanding of 'need' for these groups of people and for the services which aim to meet those needs. I explore this further in the discussion chapter.

### **Fit between personal story and social stories**

To some extent, personal stories of illness make up the social story, and again to some extent, participants drew on social stories to construct their own personal story. The 'fit' between the personal and the social, however, is not always necessarily experienced as comfortable. People who are not taking anti-retroviral therapy, people who are ill and even dying as a result of HIV, people who for whatever reason are not able to live positively with the virus - many of these find a disjunction between their personal story and the social story of HIV. Not being able to fit your experience into a generally

accepted social framework, albeit a marginal one, can create a crisis of identity and a painful sense of alienation. If a participant's story did not fit the collective discourse, they were left to construct their own meaning for an experience for which there perhaps was no discourse available and in a way that would not be socially or culturally understood. In a very painful sense they felt they did not 'belong'.

Nick has given way under pressure from the doctor, family, friends and his partner to start anti-retroviral therapy: 'I hate them. I hate being on them. It feels like every time I take the tablets it's ruling me and now I haven't got control of it any more...I'm not taking the drugs because I want them...I'm taking them for everybody else... I felt I had to because no one would listen, absolutely no one was prepared to see my reasons, my point of view.' He doesn't actually feel any different on or off the tablets but his test results have shown a massive improvement.

Before his diagnosis, Nick was always reluctant to take medication and he feels that adjusting to the drugs is the hardest part of the whole process. He believes that if he had chosen not to take anti-retroviral therapy he would have greatly distressed his family and Tony and also he feels that the medical services would have given up on him.

There is a clear distinction in these examples between how Nick experienced his own health, the discourses available to him to explain himself in society and the discourses adopted by those around him. The data suggests that the prevailing available discourse in a rural area continues to be that of illness and death, which may not be appropriate for those whose condition is stable; whereas the prevailing available discourse in an urban area is that of living well which may not be appropriate for those whose health is poor or who for some reason is not able to 'live well' with the virus. I explore this point further in the discussion section below.

Participants had different understandings of the extent to which society is homophobic and how this affected their sense of themselves. Some had a very acute sense of the bigotry that is still evident in many people's opinions whereas others felt that this had changed over the years and others felt that they could remain separate from any homophobic attitudes. To define oneself

in the face of persecution creates a particular sort of identity which then may have to be redefined if the persecution becomes less evident. This is perhaps more so on a community scale - the gay community has become less political, less radical and more commercial now that there is simply less institutionalised oppression to fight.

Peter talks vehemently about the 'gutter press in this country and the homophobic bigots...who are not only damaging gay men, but also killing heterosexual people at the same time, lying to readers in the gutter filth which gave licence to heterosexual people to not bother for such a long time.'

On the other hand Jon describes homophobia as 'becoming a non-issue. The only sad thing is that...in a way it does break down the community...now at Pride there are hundreds of thousands of people and you are not going to get that sense of single purpose...When we were a bit more oppressed, when there was a bit more bigotry and prejudice around us, we all pulled together, and as we became more accepted, there's less need for that and so we do become a community based more on commercial tastes and sex, not necessarily a bad thing but it's a bit sad...It's very hard to convince people that we're hated when I think it's very clear that in fact the majority of people don't mind us...'

The concept of being 'gay' and the whole phenomenon of HIV historically have emerged against a backdrop of oppression. If that oppression no longer exists, or if its expression has changed, this has an effect on what being gay and what being HIV positive mean in society.

Rather surprisingly, there did not seem to be a difference between the urban and rural participants in terms of actual reported instances of homophobia. To a large extent 'you see what you look for' – people who more sensitised to homophobic attitudes, or who needed them to maintain their identity, were more likely to experience homophobia wherever they lived. There was, however, a general sense in rural areas that people 'out there' were homophobic in their attitudes, whereas there was a stronger sense in London that, on the whole, people were more accepting of diversity and difference.

Many participants experienced homophobic oppression from their families, at work, in the media etc. and as a result of this, or as a result of the fear of such

oppression, many chose to be selective about what parts of themselves they showed in different areas of their lives; many chose to remain closeted at work both about their sexuality and their status simply in order to survive. Although we all show different parts of ourselves in different areas of our lives, when a participant felt that they had to conceal important and significant areas of their life and identity because of the risk of being ostracised, it created difficult tensions both within themselves and with the world around them.

'I have three sides to me'; the dutiful son at home and responsible at work; 'then there's me as a gay man; and then there's another side to me, I'm a gay man with HIV'. (James)

Nicholas says that the straight men in the navy were perfectly prepared to protect their gay colleagues and there was an undercurrent of resistance running throughout the service. There are also tacit exceptions such as the Royal Yacht 'which is basically a posting for upper class rich queens...you get accepted as long as you stay on the vague, predefined side of the line...you cannot be open about your sexuality whatsoever, although you can be as camp as tits'.

Nicholas points out that it is always assumed that gay men 'will wear effeminate clothes, will be horribly camped up, will be a hairdresser and will only be interested in shopping...our society tolerates you as long as you correspond to that image'. Nicholas has done world class caving and has been involved in a lot of cave exploration. This is, in the eyes of others, an uneasy juxtaposition with his sexuality.

To define oneself *against* – against prevailing norms, against the gay community, against one's family – is to develop a particular sense of self, one born out of struggle and dissent. Rural participants had a stronger need to define 'against' in a context of difference.

## **Identity stories**

Participants described themselves in a particular way according to whether they perceived themselves as having a strong sense of self-efficacy or experienced themselves as the victim of circumstances beyond their control.

Many of those who experienced themselves as being in control of their lives believed that this had only been achieved through an effort of will on their part. Feeling blown and buffeted by the storm of events or having a sense of at least some power over one's own destiny made a massive difference in the way they regarded their relationship with themselves and with their world.

Nick was infected as the result of a gang rape at a party and what happened was totally out of his control:

'I had no choice in what happened...I think that made me more of a strong person...After that I took control of everything...It's just one of those things that happened is the way I look at it now, it just happened and nothing can be done about it...I've taken control of my life.'

It is important to Joe to feel in control of information about his status, he thinks that the sense that you have less of a grasp on your future and on your health, makes it even more important to feel that you have an influence on other things that happen to you.

Tom says:

'I have to know things. I found it far more of a worry before I was diagnosed. When I was diagnosed it was a relief...I could then concentrate on getting as much information from people like NAM etc....I like to plan things, and say, yes, this is what I am going to do'

To be in control of our lives is perhaps for all of us a necessary illusion – our control ultimately is illusory but it is vital for us to feel some sense of power over our own destiny.

Other participants felt a victim in the face of adverse circumstances and powerless to change or improve their destiny. This created substantial difficulties in terms of the person's ability to cope. One participant's suicide attempt could be read as an attempt to exert some control over a situation where he felt at the mercy of circumstance:

The night before I was due to meet him, John took an overdose because he 'wanted to die with the little dignity I've got left...I'm frightened of staying alive, but I'm also frightened of dying, and that's why I 'phoned the police...I just feel I'm letting everybody win' (John – a rural participant)

John's story incorporated an uncomfortable level of contradiction which was an expression of his felt inability to manage his life. Whereas most of the other participants were able to frame their experience within a particular discourse which gave them at least some sense of coherence, John's story was an uneasy juxtaposition of different voices and he seemed unable to find his own voice in order to exert some control over his circumstances. Although there was no clear distinction between urban and rural participants in terms of which group had a stronger sense of self-efficacy, such a sense was harder to establish in a rural area.

### **6.33 - Creating meaning through illness**

Participants who had a stronger sense of control over their lives were often quite conscious in the way that they created a sense of meaning around HIV for themselves. HIV would become part of their life - sometimes peripheral, sometimes more central - which was integrated into other aspects of their lives. Those who struggled more with their status regarded it as meaningless, pointless in terms of the rest of their lives and an adjunct rather than as something which could fit with other aspects of self.

Tony slowly recouped to become 'an HIV+ person but someone with a life...and life wasn't just about HIV and death and bereavement...and there might be some good to come out of it...I've got HIV and you just get on with it...the better you get on with it, the more positive your life becomes and that becomes less a part of your life.' Tony believes he is a much stronger, more positive person as a result of his experiences. His health has improved massively, his blood results are excellent and he has renewed goals and ambitions.

John's story encapsulated aspects which were seemingly contradictory and demonstrate his struggle to create a coherent identity: He thinks that in fact his diagnosis may have been a false positive 'and if that turns out to be the case I will sue everyone that's involved'. John feels he is able and wants to help people and feels he has a lot to offer. He is a qualified massage therapist and a qualified healer: 'I've got a lot of love in my heart, and a lot of love to give somebody and a lot of care to give somebody' but he does not feel he can get any support. John has decided that he is going to stop his HIV treatment because he simply does not want to continue.

John's story is an example of the pain and confusion of an identity which cannot cohere. Our sense of ourselves will always encapsulate contradiction and paradox and we make decisions about which elements of ourselves we will foreground in order to have a sense of ourselves which holds together. For John, different aspects of himself are struggling for that foreground position, leaving him in a state of chaos.

Those participants who felt in control of their lives and who regarded HIV as more integrated into the rest of their lives had often struggled to get to this position. They might have been faced with a choice of telling their story as one of meaning or as one of chaos - both versions could hold truth in their lives but they had at some point come to a stage when they consciously chose a story of meaning.

Coming into Paul's life at the time it did, with the meanings that it had at that time, HIV 'fucked it up. It killed my boyfriend and loads of other friends', ideally he would still be in work and HIV challenged him profoundly in terms of surviving with it, 'but something has strengthened me with it', he has become more mature, less naive, more aware of issues of mortality and more aware of his strengths and abilities. 'I'm angry and frustrated at things which are horrible but can't be changed.' On the other hand, as far as he can, he engages with HIV as an empowering thing and attempts to control things in his life as far as he is able to.

How central HIV was in a participant's story would vary in time. It was more central at points in the day when they took their medication, when getting routine blood results, when they experienced symptoms or when they had contact with other positive people. Some participants resented the times when HIV became more central whereas other people used it as particular times to focus on the virus whereas at other times it would recede.

James says that HIV fits into his life where he wants it to fit in, for example he is pretty relaxed about when he takes his drugs because he doesn't want them to rule his life. He's been advised to stop smoking and drinking, but he wants to have some quality of life and there are only so many sacrifices he is prepared to make. He refuses to be fanatical about the way he lives with HIV, 'obsessions aren't healthy'. He doesn't like other people worrying about his health and he doesn't want people 'pussy footing around me'. 'You can't live on the edge all

the time, because there's always the fear that you're going to go over. You have to be able to take a step back and look at the wider view'.

The extent to which illness is central in someone's story is also a question for people suffering from other chronic conditions. The position of HIV is particular, however, because of issues of stigma and disclosure and also the fact that it is not a visible condition. Again, this was a source of greater anxiety for the rural participants.

### **6.34 – Stories in time**

Participants told their story in terms of time. The present only makes sense in terms of the past which in turn is translated through the present moment. The future can only be anticipated in the light of the past and through present understanding. Several participants told a past of chaos in the light of a present of meaning. Others told a story of halcyon pre-HIV days in the light of a blighted present. Sometimes the future would be seen as continuity from the present, or sometimes further change was anticipated.

Nicholas on two occasions has nearly killed himself caving 'so I thought I was well anaesthetised to this life-death thing, but actually it's not true...when you do have to face up to the fact that you are going to die, potentially fairly horribly and potentially far earlier than you'd anticipated, then yes it does have a devastating impact.' Before he got tested he had thought he had faced mortality but a positive result was very different.

Nick has never had a sense of a long term future; when he was seven he said to his mother 'I'm never going to be 40 and you'll go to my funeral'. He doesn't feel he will become and doesn't want to become old; he lives for today and the only thing he plans ahead for are holidays. He is buying a house with his partner 'because we want to *today*'

Participants tended to describe their identity in terms of their past - they recognised that their past had moulded them into the sort of person they are today - family struggles, homophobia, bereavement, illness, the influence of people they had met through their life - all these would mould them to become a particular sort of person. Some participants defined themselves in



opposition with their past whereas others saw themselves in the present as aligned to the various historical influences, but all the participants had a keen sense of their present selves in relation to their biography so far. Those in rural areas described past contact with urban gay space and community as formative to the way they were in their present lives.

### **6.3 – Identity. Conclusion**

The concept of the 'fateful moment' is useful in terms of understanding the process of adapting to an identity as HIV positive. The research data suggests that testing and diagnosis may not necessarily constitute a fateful moment, particularly for urban gay men for whom HIV is already a significant part of one's life and identity. There will, however, be significant points along an HIV trajectory which constitute a fateful moment in that they will entail a shift in a person's sense of themselves and relationship with the world. Examples of events which might constitute a fateful moment include Coming Out, death of loved ones, starting treatment, illness, relationship break-up and contact with people who become formative in one's life.

Gay identity can be a political identity but gay politicisation is principally experienced as an urban phenomenon. It was hard for rural participants to develop and maintain a politicised identity outside a politically active community.

One's identity as HIV positive is a changing identity and all the participants described the need to develop strategies of coping with uncertainty. Participants who had been diagnosed for some years may have experienced difficulty in integrating the changed and changing story of HIV; once a terminal illness and social crisis, constructed through a discourse of crisis and epidemic, they now were faced with adapting to an identity which involves living with a chronic, manageable (but still incurable) condition and social problem. The discourse of 'Living Well' with HIV was more widely evident in London whereas a continuing discourse of illness and death was more widely evident in rural areas. Participants in either area might experience a

difference between how they might see themselves and the discourse available to them in society, particularly in terms of their health. The urban participants whose health was not good or who were not 'Living Well' struggled with the changing discourse of HIV whereas the rural participants whose health was stable and who wanted to move on with their lives found the rather 'stuck' discourse of illness and crisis rather frustrating. This has implications for service provision and I examine these issues in more depth in the section on services below.

There was a question over whether or not it was relevant any longer to define oneself as a gay men within and through oppression and homophobia. For some participants these were still very current issues and for others there was a sense that the discourse of struggle was no longer relevant. For these participants there was a question over how and if that affected their understanding of being gay. Whilst individual instances of experiences of homophobia were similar across the two areas, there was a stronger sense of a general level of homophobia and anti-HIV prejudice in the rural areas.

Gaining a sense of personal control, in whatever way this was constructed, appeared to provide a sense of ontological security. The lack of that sense of control, however partial, had a significant effect on the person's ability to cope. Through their stories, participants created a sense of meaning, cohesion, 'fit'; their sexuality and their HIV status were aspects of their experience which were more or less comfortably woven into the fabric of their lives. This sense of meaning was created through time and participants told their stories in terms of their past; your past creates your present and is told through your present and it is only from your present position that you can anticipate your future.

For all participants their sense of identity was inextricably intertwined with their understanding of their health. In the next section, I examine the data in relation to participants' understanding of their health; how they coped with mental and physical ill-health and treatment and the particular complexities of one's health trajectory as HIV positive. Once again there were significant

differences between the urban and rural participants in terms of how they negotiated their understanding of their health state in terms of the discourse available.

## **6.4 – HEALTH**

Sickness lies at the apex between the individual and society. Disease/illness is a lived, personal experience, a language of distress/dis-ease, and a social and cultural phenomenon constructed through medicine as a political practice. When these three are in accord, the person experiences something stable, explicable, albeit unpleasant. HIV, on the other hand, is not a stable entity at any of these three levels and changes in personal experience, discourse and social framing is a constant source of uncertainty for individuals. Different cultures position illness at different points on the personal/social continuum and the changed and changing place of HIV on this continuum is something which the participants were constantly negotiating and renegotiating. In the modern Western world, many illnesses, including HIV, are manifested through medical procedure and expert interpretation rather than visible symptoms. Kagawa-Singer (1993) explored how people living with cancer defined health. Their definition of health was based on their ability to maintain a sense of self-integrity which included a sense of being productive, capable and valued, i.e. health was seen as a means to an end rather than as an end in itself. The participants in this study struggled when they experienced a contradiction in the definition of their illness in terms of medical discourse compared with their felt experience and their sense of efficacy.

### **6.41 Health status/health state**

Health status affects health state as well as health state leading to and defining changes in health status. Participants experienced any disjunction between health state and health status particularly troubling because this gave rise to difficulties in defining their situation. It was at these points of paradox and contradiction that participants had to make choices about how

they would construct meaning around their illness experience. These points of contradiction were experienced by both sets of participants but in qualitatively different ways which meant that the path that they found through them was also different.

There was sometimes a disjunction between a participant's felt health and their state of health as described by their blood results. If you feel well, it is confusing to be told that you are in fact ill and perhaps should start treatment which in all likelihood will make you feel ill. Many participants placed an enormous amount of confidence in their blood results and these in themselves appeared to have an impact on their felt health. On the other hand, sometimes participants would feel frustrated because their blood results were good but nevertheless they felt ill, either as a result of the virus itself or as a result of the treatment. This might have an impact on how ill they are regarded in the eyes of the world which could affect their access to benefits, their housing and whether or not they are expected to work. Good health and improved health were not always experienced as straightforwardly advantageous for participants; it could cause confusion – 'cognitive dissonance' - to someone who has worked hard at constructing an identity as an ill person. Deteriorating health could confirm people's worst fears although for some, even though their worst fears were confirmed, this was experienced in some measure as a relief because at least their health status and health state were aligned. Health symptoms might or might not be interpreted by participants in terms of their HIV. For example, they might interpret ill health in terms of life style factors - stress, unhealthy life style etc., or may decide that a particular illness is something to which anyone might succumb. Others may interpret any symptoms in terms of their HIV regardless of likely causation. At the time of interview, each participant located themselves on a particular health trajectory which might be experienced as stable or as changing but was always uncertain in the long term.

David says: 'I would call myself reasonably healthy. The only thing is I get tired after a few hours of doing something. It's difficult to tell if it's the HIV or simply getting older! One of the difficult things is telling, is it normal, is it not?'

Whilst these difficulties were very similar across the two areas, the rural participants expressed a greater degree of difficulty in negotiating a path through these sets of contradictions because it was a process that they largely went through alone and certainly they had far fewer opportunities to discuss their situation with people who also were having similar experiences.

#### **6.42 Being gay and HIV positive – urban and rural differences**

It is possible to engage in activities in both an urban and a rural setting which help to define oneself as gay, although many of these activities – clubbing etc. are not ‘health-enhancing’. It is also possible to engage in activities in both an urban and a rural setting which help to define oneself as HIV+ - attending the clinic, voluntary organisations, groups etc. However, my research suggests that it is only really in an urban setting that you are able to engage in activities which reinforce *both* identities. Many of the London participants talked very positively of the gym for positive men run by the YMCA and also of a gay men’s support group which would meet for support around HIV and then go for a drink at a gay pub. It appears that, at least socially, to combine the two together in a way that is comfortable, is only possible in an urban environment. There were also difficulties for the rural participants, as discussed above, with regard to being open within the gay community as HIV positive. Unlike the urban participants, those living in a rural area could not be certain to receive a favourable response which could lead to isolation and secrecy even within one’s supposed community of support. To be HIV positive within the London gay community is not to be ‘different’ but within a rural gay scene it is.

#### **6.43 Looking after your health**

For some participants this played a very minor part in their lives whereas for others it was a full-time project. Some people interpreted health care only in terms of allopathic medicine, others mixed allopathic, complementary and ‘folk’ medicine in various ways. For everyone, a balance had to be struck

between the freedom to enjoy life and the restrictions various treatment regimens might place on them. Participants placed themselves at particular points on a continuum which runs from a large amount of attention to minimal attention being given to the place of HIV in their lives. At the same time, participants were on a continuum between feeling that the attention that they gave HIV in their lives was anxious preoccupation with illness on the one hand or what they perceived as constructive and health promoting on the other. Some might pay particular attention to lifestyle - diet, sleep, exercise and drug and alcohol intake. Others took a more laissez-faire approach but for many these lifestyle choices gave them what they felt was a crucial sense of control over their health, and continued good health was often attributed as much to these choices as to anti-retroviral therapy. Control was critical; they needed to feel that they were able to do something themselves rather than simply being the passive recipients of medical interventions. Nevertheless, even those participants who had quite strict regimes of health-promoting lifestyle conceded a need for flexibility – a need occasionally to treat themselves or to forgive themselves for perceived ‘lapses’.

At the moment Paul is treatment naive but during the various summer Prides he finds that his viral load goes up: ‘I do like going to all of them...and take whatever is needed to carry on till the next morning. A string of hectic weekends, but ones which do have an impact on the body, anybody's really, weekend after weekend...at the moment I'm doing what I reasonably can to push treatments back a bit. Physically I'm in a very strong position and I'd like to keep it that way, but I don't want to lead the life of a monk or a hermit!’

On the one hand, urban participants readily tap into a culture of gay HIV positive men who take very positive steps to look after their health. For example, several mentioned a gym for HIV positive men which they described as playing a vital role in helping them to exercise safely and effectively, to rebuild strength, stamina, confidence and pride in their own bodies, as well as providing a social outlet and opportunity for peer support. On the other hand, the club scene is a culture of excess, of disturbed sleep patterns and high drug and alcohol intake. From their accounts, it seems that rural participants are perhaps less likely to go clubbing on a daily basis and some argued that the generally slower pace of life is better for health. On the other hand, they

are less able to meet and mix with other gay HIV positive men who are making positive health choices. Urban participants were able to create a community of positively gay, positively HIV+ men, which could operate within both a healthist and a gay environment.

#### **6.44 Drug side effects**

Many of the participants experienced the side effects of anti-retroviral therapy as just as or even more disabling than the virus. They had to deal with chronic nausea and vomiting, diarrhoea, anxiety and paranoia, lethargy and fatigue - all side effects of medication that is intended to improve health. Many participants felt it is highly counter-intuitive to take medication which is intended to improve health but which in fact is very definitely experienced as toxic. They dealt with this in different ways. Some stopped altogether or did not adhere strictly to the regime; some asked to change medication with the attendant risk of running out of treatment options and some accepted the chronicity of the side effects as something that was the price they had to pay for survival. If that was their approach, it was vital for them to believe in the ultimate efficacy of the medication and a lot of importance was placed on the blood results which had to be taken as a more reliable indicator than experienced health. Sometimes it was impossible to know if the symptoms were the virus, side effects of the treatment or something else altogether. Some participants had sustained permanent damage as a result of treatment, e.g. muscle wastage, diabetes, and some of the men had known others who had died as a direct result of the toxic effects of the treatment.

Urban and rural participants seemed to be equally informed about treatment options and choices made about treatment did not seem to be affected by location. Certainly urban participants' belief that they would not be able to access treatment out of London did not seem to be borne out by the stories from the men in Yorkshire, although to access clinical trials from a rural environment would entail a substantial commitment in terms of travel. Although urban and rural participants had similar levels of information, urban participants had greater access to peer support and 'informal' information

about living with side effects. It is standard for doctors to advise someone to start treatment when their illness reaches a certain stage and doctors in both urban and rural areas were described by participants as reluctant to stop or alter medication if it was proving successful in medical terms. Several participants were reluctant to go against their doctor's advice and struggled to find a position from which they could criticise the doctor. In urban areas participants could talk to other positive men who in turn knew others and could in this way tap into another discourse about the side effects of medication; in rural areas, participants had to rely on written information to validate and give a language to their own experience. Once again it appears that the urban participants had easier access to a diversity of possible ways of positioning themselves in relation to medication whereas the rural participants were largely isolated apart from the relationship with their doctor which provided them with one way of regarding both their health and treatment options.

Joe describes his 'protease experience': 'I was feeling really awful all the time, throwing up, on the toilet all the time, becoming slimmer and slimmer, but in terms of my bloods I was excellent because my viral load was down here...but I felt absolutely lousy...Joe persevered for 18 months; at the time the only options were to try another protease inhibitor which might well have had the same effect, or to halt treatment 'which I haven't ever really thought of as an option, I think once I had started...I was assuming that I would stay on it'.

There is an issue here which was common to several of the participants about identity and medication. It can be difficult to start medication as that implies assuming an identity as a sick person – as symptomatic – but on the other hand, once the drugs are integrated into the person's life and are regarded as preventing ill health, it can be difficult to stop or change the regimen.

'I saw HIV as a problem which was actually being held in an OK state because of the drugs, so even though I was having dreadful problems on the drugs, I was feeling, at least I'm not having horrible infections and hospitalisations and things like that all the time, which, when I first found out that my CD4 count was in the hundreds, I was expecting that all these awful things would happen, and so I felt happier on the drugs, even though they had a horrible impact, rather than being off the drugs and perhaps having other things happen...having opportunistic infections has always seemed to be the highest in a hierarchy of horror.'



Different illness meanings carry a different significance; to be ill because of the medication is different from and may therefore be experienced differently from being ill as a result of the virus.

#### **6.45 'Listening to your body'**

There is a body of anthropological literature which attempts to articulate the idea of being aware of one's dis-eased body (e.g. van Manen, 1997, 1998, Leder, 1990). We are not usually aware of our bodies in the world except as a kind of 'unaware awareness' but when we are sick, we are far more conscious of our bodies and this in turn affects how we relate to the world around us. When we are in pain, we become aware of our bodies but also experience ourselves as separate from our bodies: 'At the moment when our wellness is disturbed, then we discover, as it were, our own body...the body reflects on itself as body' (Van Manen, 1998, p12). Several participants talked about how they had learnt to 'listen' more carefully to their body and now they were more able intuitively to know what was 'right' or 'not right' for them. This was an effective way of dealing with the conflicting messages that they might be receiving about treatment and lifestyle choices.

For the first six months after he was diagnosed Jon got very tired, but he thinks that was because he was processing his diagnosis and that was another thing he had to do on top of his normal life. He now takes care of himself; he still drinks and smokes but 'if I feel tired I'll go to bed, if I feel hungry, I'll eat, if I don't, I won't...I listen to my body a bit more. My body knows what's right, so if it's sending me a signal, I'll obey it.'

Kleinman's (1988) explanatory model of illness demonstrates how people attempt to create order and meaning in sickness situations, the effort to normalise and legitimise the sickness process is an attempt to avert chaos, although the means by which it is done may differ and the boundaries of what are deemed to be normal are fluid. So, rather than be faced with a situation that is not normal, we will alter our parameters of meaning. HIV represents a problem of meaning, both for the participants and the society of which they

are a part. Kleinman's model attempts to encapsulate illness as an embodied experience which the individual can formulate into a narrative which can be shared with others and which can give coherency to the illness experience. Although participants' explanatory models drew on social discourses, they were experienced as personal and unique. An attempt to articulate embodiment was crucial to participants' understandings of themselves and the world. They all drew on various available discourses in order to create an explanatory model of their illness, but the urban participants had easier access to a variety of discourses than those in a rural setting. Participants had to reach some sort of understanding of their condition given what they experienced as a day-to-day physical reality and what they were told by their doctors. This involved a complex interweaving of different discourses for the person to reach their own understanding of their physical state.

Swale was expected to die quite some time ago. He has experienced numerous health difficulties as a result of HIV, not the least of which was stomach cancer which was expected to be terminal and he was admitted to a hospice. He ceased taking any medication because there didn't seem to be any point but he has actually continued to live in the face of all medical prognoses and says he will just carry on for as long as he can. He says the only way in which he feels himself to be affected is that he is no longer able to play football.

#### **6.46 Poor health**

Both sets of participants expressed far more concern about symptoms that were visible; lypodystrophy for example could have a significant effect on a person's self-confidence, self-worth and identity, and of course visible symptoms carry the attendant risk of your very body Out-ing you. Participants also became very frustrated by the fact that they were tired a lot of the time because it led them to make lifestyle choices which again impacted negatively on their self-image; they were less able to socialise, to work, to go clubbing - activities which bolster one's identity, confidence and sense of being in the world.

The majority of the participants at some point experienced some impact of the virus on their mental health, sometimes heightened anxiety, often depression.

The uncertainty of the condition, its chronicity and its stigmatising nature were all factors which might affect mental health. Some also experienced survival depression after the accumulated loss of friends and loved ones. Mental health is jeopardised at times when the individual's felt and lived experience is at odds with the discourses available to him to frame that experience.

In terms of his mental health, Gareth says 'I think I've always suffered from depression on and off all my life, I think...it's always going to be there and it's something I've learnt to live with'. He feels going back to work is one thing which will help to keep the depression at bay. The depression coincided with the HIV and the HIV certainly fed the depression.

Throughout 1996 Paul found that the cumulative grief of multiple bereavements was sitting very uneasily with his ongoing physical relatively good health: 'I couldn't bring these two together in a way that felt easy and right in the slightest, ...Something which had been developing really came to the surface, a developing sense of profound depression...swirling chaos'

#### **6.47 Health/Work/Benefits**

Almost all the participants experienced some difficulty in the relationship between their health and being in work or being on benefit. If you are feeling reasonably healthy, or even if you do not but your blood results are good and you are not suffering from opportunistic infections, then your access to benefits may be questioned and you may be expected to go back to work. Going back to work, or staying in work can reinforce an identity as 'normal' and as an effective, contributing member of society, but if other areas of one's life are creating an identity of sickness, it is very difficult to maintain oneself in employment. Thus, when health state and health status were at odds, there was an uncertainty about social status as well. This created an enormous amount of stress and anxiety. Most of the participants still experienced lethargy, fatigue, digestive difficulties etc. which make a working day problematic. There are often difficulties around being Out at work but on the other hand being forced back into a closet has an emotional cost. Participants who had been on a full rate of benefit were unlikely to find employment which left them financially better off and anyway it is harder to find a job when there

is an inexplicable large gap on one's employment record. This can also have a devastating impact on someone's sense of identity. If you have been used to seeing yourself as sick, or at least as a non-working person, it takes a significant shift in identity to believe that once again, or even for the first time, you can be part of the workforce. Another difficulty for participants who were HIV+ and not in employment was accessing benefit. The benefits system tends to judge people on the basis of physical, tangible, permanent symptoms; so many of the symptoms of HIV; lethargy, mental distress and sporadic symptoms, do not carry as much weight in benefit assessments, or at least they are harder to prove.

Talcott Parsons (1951 in Gerhardt, 1989) described society in terms of its structures and institutions and individuals in terms of the functions they fulfilled within society. According to this model sickness is perceived as fulfilling a particular role within the social world. Parsons' theories are significant in that they describe a particular role which may be adopted by the sick person and how the sickness can become an integral part of their personal and social identity. This seemed to be the case for several participants and yet their 'fit' in the sick role was always in doubt and their position precarious. The concept of the sick role helps us to see how sickness and health are defined in society and how this definition affects and is affected by how we evaluate things as desirable, important and appropriate (Turner, 1987, p215). The idea that someone is only valued for their contribution to the labour market is a lived political reality for anyone dependent on the welfare state. Participants may have dealt with their 'deviant' role by distancing themselves altogether from the ideals of the labour market, but in a world of improved health and uncertain benefits, they may find themselves having once again to embrace those principles.

Anxiety about the relationship between health, work and benefits was expressed by participants in both areas, but the rural participants expressed more anxiety about the possibility of homophobia and anti-HIV prejudice in terms of accessing employment, and they were also less likely to disclose either their sexuality or HIV status within a work environment. This created

practical difficulties for the rural participants who were in work as none of the clinics in the areas of Yorkshire covered by the research had weekend or evening clinics, making regular days off work a necessity to access medical care.

#### **6.4 – Health. Conclusion**

Both sets of participants negotiated a more or less uneasy relationship between their health status and health state and paradox and contradiction were more or less comfortably incorporated within someone's understanding of their health. There was often a sense of cognitive dissonance with regard to health and different participants adopted different strategies to manage that dissonance – e.g. feeling well but being told you are ill and feeling ill but told you are well. Certainly all participants experienced at least some level of uncertainty – an uncertain state of health in the present and uncertainty regarding future prognosis. In order to cope with this uncertainty and cognitive dissonance, participants more or less successfully constructed unique Explanatory Models to frame their physical selves and interpret their physical experiences. This process was different across the two areas; urban participants had a wider variety of discourses readily available to them with which they could frame their experience whereas the rural participants had fewer alternatives to the discourse provided by the clinic.

In both areas health was experienced at least in some ways as a lifestyle choice and participants had to make decisions about how and to what degree to look after their health. This was in some ways easier in an urban area where there is a culture of the gay community adopting a health promoting philosophy, but on the other hand that same community also promotes a culture of excess which can debilitate health.

Anti-retroviral therapy had an uneasy position in many participant's lives, particularly if it served as reminder of HIV and if the side effects were experienced as disabling. Significantly, there was no difference across the two sets of participants in terms of access to medical treatment and information.

Participants had to negotiate their health in terms of their role in society; to what extent they would or had to adopt a 'sick role' in terms of benefits, employment etc. This was an anxiety across both areas but anxieties about employment were greater amongst the rural participants because of fears regarding homophobia and anti-HIV prejudice as well as a relative scarcity of available jobs.

Accessing medical services was an important aspect for the participants of understanding their health and although the actual treatment was the same across both areas, the surrounding context of accessing the service was significantly different. There were also very marked differences in terms of attitudes toward and availability of other services between urban and rural areas. In both cases attitudes towards services, expectations of services and actual service delivery were closely inter-related. In the next section I will explore the data in terms of the participants' relationship with professionals, treatment and services.

## **6.5 – RELATIONSHIP WITH PROFESSIONALS, TREATMENT AND SERVICES**

HIV is located at the cutting edge of contemporary medical advances but, in spite of this, it is a field in which medical discourse co-exists with a proliferation of alternative discourses. One of the dilemmas facing people living with the virus is how to cope with the pressure to construct their HIV status in medical terms and to accept medical treatment, given the proliferation of other treatments and discourses available. My data indicates that, however an individual positions themselves in terms of a medical model of the virus, this model will have a significant impact on their understanding of what it means to be HIV positive. This changing dynamic has been the case for many gay men who are part of vocal urban gay communities but many gay men from rural areas have not been in a position from which they can

question the doctor. It is harder to question a social hierarchy and a hierarchy of expertise from a community in which these norms are not being challenged.

### **6.51 Allopathic medicine**

Almost all the participants had little or no relationship with their GP. The GP might not even know their status. There was a widespread belief that, because the GP would not be knowledgeable about or experienced in HIV it was better to go straight to the clinic, even for seemingly unrelated complaints and usually the clinics were happy to support this (see also Petchey et al., 2000). There was also a strong anxiety from the rural participants about the degree to which confidentiality may be compromised if they accessed the GP; the likelihood of meeting someone in the waiting room and the degree to which reception staff had access to confidential records were among the anxieties expressed by some of the men.

Participants had varying relationships with their consultants and different histories with different consultants. Comparison across the data suggests interesting differences in patient expectation. In London there was an expectation that the consultant would be good, so when they were, this was not regarded as particularly remarkable. Participants in rural communities seemed to have more of a struggle to find a consultant whom they could trust and with whom they could build a rapport. This might mean changing clinics and travelling a significant distance out of area. Once a suitable consultant was found, he/she was very greatly appreciated and the relationship was not in any way taken for granted. Participants wanted similar things from their consultants; they wanted to be heard, they wanted to be appreciated holistically and they wanted to feel that they had some choice and jurisdiction over their treatment.

Shaun doesn't go to his local HIV clinic because the consultant there is 'a typical doctor who's right...a real pill pusher who puts the fear of God into people...not giving personal choice in my opinion.' ..he said to himself, 'Use your instinct; who's good for you' and transferred his

treatment to a larger treatment centre in South Yorkshire which is a 45 minute journey from his home.

Joe almost always sees the same doctor and finds him very approachable. He will think about what Joe says and will take his point of view into account. When Joe was feeling so terrible, he did become a bit frustrated that the doctor wasn't more proactive but in hindsight he was trying as hard as he could; 'there are times when people are in a situation where all the alternatives feel awful and it's hard to choose'. He says that he could have got angry and kept changing hospital, but that wouldn't have achieved anything and, because he has always kept himself informed, he has always been sure that the health care he has received has been of good quality.

Robert has suffered some debilitating side effects which he feels the doctors don't take seriously: 'they're middle class, upper class with high salaries; they live in a totally different world to my world'. Robert feels that Anti-retroviral therapy is being promoted as the answer and gives people a false sense of security

There was a perceived difference between consultants in higher and lower prevalence areas. Consultants in lower prevalence areas were regarded as lacking in skill and knowledge and were also experienced as being far more draconian and authoritarian in their approach. Participants believed that this could directly affect their prognosis. On the other hand, consultants in higher prevalence areas and particularly in London were perceived as experts in their field. They also were experienced as accommodating to people's own preferences and needs and there was an attitude of the patient as an expert in their own condition. There was a sense of more honesty in the relationship - it tended to be the London doctors who would tell people that they simply did not know. The urban participants were critical of doctors outside London although in fact there was no difference in medical treatment. There was, however, a difference in approach. Some, although clearly not all, consultants in the rural area had a far more traditional approach to the doctor/patient relationship in terms of where the power was located.

A key difference between the urban and rural participants was the degree of choice they were able to exercise over which clinic they attended. Although rural participants had less choice, their choice of clinic seemed so important



that they would exercise what choice they had, travelling to clinics outside their area and even travelling to London, either regularly or at key points in their HIV trajectory.

James still travels to his original clinic for treatment which involves leaving home at 7.15 for an 11.00 appointment. He decided to stay with his original clinic 'because they know me and I can call on them at any time'. He also had a bad experience in a local hospital. It is, however, inconvenient for him to travel so far to the clinic as he has to take day's holiday from work.

All the participants were clear that their relationship with their doctor was extremely important. They needed to respect his or her opinion, they needed to be able to be heard and to be treated holistically. HIV doctors in London have been left with no choice by a politically activist and informed gay community but to enter into a process of negotiation with their patients and to dissolve the mystique of expertise that traditionally surrounds medicine. Doctors in rural areas may also welcome this approach with their patients but HIV consultants who have a far more traditional approach are able to continue to practice in a rural area whereas they would not be able to continue with that perspective in London. It may also be significant that doctors treating HIV patients in low prevalence areas will not only work in HIV; their background will be a related field such as GU medicine, haematology or even general medicine.

It was easier for urban participants to criticise services and did this by tapping into the collective political voice of the HIV community. Rural participants might individually be no less vocal and no less effective but they were lone voices 'in the wilderness' and their struggle with substandard services was correspondingly harder. Also it is more difficult to criticise services when you have nothing against which to compare it; urban participants could talk to people who accessed other clinics and organisations but it was often hard for rural participants to make such comparisons. In rural areas, voicing criticism carries a higher risk; in a context of few services you cannot afford to burn all your boats so the temptation to put up with something which you suspect is substandard is correspondingly higher.

Paul feels he has a reputation of being 'the tolerated angry person because there's more or less only one of me that's looking over the parapet and seeing the picture...An irritant, or a Tony Benn position of someone who's allowed to be radically different, knowing that the rest of us are so secure that we don't have to take any of what he's got to say on board.'

Each of the participants had some position in relation to anti-retroviral therapy – it is impossible to live with HIV in this society and remain unaffected by allopathic medicine. There was a range of responses to anti-retroviral therapy: some participants were settled on a particular regime of drugs with minimal side effects and inconvenience; some had a more problematic relationship with their drugs. This might be because they felt unhappy about taking them in the first place either because of their toxicity and uncertainties around long-term usage or because taking them reminded them that they were HIV positive. Some were severely affected by the side effects of their medication which can have a very detrimental effect on both physical and mental health. Adherence was an issue for some and participants tended to create their own personal position in relation to adherence which was seldom 100%. Some participants were not on anti-retroviral therapy, either because their blood results did not indicate that they required it, because they decided they did not want to go down that road or because it was no longer effective for them.

Robert has a long standing love-hate relationship with anti-retroviral therapy, partly because of his suspicion of its efficacy and partly because of the difficulties of facing a renewed future which Robert had adjusted to losing. He has also suffered some debilitating side effects which he feels the doctors do not take seriously. Robert feels that anti-retroviral therapy is being promoted as the answer and gives people a false sense of security.

James takes the medication most days but when it suits him rather than sticking to a rigid regime because he does not want to let the tablets rule his life. For example, the previous weekend James had gone to Manchester. He did not plan to stay the night but he ended up staying over and missing his medication so he took one dose 6.00 on Sunday night and again when he went to bed, 'It's the only thing in an average day which makes you think about your HIV status'

Anti-retroviral therapy was available to everyone regardless of where they lived but there was a perception held by many of the London participants that they would not be able to access the choice of drugs outside London and particularly drugs which were only available on a trial basis. Several of the London participants said that their reason for living in and staying in the capital was access to the cutting edge of medical expertise and access to the latest developments in drug technology. It is interesting that the rural participants did not feel that they were prevented from accessing the medication they required. There is a perception in London that services and facilities outside the capital are limited and substandard but in fact in terms of what is concretely available there seemed to be little or no difference. There is a difference in culture, attitude and ethos as well as a difference in choice but in terms of actual availability of medical treatment it seems that the different services are equitable, certainly in terms of anti-retroviral therapy.

On the other hand, several of the London participants were taking viagra for sexual dysfunction but none of the rural participants mentioned this. This might be because they did not want to discuss sexual dysfunction, either with me, or maybe with their doctor. It might be that viagra is available and not being requested or it may be that it is a problem which is more recognised and talked about on the sexually energised London scene.

Several of the participants had adopted a medical discourse almost exclusively as a way of constructing HIV and understood their condition largely in terms of their blood results and treatment options. This medicalised language can give someone a sense of belonging and connectedness – to others who would also understand and use the terminology of CD4 counts, viral loads etc. – and in itself created a secure community of discourse. This language, however, is largely an urban phenomenon; many of the rural participants could only talk in this way in the clinic.

### **6.52 Talking therapies**

Some participants were very scathing or critical about the role of talking therapies, particularly the role and calibre of pre- and post-test counsellors. Other participants had found talking therapy one of the most or even the most helpful support since their diagnosis.

After their diagnosis, John and Gordon were sent to see a psychologist and Gordon describes the resulting change in their perspective as 'amazing': 'We went in to see him thinking that we were going to die, we came out thinking what are we going to do with our lives...John did his accountancy qualifications, I got on with a life in theatre...we got on with our lives rather than feeling sorry for ourselves and that's actually stayed with me.'

Whilst there was no difference in the perceived calibre of talking therapies across the two areas, participants in rural areas tended to form closer relationships with a counsellor, psychologist or therapist. In the absence of a close community of like-minded friends or a strong network of other HIV positive gay men, it might be that these participants were in greater need to talk to a professional in a context of respect, honesty and positive regard. Talking therapies were available in both areas but there was a greater choice and ease of access in London as opposed to Yorkshire.

### **6.53 Complementary medicine**

Again, the response regarding complementary medicine was mixed. Some participants dismissed any claims for its efficacy, others found massage, aromatherapy etc. helpful but not central to their treatment. Others regarded it as the focal point of their treatment, with allopathic medicine playing a secondary role. Participants from both areas seemed to be able to access practitioners and funding but there was an increasing belief held by participants in both areas that funding for such therapies will not be so easily forthcoming in any area in the future.

'Perhaps I'm being unkind, but I think it's more about people wanting to do something, I don't think there's any real connection. It's very nice but it's not really doing anything for me.'  
(David)

Shaun is happy to go to the doctor for a diagnosis but likes to use alternative treatments, particularly acupuncture. Shaun understands acupuncture and totally believes in its beneficial effects, that it releases energy to flow through the body.

### **6.54 Voluntary and other organisations**

Partly because of the reframing of HIV as a chronic, manageable condition, AIDS Service organisations have undergone some radical changes in the last few years. Organisations formed reactively during the 1980's, growing quickly as the need demanded and fuelled by the energy and commitment of an often unpaid few. AIDS was a crisis of unknown proportions and there was much to be done. Now people argue that AIDS is no longer a crisis in this country, and even if it still is, it is certainly a changed and changing one. Although there are still the dying and bereaved, many people want/need to get back to work, to reclaim their lives, to work out their relationship with treatment and so on.

The extent to which organisations reacted (or not) to this changing picture (which also in some respects and for some people has remained the same) has influenced the funding decisions which have been made. Organisations have closed and there have been a number of mergers which, at least to some extent, have been financially driven. The urban and rural pictures are different in this respect. There was not the rapid proliferation of services in low prevalence areas as there was in London. Even with the eclipse of distance made possible by increased travel, the internet etc., life moves at a slower pace in a rural area and this includes changes in people's experiences and changing cultures. In recent years The Terrence Higgins Trust has opened regional branches in areas outside London. The arguments for such a move are persuasive; standards of excellence can be set up and maintained at less cost and there will be less needless duplication. There are, however, risks attached to such an enterprise in terms of potentially homogenising services

across areas of difference where the experiences of the service users are qualitatively different.

There was a distinct difference between the role and perceived efficacy of voluntary organisations across the different areas. In London, on the whole, voluntary organisations are regarded as political, vocal, energised and professional. People with HIV are involved throughout all aspects of the work. There were inevitable criticisms of various organisations, but in the same way as the participants could often find some sort of niche for themselves within the gay community, they had a choice of places to access and on the whole most participants could find some place which fulfilled their needs as they experienced them. One of the most valued aspects of all the voluntary organisations was the peer support accessed through a positive gay men's group but people also valued 1:1 support from professionals. Some participants experienced the changes in the field very unsettling but others felt that these were necessary and appropriate given the changing nature of our response to the virus.

Michael feels that there are too many HIV services in London and it is appropriate that some of them should close. He feels that the expectation some people have that HIV positive people should receive free services such as complementary therapies etc. is no longer appropriate: 'There's a lack of sympathy that will happen in the end because people will say well you should be doing a little more for yourself.'

It was at a particularly low point that Michael decided to join a positive Gay Men's Group 'and that was really quite a life saver. I was really very low. Michael has found the group enormously beneficial; he appreciates being able to talk with people who have been through the same experiences and are dealing with the same difficulties. He regrets not having joined such a group earlier and feels that such services are inadequately promoted and supported.

Participants were not uncritical of London support services. Some people felt that voluntary organisations tended to be unprofessional and chaotic, others felt that they encouraged a victim mentality and allowed people to define themselves only in terms of their HIV.

Gordon, who describes himself as an 'old hack' is scathing about some of the London-based organisations, one of which he describes as 'full of people who'd been diagnosed five minutes being completely pathetic and feeling sorry for themselves; he himself finds more support through friends rather than structured groups.

David says: 'everybody sat around like they were in a library...I really don't want to be like this!...they were sitting like they were waiting for a knock on the door...places are just too quiet, there's no life in them...relatively minor problems get escalated, it encourages people to be worse to get the most out of the system.'

This was an almost universal criticism of the voluntary organisations in rural areas. The participants' perception was that the prevailing culture is passive and that service users regard themselves as victims. Some participants blamed the employees of the agencies for this and others felt that the users of the service were responsible for the general ethos and the employees were doing well against difficult odds. A significant number of the rural participants did not feel that they were getting the support they required from their local voluntary organisation.

'if you gave me that magic wand that solves everything I would...close all the organisations and reorganise them according to...the areas in which they do well and areas in which they do badly...On paper you would have a smaller service provision, but it would be targeted and aware and responsive.' (Paul)

In both London and in rural areas, one of the purposes of voluntary organisations for participants was simply to meet other people with HIV and to socialise with them. This was far more successful in urban than in rural areas.

Most people were in agreement that HIV positive people should be more involved in the running of voluntary organisations, both as volunteers and as paid employees. Several of the participants had used volunteering as an alternative to paid work and on the whole had found it a positive experience. On the other hand, both in London and in rural areas, voluntary organisations are characterised by internal politics and funding problems which could at times affect the work that they did. Participants in their roles as volunteers, service users or paid employees were aware of internal dissent and on the

whole were frustrated by the way internal political divisions could at times block the work.

Peter has been a volunteer and involved with London HIV services for 16 years. He feels that there have been difficult times but he has avoided becoming too embroiled with the politics within the organisation. He has worked on a help-line, 'and whatever is going on around, I know that my reason for being there is for the caller at the end of the line'.

There have been so many changes in HIV services that Peter has come to realise that change is the only constant. He feels also that people are very keen to come along, reinvent the wheel and then leave again in three months time. He also feels cynical about the fact that people have made a great deal of money from HIV.

In urban areas, some of the stated functions of gay men's organisations are service delivery, activism and providing individuals with the opportunity to voice opinions and feelings in a collectively affirming and politically efficacious environment. In rural areas, the data suggests that it is far more difficult for voluntary organisations to fulfil these functions. There seemed to be a difference in culture across the two areas; urban services involved positive people as employees, volunteers and on a consultative level. The participants' perception of rural services on the other hand was a culture of 'them and us'; a clear distinction between staff and clients which created a culture of 'doing for' services which could be experienced as patronising and disempowering. At the same time, fewer of the rural participants expressed a sense of wanting to get involved in the running of their local voluntary organisation and certainly a participant who had gained paid work in his local service had not found it a straightforward process. In an urban area where there is a choice of services it may feel easier to be involved as a service user as there is always the possibility of moving to another service in a purely 'client' role. Managing a multiplicity of roles in a context of small numbers and few services may feel too risky or too complex. Again it seemed to be an issue of keeping different parts of one's life separate. In London you can be a gay positive man volunteering or working for an AIDS Service Organisation and have a friendship group of gay positive men distinct from one's work colleagues, and again access another organisation in a purely client role. In a rural area,



because of the size of the gay scene, those worlds would be inextricably linked. To work as a gay positive man in an AIDS service organisation is to merge one's work, friendship and sexual worlds as well as any context within which one can seek support.

Those people who attended the London YMCA gym for positive people universally said it was an extremely beneficial service. The gym was able to provide a forum where participants could regain physical confidence, train their bodies in a way that was appropriate for them, meet other gay men in a safe environment, and it provided a structure for many people's week.

Gordon goes regularly to a gym for men with HIV which is 'brilliant, truly wonderful'. It is a social occasion and it has enabled him to become a lot stronger, repairing some of the muscle damage in his legs caused by AZT'. It is affordable and while 'not officially a gay space, it...seems like it is sometimes.'

### **6.55 Participation and politicisation**

In London it is easy to participate and it is easy to make sexuality and HIV status a political issue; there are forums to focus one's energy and others with whom one can stand collectively. In a rural environment, those opportunities may be there but they are far more scattered, the risks are higher and you are more alone. For example, if you choose to work in the HIV field in a rural area, you will be working closely with the people from whom you would also be receiving services. If you are active in the field, your status is likely to become public, if you participate in your local voluntary organisation, you may be the only HIV positive person, you may be the only gay man, who chooses to become involved in that way. It does not seem as if any blame should necessarily be placed on other users, nor on the employees of the various agencies; the difference in culture is a natural result of lower prevalence and the greater distances involved.

'The days of your cottage charities are over...the way is not complain...it is to get in and get involved and make them see the worth of more customer focused services...that is the way forward and that is the way I intend to play it.' (Nick)

### **6.56 Benefits**

Many of the participants had some anxieties in relation to money and benefits, largely a result of the changing status of HIV in terms of accessing employment and sickness benefits. If someone was diagnosed in the 1980s or early 1990s, HIV was classified as a terminal illness, you were given a six month prognosis and could immediately access the highest levels of Disability Living Allowance with all the associated benefits. Whether or not they were ill at the time, people were encouraged to give up work, get their house in order and enjoy the time they had left as best they could. HIV is now categorised and experienced by many as a chronic but manageable condition. Some people who gave up work years ago feel cheated of all the benefits (not just financial) that employment brings and those who are still on benefits are afraid that they will be taken away from them. People are put in the invidious position of needing to be more ill than they actually are in order to stay on benefits but on the other hand needing to be more healthy than they actually are in order to access and stay in employment. The uncertainty around how long benefits will remain available to people with HIV caused an enormous amount of anxiety for many participants. Rural participants might find it harder to get back into work, particularly after a lengthy period of not working, than in London where part-time work and casual work is more readily available. Rural participants were also more anxious about lack of understanding and discrimination from employers.

### **6.57 Information**

Participants used different resources to obtain information - other HIV positive gay men, The National AIDS Manual, the Internet, the clinic, voluntary organisations etc. Rural participants relied more on written and online information than information from peers. These different sources of information will cover factually similar topics but in qualitatively different ways. Rural participants were able to access factual, medical information but lacked

the informal 'folk' information that one can gather from people in the same situation as oneself.

## **6.5 – Relationship with professionals, treatment and services. Conclusion**

The medical discourse of HIV is a discourse of power but is increasingly one among a pluralisation of potential discourses which can be used to frame the experience of being HIV positive. The data indicated that doctors and clinic staff had more perceived power to define a patient's condition in rural areas, as opposed to urban areas. As a result, patients had less perceived choice and control over their treatment in rural areas although access to Anti-retroviral therapy was the same, despite the perception by London participants that patients in rural areas would not have equal access to medication. It was a struggle for any participant, regardless of locale, to define themselves against a medical discourse in relation to anti-retroviral therapy. In addition, medical discourses have defining power in terms of accessing other systems – housing, benefits etc. which can prove particularly problematic for those participants whose experience does not comfortably fit that frame.

HIV organisations have a particular set of politics, culture and history of development and current service provision in all areas needs to be considered in the light of that context. HIV can be framed as a political statement, but not all participants wished to adopt an activist discourse and services need to consider what service users actually want from a service. Peer support, both formalised and informal was beneficial to many participants. This is easier to set up and to access in urban areas simply because of the larger number of people accessing the service and ease of access. On the other hand, organisations in rural areas are drawing on a smaller group of people who are geographically more distant, and for whom confidentiality may be an issue which may inhibit access and disclosure.

In recent years there has been an increasingly dynamic relationship between organisations and service users, which is very important to bear in mind when

considering how to change and improve services. Services, whether or not they involve their users, may or may not reflect the expectations of those users and, conversely, users' expectations may or may not be framed by the services which are available. If there is a victim mentality, a culture of 'them and us' and of 'doing for' in rural areas, I suggest that this has been created in the dynamic relationship between the providers and users of that service *and* the spatial context of that service, and if changes are to be considered, they need to be considered in each of these three areas using a systems perspective. In the following section I draw together the four themes of community and space, relationships, identity and health again to look specifically at what services may be required across urban and rural areas; aspects of continuity across the two and aspects of difference.

## **6.6 DATA ANALYSIS – CHAPTER CONCLUSION**

I began this chapter by exploring the data in relation to community and space to argue that the way in which gay space and gay community are constructed in urban and rural spaces had a significant effect on the ways in which participants constructed themselves both as gay and as HIV positive. I then analysed the data in relation to participants' relationships with sexual partners, friends and family, illustrating that the spectrum of relationship needs are differently constructed across urban and rural spaces. The next theme, which was both pre-set and emerged throughout the data was identity and I drew on the two preceding sections to demonstrate how differences in space, community and relationship give rise to differences in the participants' shifting understandings of themselves, both as gay and as HIV positive. Central to participants' identity was their self-understanding in relation to health and in the fourth section of this chapter I suggest that there are differences across the two groups of participants in terms of how they constructed meaning from their diagnosis. Finally I drew on each of these four preceding themes to explore how the participants across the two areas accessed medical and support services and what were their experiences of those services.

A number of key themes emerge from this analysis which I summarise here and discuss in more detail in the following chapter.

### **6.61 Community and space**

The data demonstrates that, in order to create an identity for oneself as gay, an individual needs to create some contact with other men who also identify as gay. These connections occurred in particular urban spaces; all the rural participants had spent some time in an urban space and within at least some kind of community of gay men. Rural participants reached their own understandings of terms such as 'gay' and 'HIV+' in terms of their own lives but this also took place within the general context of a more traditional community which is regarded as suspicious of difference in any form. For some rural participants this was a frustrating, difficult and isolating process; others did not experience it as problematic.

Identity is experienced as both personal and social but, significantly in both an urban and a rural area the gay scene is constituted in a particular space and by people who, although within it, regard themselves as outside it. Identity formation is a process of defining oneself 'in relation to' as well as 'within'. In both contexts, there is a general understanding that, although a useful form of short-hand, and although they describe something real, the terms 'gay' and 'community' are terms around which one can position oneself but are invisible at their centre.

HIV is now more integrated – part of the urban gay scene – and that scene is largely a supportive space in relation to HIV. This contrasts with the rural scene where HIV is not integrated and positive men do not always experience this scene as a supportive space. Differences in prevalence lead to differences in self-understanding and identity as an HIV positive man as well as differences in behaviour around disclosure.

There are urban and rural differences regarding the relationship between gay space and heterosexual space. In a rural context, gay spaces are either more

integrated into straight spaces, or they are 'hidden' from the heterosexual eye. This contrasts to urban gay spaces which are identified as gay and yet also known to and accessed by the straight community. Participants established and maintained a gay identity differently in an urban and rural area partly because of the different ways gay space is constituted in the different areas. Rural gay men may experience exclusion from straight culture *and* from a gay community perceived as distant and inaccessible whereas it is more likely for an urban gay man to be able to inhabit both worlds and move between the two. Public sex environments in a rural space provide the same anonymity as an urban bar culture but rural participants were far more anxious about the possible consequences about being open both about their HIV status and their sexuality in all areas of their lives.

Gay HIV positive men tread a balance between differentiation and merging, separateness and community according to their perceived available choices and changing needs. This process of identity formation is very closely related to the spaces they inhabit.

### **6.62 - Relationships**

Different participants had different understandings and experiences of family and friendship networks and these were lived out differently across urban and rural space. Participants found themselves having to negotiate different ways of framing their relationships or conforming to a heteronormative blueprint. Intimate relationships in a rural space seemed to correspond more closely to that blueprint than their urban counterparts. HIV played a significant role in negotiating sexual and emotional intimacy and this was perceived as more problematic for the rural participants. Rural participants were less likely to disclose either their HIV status or their sexuality and would make strategic decisions based on their judgement about someone's potential reaction.

Participants re-evaluated friendships and relationships in the context of a changed and changing identity. The need for one's relationships to shore up one's identity of choice was harder for rural participants who did not

necessarily have a friendship group of people who were perceived to be similar. There was also an urban and rural difference in the experience of bereavement and loss. Whilst rural participants may not have had to cope with multiple losses, there was a stronger sense of isolation and alienation from the rest of the community. Rural participants were more likely than urban participants to have more contact with their families and rely on them more for emotional and practical support.

### **6.63 - Identity**

The data suggests that testing and diagnosis may not necessarily constitute a Fateful Moment, particularly for urban gay men for whom HIV is already a significant part of one's life and identity. There will, however, be significant points along an HIV trajectory which constitute a Fateful Moment: for example, Coming Out, death of loved ones, starting treatment, illness, relationship break-up and contact with people who become formative in one's life.

Gay politicisation is principally experienced as an urban phenomenon and rural participants tended not to develop and maintain a politicised identity outside a politically active community. Some experienced this as frustrating, others did not find it problematic.

All the participants described the need to develop strategies of coping with uncertainty. Participants who had been diagnosed for some years may have experienced difficulty in integrating the changed and changing story of HIV; once a terminal illness and social crisis, they now were faced with adapting to an identity which involves living with a chronic, manageable (but still incurable) condition and social problem. The discourse of 'Living Well' with HIV was more widely evident in London whereas a continuing discourse of illness and death was more widely evident in rural areas. Participants in either area might experience a difference between how they might see themselves and the discourse available to them in society, particularly in terms of their health. For some participants homophobic oppression was still a very current

issue and for others there was a sense that the discourse of struggle was no longer relevant. There was a stronger sense of a general level of homophobia and anti-HIV prejudice in the rural areas.

Gaining a sense of personal control appeared to provide participants with a sense of ontological security and the lack of that sense of control had a significant effect on the person's ability to cope. Through their stories, participants created a sense of meaning, cohesion, 'fit'; their sexuality and their HIV status were aspects of their experience which were more or less comfortably woven into the fabric of their lives.

#### **6.64 - Health**

Both sets of participants negotiated a more or less uneasy relationship between their health status and health state and different participants adopted different strategies to manage that dissonance. All participants experienced at least some level of uncertainty – an uncertain state of health in the present and uncertainty regarding future prognosis. Participants more or less successfully constructed unique Explanatory Models to frame their physical selves and interpret their physical experiences and this process was different across the two areas; urban participants had a wider variety of discourses readily available to them whereas the rural participants had fewer alternatives to the discourse provided by the clinic. Making choices about looking after one's health was in some ways easier in an urban area where there is a culture of the gay community adopting a health promoting philosophy, but on the other hand that same community also promotes a culture of excess which can debilitate health.

Anti-retroviral therapy had an uneasy position in many participant's lives, particularly if it served as reminder of HIV and if the side effects were experienced as disabling. Significantly, there was no difference across the two sets of participants in terms of access to medical treatment and information. Participants had to negotiate the extent to which they adopted a 'sick role'. This was an anxiety across both areas but anxieties about employment were



greater amongst the rural participants because of fears regarding homophobia and anti-HIV prejudice as well as a relative scarcity of available jobs.

### **6.65 - Relationship with professionals, treatment and services**

The data indicated that doctors and clinic staff had more perceived power to define a patient's condition in rural areas, as opposed to urban areas. As a result, patients had less perceived choice and control over their treatment in rural areas although access to anti-retroviral therapy was the same. It was a struggle for any participant, regardless of locale, to define themselves against a medical discourse in relation to anti-retroviral therapy.

HIV organisations have a particular set of politics, culture and history of development. HIV can be framed as a political statement, but not all participants wished to adopt an activist discourse. Peer support, both formalised and informal was beneficial to many participants but this is easier to set up and to access in urban areas. On the other hand, organisations in rural areas are drawing on a smaller group of people who are geographically more distant, and for whom confidentiality may be an issue which may inhibit access and disclosure.

Services may or may not reflect the expectations of their users and, conversely, users' expectations may or may not be framed by the services which are available. If there is a victim mentality, a culture of 'them and us' and of 'doing for' in rural areas, I suggest that this has been created in the dynamic relationship between the providers and users of that service *and* the spatial context of that service.

## **CHAPTER 7 - DISCUSSION**

'What seems to be required is a sensitivity to listen to an ever-growing array of stories and to shun the all too tempting desire to place them into a coherent and totalising narrative structure' (Plummer, 1995, p165)

Research is about making meaning and in this piece of research the process of making meaning takes place at each stratum: the participants told their stories and in the process of doing so refined their understandings of what it meant for them to be themselves in relationship with others and their world. As a researcher, my intention has been to refine and extend my understanding and the process of the research has been a personal process of making meaning, both as an individual and within the literature in this field. You as reader are also engaged in a process of making meaning both for your own life and your understandings of others. These processes are intertwined and continually shifting, and the meaning patterns we create in such an enterprise are always contingent. There is always a slippage between the understandings we hold, what we articulate, and the phenomenon itself, always something 'lost in translation' and in writing this final part of the research I am trying to hold on to the ephemeral 'spirit of the stories' told to me.

In writing this final conclusion to the research, I draw largely on the work of Ken Plummer (1995) and his analysis of sexual stories. I return to the five themes of the literature review and data analysis: community and space; relationships; identity; health and relationship with services and re-conceptualise them as narrative performances, caught in a particular space and time. I conclude the research with a meta-analysis of these narratives. The research itself is a post-modern narrative performance; a celebration of the space between binary oppositions: urban/rural; gay/straight;

positive/negative; healthy/ill; community/individual; belonging/not belonging and so on. These spaces – whilst constructed and problematic ‘fictions’ – are core to our understandings of self and other. We orientate ourselves towards and away from, and both yield meanings and new (yet always fictionalised and contingent) ‘truths’.

## **7.1 - STORIES IN COMMUNITY AND SPACE**

Sexual stories and stories of HIV are spatial and social. The participants in this study created and told these spatial and social stories differently according to different contexts, experiences and opportunities. Gay HIV positive men tread a balance between differentiation and merging, separateness and community according to their perceived available choices and changing needs. This process of identity formation is closely related to the spaces they inhabit. In this section I draw conclusions about spatial stories as gay and HIV+ as evidenced from the data and its relevance in relation to the other literature in the field.

### **7.11 - Coming Out Stories as spatial discourses**

The data demonstrates that, in order to create an identity for oneself as gay, an individual needs to create some contact with other men who also identify as gay at the same time as experiencing themselves as anonymous and absorbed. Coming Out is both an intra-personal shift of identity *and* a physical, geographical action. It is an individual story which can only be told in and through a community story. Furthermore, these connections occur in particular urban spaces; although the gay ‘scene’ is not easily defined or identified, people hold a clear, individualised sense of what it is. However, once the Coming Out story has been told for the first time, in a process of defining *oneself* as gay, to oneself at least, it can then become told and retold away from and perhaps in opposition to the community stories.

Community stories create the 'scene' which is, at its core, a fiction, but a fiction which is told and retold in particular spatial locations and within particular groupings. These individual and social stories are not static; through multiple re-tellings they interweave in and through each other and at each re-telling new individual and collective understandings are created. Thus the space between individual and collective is conflated, at least for a time, in order to create a Coming Out story.

### **7.12 - The spatial experience of urban gay HIV experience**

This study, like Gatter's (1999), defines identity as social. Self-perception is created and changed in the context of social networks. We articulate the geography of a sexual community in terms of interrelationships. Like Gatter's, this study conceptualises identity as dialogic, as a site of contestation and in a continual process of becoming. However, in identifying fundamental differences in social identity construction in different geographical areas, urban identity stories are also made problematic. We have a paradox – urban space and community can be both liberating and oppressive, freeing men from the shackles of cultural normative pressures and recreating them in a different guise.

Very few participants in this study had an uncritical position in relation to the scene, and in many cases chose to place themselves in attitude outside it whilst physically within it. Nevertheless, the scene can hold an irresistible, perhaps magnetic urge. Whilst criticised for an emphasis on surface, the material, for hedonism and excess, it may also be experienced as an exciting environment, affirming of one's sexuality, providing a sense of collectivity, of community.

The story of the urban gay scene has changed. In previous years it has been a politicised story, its language the language of activism, outrage and resistance. There is a tension between this story and the materialist story of excess and individuals create their own stories within this space. This tension is manifest in the spatial story of Pride: to what extent does and should Pride

continue to be a politically charged space? Is it, in its colourful carnivalesque, a political gesture or not? (see also section 7.33)

### **7.13 - The spatial experience of rural gay HIV experience**

Weeks (1985) argues that politicised sexual identities need certain conditions for their emergence, including large numbers of people in the same situation and a geographical concentration of such people. This research suggests that in order to create an initial story of self as gay, individuals create these conditions through spatially re-locating themselves if necessary.

As with the urban cohort, the rural participants constructed gay community and gay space in terms of dichotomies: in/out, collective experience and individuation, sameness and otherness, holding a tension between the need to belong and the need to be different. In his research into rural gay spaces, Flowers (2000) illustrates that his subjects felt isolated and excluded both from the straight culture which surrounded them *and* from an imagined gay community which was perceived as distant and inaccessible. The findings in this study suggests that living as an HIV+ gay man in a rural space is further complicated; individual men express the problematic between individual and community in various ways. The data shows three general trends in the ways in which rural participants lived their gay identity. Some established and maintained a gay identity in spite of and in contrast to the prevailing norms around them and they believed that to retain a strong identity as a gay man was important to their sense of self. On the other hand, others defined themselves in relation to the people around them and incorporated some sex eroticism into those prevailing norms. Alternatively, rural participants described a small but tightly knit community of gay men within a rural setting, in which group norms and group identity are particularly important in terms of defining the group against the prevailing rural norms.

In rural areas, both the spatial and the experiential boundaries between in and out and between straight and gay are far less differentiated than in an urban context. This fluidity can present difficulties in creating a clearly differentiated

sense of oneself as a gay man. Not one of the rural participants placed themselves within the rural gay scene although most accessed it in some form which implies that, although there are definite difficulties with a rural gay scene, it is still necessary in terms of maintaining an identity as a gay man. However, because of the ephemeral nature of this scene, rural participants in addition drew their identity as gay from experience which was distanced in space and/or time rather than from their immediate context.

#### **7.14 - Fictionalised spatial identity stories**

The gay community is a concept which cannot be absent from a gay positive man's identity, even if it is one against which he defines himself, and it is certainly problematised in both urban and rural spaces. Gay men living with HIV, whether in an urban or rural environment, have to tread the space between individual and community identity; a 'detour through the other that defines the self' (Diana Fuss, 1995, p6). The research participants constructed gay community and gay space in terms of in/out, collective experience and individuation, sameness and otherness. They held a tension between the need to belong and the need to be different. Whilst identity is experienced as both personal and social, in both an urban and a rural area the gay scene is constituted in a particular space and by people who, although within it, regard themselves as outside it. Identity formation is a process of defining oneself 'in relation to' as well as 'within'. Yet identity *is* socially constructed and socially maintained; it is through others that we find a language to conceptualise ourselves.

There is a general understanding that, although a useful form of short-hand, and although they describe something real, the terms 'gay' and 'community' are terms around which one can position oneself but are invisible at their centre. Whilst the concepts 'gay man' and 'gay community' may not exist as concrete realities, they still tell 'necessary fictions'. 'Gay' is an invisible point around which are clustered different identities and communities. 'Gay community', 'gay man' and 'gay scene' are short-cut terms to evoke something complex and in some measure indefinable.

### **7.15 - The spatial stories of HIV**

Participants established and maintained an identity as HIV+ differently in an urban and rural area partly because of the different ways gay space is constituted in the different areas. The urban story of HIV has changed more than the story in a rural area. In London the discourse of HIV is increasingly one of 'living well' with the virus. The community or solidarity of positive men is in danger of fracturing as a result of new health technologies relating to recency of diagnosis, treatment history, treatment failure or drug resistance which shape and define new types of HIV positive gay men with unique and differing responsibilities. These identities are set in opposition to those who do not 'live well'. In rural areas, the process of changing the story from one of illness and death to one of living well is slower and less certain. This is reflected in the ways in which the different participants continue to describe their experience. In London it is easy to participate and to make sexuality and HIV status a political issue; in a rural environment, those opportunities are far more scattered, the risks are higher and there is little sense of collective activism. Differences in prevalence lead to differences in self-understanding and identity as well as differences in behaviour.

### **7.16 - Straight and gay spaces**

There are urban and rural differences regarding the relationship between gay space and heterosexual space. In a rural context, gay spaces are either more integrated into straight spaces, or they are 'hidden' from the heterosexual eye. This contrasts to urban gay spaces which are identified as gay and yet also known to and accessed by the straight community. A gay identity may be established and maintained differently in an urban and rural area partly because of the different ways gay space is constituted.

Stories are lived and told in a particular spatial context and are both influenced by and influence that context. It is perhaps more appropriate to consider spaces and communities to reflect the increasing fluidity and

diversity of where people live and with whom they spend time. Gay HIV positive men tread a balance between differentiation and merging, separateness and community according to their perceived available choices and changing needs. This process of identity formation is very closely related to the spaces they inhabit. Whilst the data demonstrates that gay identity needs to be established in relation to other gay men, this need not be a permanent spatial and community location; the men in rural areas as well as some in urban areas chose then to return to a more heteronormative space or spaces for some or all of the time.

### **7.1 Stories in community and space. Conclusion**

To create an identity as gay and as HIV+ in a rural area is a different – not necessarily harder – process than in an urban space. Stories are a collective enterprise, to be told from and to a community of other narrators and listeners located in space and time. Plummer argues strongly for the need for a community for narrative:

‘For narratives to flourish there must be a community to hear; that for communities to hear, there must be stories that weave together their history, their identity, their politics. The one – community – feeds upon and into the other – story. There is an ongoing dynamic or dialectic of communities, politics, identities and stories’ (Plummer, 1995, p87)

This community of course also exists in time. To identify as ‘gay’, as ‘HIV+’ the person locates themselves in a community of gay men in the past as well as in the present; they locate themselves in a particular relationship with historical gay icons as well as iconic events such as Stonewall. They also locate themselves in a particular relationship to the category heterosexual in the hetero-/homosexual dialectic. Similarly, in identifying as ‘HIV+’, the person locates themselves in a particular relationship to the history of HIV and HIV communities as well as to the HIV negative Other and their own history pre-diagnosis.



The process of creating a community from which and to which to speak one's story was different for the rural participants, but still possible because of fluidity of movement and explosion of communication in the modern world. Once again, they tell their story in a particular time. The participants, particularly those in a rural location, had to tread yet another dialectic – of globalisation on the one hand, and the particular character of local communities on the other. We are all interconnected as never before but this does not necessarily lead to homogeneity; rather one hopes a dialogue between distinctly different communities and spaces. This has relevance for services in rural communities which I discuss further below.

## **7.2 - STORIES OF RELATIONSHIPS**

The spaces we inhabit are inextricably intertwined with those with whom we share those spaces, and the definitions we create of ourselves derives from and in turn recreates our space and our connection with others. This section draws on the connections between spatial and community stories and the stories we tell of individual relationships. Individual relationships once again tell a story of the dialectic between self and other, a space between belonging and not belonging.

### **7.21 – Stories of friends, families, partners**

We look to our relationships – intimate, friendship and familial – to reflect and reinforce our understandings of who we are. We share similar relationship needs but the way in which those needs are met across the spectrum of possible relationships differs according to the spaces we inhabit. Our relationship needs may not necessarily be fulfilled through traditional roles; different participants had different understandings and experiences of family and friendship networks and these were lived out differently across urban and rural space.

## **Sexual stories**

Sex, emotional intimacy and HIV are experienced in a complex inter-relationship. Sex itself conflates the space between self and other and thus the negotiation of intimate narratives are particularly formative. If you cannot or do not have sex, your understanding of yourself as a gay man will be affected and your sense of your body as infected and infectious may also be affected. The categories used to describe HIV implies that the virus exists within individuals whereas in the lived reality of relationships, HIV exists within relationship in a way which had to be negotiated and managed by both partners whatever their status. Thus HIV has a particular spatial location within the relational and/or sexual dyad. HIV plays a significant role in negotiating sexual and emotional intimacy and this was perceived as more problematic for the rural participants. Rural participants were less likely to disclose either their HIV status or their sexuality and would make strategic decisions based on their judgement about someone's potential reaction. This has an impact on identity: disclosure is an act of identity formation; telling others, or withholding, one's sexuality and/or HIV status changes one's perception of oneself. When participants framed their experience in words in order to tell, it changed their understanding of themselves in a way which echoes Coming Out stories. Once again, these stories of disclosure are spatially located. Participants found themselves having to negotiate different ways of framing their relationships or conforming to a heteronormative blueprint. Intimate relationships in a rural space seemed to correspond more closely to that blueprint than their urban counterparts.

## **Family and friendship stories**

According to our spatial location in relation to others, we create different understandings and experiences of family and friendship networks and will live them differently across urban and rural space. Not only are relationships formative in terms of identity, but we also re-evaluate friendships and relationships in the context of a changed and changing identity. There is a felt

need for one's relationships to shore up one's identity of choice but this was harder for rural participants who did not necessarily have a friendship group of people who were perceived to be similar. There was also an urban and rural difference in the experience of bereavement and loss. Whilst rural participants may not have had to cope with multiple losses, there was a stronger sense of isolation and alienation from the rest of the community. Rural participants were more likely than urban participants to have more contact with their families and rely on them more for emotional and practical support.

## **7.2 - Stories of relationships. Conclusion**

We make meaning through measuring ourselves against difference and once again this is apparent at each stratum of the research. We create understanding of how something is by exploring what it is not; we create understandings of who we are by comparing ourselves with others. The participants expressed their understanding through dyadic tensions: urban/rural, present self/past self, present self/future self, self/others as gay, self/others as HIV+, gay/straight, HIV+/HIV-. These were particularly charged in intimate relationships where the location of HIV could become problematic and the act of disclosure both created risk, dispelled risk and changed the self as mirrored by the Other who knows.

In defining ourselves 'against' there is often (perhaps inevitably?) a power differential and this is created both collectively and individually (Edelman, 1994, Crossley, 1997). The participants in the research were socially and culturally 'Other' in relation to sexuality and HIV status, but these positions were performed as part of a complex web of other dyadic relationships which held their own power and resistant energies. The urban participants placed themselves in relationship to their rural counterparts and vice versa; the recently diagnosed in relation to those who had been diagnosed for some time; the politicised in relation to the less politicised, and so on. In defining ourselves against we also define ourselves in relation which provides us with a sense of connection. The extent to which it is inevitable that dyadic comparative understandings of identity are hierarchised would be a useful

topic for further research. What the data from this study demonstrates is the extent to which identities are created and understood socially; we only understand ourselves in relationship. This had clear implications for defining oneself as gay and HIV+ in rural areas where connection with others who similarly defined themselves was less straightforward.

This dyadic tension was an explicit part of the research framework; a comparison between urban and rural space and community. Implicit through the process of doing this work is my attempt at understanding relationships across difference, both in terms of the explicitly comparative nature of the study and my own position of difference within it: I as researcher am not a gay man, I am not HIV+ and my understanding of the participants can be honed by this 'other' perspective. Similarly, the reader will create new understandings both of themselves and the participants by their position of sameness and of difference. We orientate ourselves towards or away from, and both yield meanings and new (yet always fictionalised and contingent) 'truths'.

### **7.3 IDENTITY STORIES**

Identity is about belonging and differentiation (Weeks, 1991). Understandings of self emerge through the complex map of our relations with others. Modern stories of identity have become ever more complex and confusing. Each of us live with a variety of potentially contradictory identities, which cohere more or less comfortably. Identity is an individual narrative, a bodily experience and a social, cultural and historical construction held in a unique balance for different people at different times in their lives. We develop our sense of ourselves through our relationships in time and space with ourselves and with others. This may be experienced as more or less liberating and/or oppressive according to individual circumstances. Gay men living with HIV may have a particularly problematic relationship with their world. The extent to which they define themselves in relation to their bodies, sexuality, their place in time, space, community and relationships will have a significant effect on their

sense of themselves. Issues of space and community and the relationships performed within these spaces have a particular effect on gay positive men's identity stories. In this section I draw together identity stories of gay sexuality and HIV, locating them within a specific political and historical moment. Once again this narrative treads and problematises the fictionalised spaces between gay/straight, positive/negative, chaos/meaning.

### **7.31 - Stories of sexuality**

The essentialist claim of innate sexual orientation has been widely criticised, but in the lived reality of people's lives, as evidenced in the data, it is an enduring story, albeit another fiction. We have an inherent, pre-given sense of who we are sexually in relation to ourselves and to others which will always be greater than our sexual expression in the social world. We need to conceive of nature and culture as mutually determining sexuality without losing the complexity and richness of either debate. We should not deny a pre-given sexual orientation in our consideration of how this is mediated in our particular context. It is this which makes sexuality and sexual discourse so powerful, liberating and dangerous.

Similarly, whilst identity politics has been undermined by the claims of Queer theory, the fact that identity categories endure is significant. Weeks (1995) conceptualises the space created between sexuality as both innate and as a social construction by expressing the body as 'an ensemble of potentialities which are given meaning...in society' (p122). Our need to 'belong' with others is placed in tension with our need to articulate the unique nature of our individual experience. His claim that we need to construct sexual identities to protect ourselves from the chaos of limitless choice makes practical sense and is born out by the data in this study. Sexual identities are the media through which we negotiate our sexual selves in the world and as such they cannot be willed away. The 'necessary fictions' which are sexual identities are a matter of a continual process of choice, a narrative quest which spurs us into thinking again about what we value and desire.

It may be that the image of a web of polysexualities is more effective at problematising categorisation and the very insistence by a heterosexist culture of the existence of a discrete category of homosexuals itself raises concerns about the categories themselves. On the other hand, it is difficult to conceive gay liberation and the politics of gay sexuality without some at least provisional attempt at forming and performing a personal and collective gay identity, and the sense of one's own personal sexual identity within a collective group helps to make sense of ourselves in the world.

We need something against which we define ourselves; to create a story of self we require a story of other. If we argue that heterosexuals need homosexuals to shore up their own identity, homosexuals will continue to need heterosexuals to shore up theirs. Participants suggested that the gay community, by reinforcing a strong identity pitted against heterosexuals, is in danger of perpetuating its own oppression. If group boundaries are overly rigid, there is a danger of transgression becoming an end in itself; to cross a boundary is merely to set up another boundary further off. It is, however, possible to have groups and communities which allow people to enter, leave, or be partially affiliated to them. They do not feel as safe but neither do they exclude people, nor are they overly rigid or claustrophobic to their members. We engage in a balance between safety and risk; chaos of limitless choice and overly prescriptive categories of how to be.

### **7.32 - Stories of HIV**

Creating a story as HIV+ problematises the sexual story. Sexuality is about the merging of self and other and HIV potentially redefines this as an act of risk, infection and harm. To create a story as HIV+ will necessarily redefine one's story of sex and sexuality. I explore this further in section 7.4 below.

The process of creating one's story as HIV+ takes place in opposition to as well as in relation to the Other. Crossley's (1998) claim that those people who have been able to build a 'robust' theory of the meaning of their diagnosis have done so by constructing oppositional images of self and other seems to

be born out in the data from this research. These 'Others', identified as the 'weak-minded, negative, HIV+ individual', and the 'newly diagnosed' serve as negative prototypes of the 'healthy' self.

Crossley (1999a&b, 2000), Schwartzberg (1996) and Ezzy (2000) create various narrative groupings to explore and understand stories of HIV. Crossley's normalising story, story of loss and growth story correspond to Schwartzberg's Camouflage, Rupture and Impassivity and Ezzy's linear restitution narrative, chaos narrative and quest narrative. Crossley's concept of living with a philosophy of the present and growth story, Frank's (1993, 1995, 1998) quest narrative and Ezzy's polyphonic narratives all correspond with a postmodern 'life politics' which incorporates fragmentation, discontinuity and contradiction. The data from this research implies that these narrative 'genres' can be found in individual stories, but that each individual narrative incorporates aspects of all of these – the result being a far richer and more complex picture incorporating contradiction and paradox – tragedy inheres within comedy and the farce transforms to become an epic myth.

At its heart HIV is an issue of identity: people living with HIV need to manage a changing understanding of who they are and will construct stories that will fit their experience of themselves. Individuals who have a strong sense of self efficacy may be quite conscious in the way they create a sense of meaning around HIV for themselves. HIV becomes part of their life - sometimes peripheral, sometimes more central – to be integrated into other aspects of their lives. People who struggle more with their status may regard it as meaningless, pointless in terms of the rest of their lives and an adjunct rather than as something which could fit with other aspects of self. HIV, like other illnesses (see section 7.34 and 7.4 below) renders this process of narrative meaning construction a more conscious process.

HIV is a story constructed in space and communities, and individuals will both draw from and impact this cultural story. It is a changed and changing story in which we make sense of ourselves and our world, our past, present and future. It is an additional challenge to HIV+ people, especially those who have

been diagnosed some years, to integrate the changed and changing story of HIV, which may or may not feel relevant. The discourse of 'Living Well' with HIV is more widely evident in London whereas a continuing discourse of illness and death is more widely evident in rural areas. Participants in either area might experience a difference between how they might see themselves and the discourse available to them in society.

### **7.33 - Political stories**

Both gay sexuality and HIV can be expressed as political stories and certainly historically this is the case: both have emerged against a backdrop of oppression and social exclusion. Once again, however, this is a changing story; if that oppression no longer exists, or if its expression has changed, this has an effect on what being gay and what being HIV positive mean both in society and thus to the individual. To define oneself *against* – against prevailing norms, against the gay community, against one's family – is to develop a particular sense of self, one born out of struggle and dissent. If there is less struggle, can a politicised identity survive? HIV can be framed as a political statement, but not for everyone, and perhaps this historically is becoming simply less relevant. New collective stories are being created which are less political but still inhere within community.

### **7.34 - Stories of crisis**

Giddens' (1991) definition of a crisis as a point when 'activities concerned with important goals in the life of an individual or a collectivity suddenly appear inadequate' (p184) can define the story of living with HIV as one of fluctuating yet permanent crisis.

Brian Heaphy (in Weeks & Holland 1996 & Barber & Huby, 1998) developed Giddens' (1991) concept of the 'fateful moment' to explore how people reach an understanding of what it means to be HIV positive. He regards identity formation in the context of HIV as a reflexive act in response to the need for



ontological security in the face of uncertainty. The data problematises Heaphy's definition of testing and diagnosis as necessarily constituting a Fateful Moment, particularly for urban gay men for whom HIV is already a significant part of one's life and identity. There will, however, be significant points along an HIV trajectory which constitute a Fateful Moment: for example, Coming Out, death of loved ones, starting treatment, illness, relationship break-up and contact with people who become formative in one's life. Participants described such moments in their narrative where meaning was shattered and uncertainty prevailed, necessitating a radical redefinition of self.

### **7.35 - Stories of uncertainty / stories of meaning**

The way in which we construct our reality is born out of an attempt to find both meaning and security in a world of infinite possibility (Turner, 1992, p83). Heaphy explores identity formation as a search for ontological security. Positive gay men are living in an increasingly uncertain world with uncertain choices, needing to engage in a process of identity formation in order to manage that uncertainty to create a meaningful sense of themselves in the world. To be in control of our lives is perhaps for all of us a necessary illusion but it is vital for us to feel some sense of power over our own destiny. Identity as HIV positive is a changing entity and individuals need to develop strategies of coping with uncertainty. Participants described themselves in a particular way according to whether they perceived themselves as having a strong sense of self-efficacy or experienced themselves as the victim of circumstances beyond their control. Gaining a sense of personal control provides a sense of ontological security, albeit contingent, and the lack of that sense of control has a significant effect on the person's ability to cope. Through their stories, participants created a sense of meaning, cohesion, 'fit'; their sexuality and their HIV status were aspects of their experience which were more or less comfortably woven into the fabric of their lives.

We tell identity stories in time. The present only makes sense in terms of the past which in turn is translated through the present moment. The future can

only be anticipated in the light of the past and through present understanding. A past of chaos can be told in the light of a present of meaning. Alternatively a story of life pre-HIV can be told in the light of a blighted present. Sometimes the future is envisaged as a continuing story from the present, or sometimes further change is anticipated.

### **7.36 - Stories of our time**

Giddens' (1991) claim that the modern Western world emphasises the role of the individual in creating their own subjectivity from a bewildering array of choices is born out by the data in this study. Life has become far more contingent and uncertain; this can give rise to a sense of liberation but also a crippling existential anxiety. Not only are we faced with different choices and the responsibility for fashioning our lives out of those choices, but the moral and ethical frameworks on which to hang the decisions that we make are further problematised. To become aware of all the choices that we make and all the risks involved would be to collapse into existential angst; in order to live in the world we need to balance active choice making with a denial of some of the choices and attendant risks.

The data suggests that HIV+ gay men sit more or less uneasily between a belief that they can create their own reality and a sense of the restrictions placed on their ability to do so. This may alter over time and will be affected by their spatial and community contexts. Crossley (1998, 1999) develops Giddens' (1991) distinction between emancipatory and life politics to suggest that each of these stories afford both liberatory and repressive potential according to the person's life world at any one time. The degree of belief in self responsibility for creating one's own story is a fundamental issue for HIV+ gay men in many aspects of their lives: from one's understanding of one's sexuality as a choice or essentially given; one's understandings about the role of one's own actions in infection; and the degree of responsibility one feels about managing the virus. A 'healthist' discourse can both liberate and repress according to the spatial and community context within which the individual is placed. I discuss this further in 7.4 below. The discourse of 'Living

Well' with HIV is firmly based within a healthiest paradigm and was more widely evident in London whereas a continuing discourse of illness and death was more widely evident in rural areas. Participants in either area might experience a difference between how they might see themselves and the discourse available to them in society, particularly in terms of their health.

### **7.3 Stories of identity. Conclusion**

Weeks (1985, 1989, 1991, 1995, 1996 a&b) highlights identity as a necessary fiction: a story of ourselves which undergoes a continual process of re-telling and will shift at each re-telling. The living of our identities is greater than any label we try to assign to them and in the process of making meaning there will always be a slippage. This is not, however, to detract from the importance, even the necessity, of this process. The research participants created identities for themselves as gay, as HIV positive which held veracity for them in that time and space and in relation to the research in which they were participating. This is the same process of identity formation which all of us undertake but for these participants their sexuality and HIV status made them more conscious of creating their own story – a story told as a micro-resistance (Edelman, 1994) to the heterosexual, HIV negative majority. It is striking that this process also involved micro-resistances to the given identities of gay and HIV positive; that many participants whilst acknowledging the categories 'gay' and 'HIV+' defined themselves in opposition to those categories whilst also realising that they would be perceived as belonging within them.

The tension held by the participants is between belonging and not belonging. There is a felt need to place ourselves in relation to others who we perceive as similar and to tell the story of our identity in relation to that perceived similarity and connection. This helps us to create more or less stable meanings for ourselves and more or less clear affinities with others. At the same time, and no less important, is the need to voice our uniqueness and resist the limitations of any given category. The thread running through many of the men's stories is this tension: I am gay, but not like other gay men, I am HIV positive, but not like other HIV positive people. I am these things but I am

more than these and I live these aspects of my life uniquely. There is no inherent truth or validity in these labels but to emphasise the process of their construction makes them no less real. Being 'gay' and being 'HIV positive' are a convenient short hand for a reality which manifestly exists but which is invisible at its centre. As Plummer (1995) argues, there is quite literally a process of 'coming to terms' (p88); finding a language which is shared and understood by others in which we can explain ourselves.

This process is, of course, further complicated by the fact that we hold an infinite complexity of actual and potential identities at any given time. The research particularly focused on sexual and HIV positive identities but these are held in conjunction with a unique ensemble of other meaning frameworks for each participant. In analysing these stories, I chose to pick out specific strands: space and community, relationships, identity, health, and relationship with professional services but I could as easily have picked out others to create a different understanding (for example, spiritual beliefs were mentioned in many of the interviews and would be an interesting topic for further research). In the analysis of these strands or threads, we need to remember that these participants also hold an infinite variety of aspects of identity: we should not lose our sense of the whole story which is these people's lives.

At this historical moment, sexual orientation as a gay man and HIV status are two closely interwoven identity threads but again these intertwine differently for individuals and at different points in their lives. For some they were closely conflated, for others less so although in all cases they informed each another in terms of how that identity was understood, how it was lived, and the dynamic between the two.

Gatter's (1995, 1999) dialogical approach to identity formation has relevance to the ways in which participants managed their lives as HIV+, as gay, as living in particular communities, spaces and relationships. For each, identity formation was a site of conflict, contestation, of flux and was in a continual process of becoming through dialogue between these different aspects of their lives. For example, not only has being HIV+ changed as an experience

post anti-retroviral therapy, but, because of these changes in HIV, the experience of being *gay* and HIV+ has also changed; in addition, living in particular spaces and communities been affected by anti-retroviral therapy, and so on. Thus, changes in one aspect of identity creates changes in all aspects of self. Similarly, Crossley (Davies, 1997) writes about the uncertainty of HIV+ individuals' understanding of time; this has become *more* uncertain post anti-retroviral therapy when different and opposing future possibilities present themselves.

## **7.4 - STORIES OF THE BODY**

We live embodied lives and HIV is an embodied experience. In this next section I draw together phenomenological understandings of narrativised bodies and the embodied narratives of the participants in this study.

### **7.41 - Stories of illness**

Sickness lies at the apex between the individual and society. Illness is experienced bodily within the individual; it is a lived, personal experience, a language of distress/dis-ease. This is experienced in a dialectical relationship with illness as a social and cultural phenomenon constructed through medicine as a political practice. When these are in accord, the person experiences something stable, explicable, albeit unpleasant. HIV, on the other hand, is not a stable entity at either of these levels and changes in personal experience and social framing, and the discourse expressing both of these, is a constant source of uncertainty for individuals. Different cultures position illness at different points on the personal/social continuum and the changed and changing place of HIV on this continuum is something which has constantly to be negotiated and renegotiated.

HIV as a socially constructed phenomenon carries particular resonances and meanings within society which will inscribe the experience of living as an individual with HIV. At the same time, the experience of an HIV positive person is about themselves and their own relationship with their physical

being. This has a symbiotic relationship with but is separate from the social construction of this particular pathology.

Illness from a phenomenological perspective attempts to reconcile the experience and the meaning given that experience. Kleinman (1988) conceptualises illness as an embodied experience which can be narrativised; in fact the central task of successfully managing an illness is to form such a narrative to be shared with others and to give it coherency. Kleinman believes that through the sharing of such a narrative, the ill person's body can become communicative in new ways and that those around them can also experience their bodies differently in relation to that person. So if illness is at least in part a problem of meaning, we need to formulate stories, albeit contingent 'fictions' in order to account for the inexplicable. We do this socially and also individually. HIV represents a problem of meaning, both for the participants and the society of which they are a part. Although participants' explanatory models drew on social discourses, they were experienced as personal and unique.

Hyden (1997) builds on Kleinman's work to explore the functional role of illness narratives. His suggestion is that narratives articulate illness, positioning the illness in time and space and in terms of a personal biography. This is born out by the research data: participants created more or less coherent illness narratives in order to make sense of their HIV in terms of time, space and relationships. This was a changed and changing story and Hyden argues that illness narratives by definition serve to establish changed relationships between self, world, the body and one's personal biography which incorporate the illness experience. Illness narratives formulate the illness in terms of one's own life and as part of a shared culture, and the participants clearly told both an individual and a social story. This transforms illness from an individual to a collective phenomenon: the illness becomes part of a political and social narrative and context and this is particularly evident in the context of HIV.

Hyden (ibid) also argues that illness narratives are built around three central tensions: to gain a public voice in order to relate a private experience; to sustain the primacy of one's own voice in relation to the voice of medicine (and, I suggest, other discourses) and to balance the illness experience against the scheme of one's own life. Each of these three tensions is particularly pronounced in relation to HIV because of the nature of the virus (see 7.43 below).

In order to cope with this uncertainty and cognitive dissonance, participants more or less successfully constructed unique Explanatory Models to frame their physical selves and interpret their physical experiences. This process was different across the two areas; urban participants had a wider variety of discourses readily available to them with which they could frame their experience whereas the rural participants had fewer alternatives to the medical discourse of their HIV clinic.

#### **7.42 - The story of medicine / Anti-retroviral therapy**

The medical discourse of HIV is a discourse of power but is increasingly one among a pluralisation of potential discourses which can be used to frame the experience of being HIV positive. It retains, however, a strong defining influence. Illnesses, including HIV, are manifested through medical procedure and expert interpretation rather than visible symptoms. The HIV+ individual has to negotiate the extent they invest medical discourse with this definitional power. Several of the participants had adopted a medical discourse almost exclusively as a way of constructing their experience of HIV. This medicalised language can provide a sense of belonging and connectedness and in itself creates a secure community of discourse. In addition, medical discourses have defining power in terms of accessing other systems – housing, benefits etc. This can prove particularly problematic for those participants whose experience or interpretation does not comfortably fit that frame.

Anti-retroviral therapy is a complex phenomenon and held an uneasy position in many participant's lives, particularly if it served as an obtrusive reminder of

HIV and if the side effects were experienced as disabling. There is something profoundly counter-intuitive about taking a medicine when one feels healthy, knowing that the side effects will make one sick. Even when anti-retroviral therapy created improvements in health, it is clear that the improvements are usually limited to physical health and in fact other stressors can be exacerbated. Gay positive men now have to deal with unpredictability of outcome as well as the complexity and burden of the current treatment. There are clear differences between clinical and social change. It is vital to balance medical advances and success with a concern about people's lived experience in the context of anti-retroviral therapy (see section on service provision below).

Mental health is jeopardised at times when the individual's felt and lived experience is at odds with the discourses available to them to frame that experience. HIV is not a stable entity and changes in personal experience, discourse and social framing is a constant source of uncertainty for individuals – to be constantly negotiated and renegotiated. People living with HIV enter a constant process of renegotiating their sense of themselves in space, time and relationships. In a context where the discourse is so much more about living healthily with HIV on anti-retroviral therapy, there is a particular need to recognise the stories of those who are not able to define themselves within that discourse.

### **7.43 – HIV: not just a virus**

HIV inhabits a particular place between self and other; a physical condition which is individually experienced, it is also inherently relational because of the way it can be transmitted. As well as being an individual and relational experience, HIV is a political and cultural phenomenon; understood and experienced socially and spatially. HIV is very much a disease of this time. In 20<sup>th</sup> and 21<sup>st</sup> century Western society, sex, health, bodily fitness and well-being and the avoidance of death are principle elements of personal identity; an epidemic which associates sexuality with the disintegration of the body and death therefore has a profound existential impact (Murphy, 1994). HIV carries



potent meaning: 'it is an 'enemy' virus that threatens to destroy us not from the outside but from within...And this internalisation of the other can lead to our auto-destruction' (McGrath in Boffin & Gupta, 1990, p144); it infects through fluids associated with the transgression of boundaries; it feeds off the very system which serves to protect the body against it; it actually becomes part of the body, so that the body is literally destroying itself.

Thus HIV is individually, relationally and collectively destabilising because it is located at the cusp of the boundaries we draw between self and other, self and world, public and private etc. It is this which makes HIV the focus of so much fear. Issues of homophobia, stigma, disclosure and risk also police these borders and further problematise the experience of being HIV+.

HIV is very clearly a phenomenon around which we have assembled a whole range of cultural stories as we collectively have attempted to make sense of the virus and it is from within these stories that this research takes place; we conceive, articulate and understand the virus within a particular cultural frame. Myths are created as stories are told, retold and refined until the reality becomes figurative (Foster in Barbour & Huby, 1998). HIV is constructed in and through particular cultural discourses which are both affected by and affect the way it is manifested. These not only have a tangible impact on those living with the virus but also create a framework of meaning within which people may or may not be able to fit their experience.

Participants who had a stronger sense of control over their lives were often quite conscious in the way that they created a sense of meaning around HIV for themselves. HIV would become part of their life - sometimes peripheral, sometimes more central - which was integrated into other aspects of their lives. These individuals had usually established a relationship with HIV through contact with other HIV+ people pre-diagnosis, so that their own diagnosis presented narrative continuity rather than rupture. Those who struggled more with their status regarded it as meaningless, pointless in terms of the rest of their lives and an adjunct rather than as something which could fit with other aspects of self.

#### 7.44 - The story of the body

An anthropology of the body articulates the changing consciousness of the body as diseased, including a heightened awareness of the physical and a new dialectic between self and body (e.g. van Manen, 1997, 1998, Leder, 1990). To inhabit a dis-eased body creates a different relationship between self and body, between body and the space it inhabits, and between body and other bodies. To inhabit this body with its changed relationships creates a different set of responsibilities around living a physical self. The body, sick or healthy, is no longer simply a bio-medical physical entity but something placed at the dynamic between the individual and society. Health is not a description of a person's physical state but their own sense of their relationship with themselves, others and the world: the body is no longer a biological given, it is a series of potentialities which we invest with reality and meaning (Weeks, 1985, p122).

Whilst our experience of our bodies is mediated through discourse, the essence of our embodied self is perhaps something beyond and irreducible to discourse. The challenge for participants was to live their bodies as HIV+ and as potentially or actually sick. To articulate the body is to locate it in space and in relationship and is integral to the process of identity.

To live as HIV+ post anti-retroviral therapy involves negotiating the space between health status and health state and the uncertainty of how health can be understood and lived within that space. As well as stories of illness, negotiating the physical self may also involve stories of health. These can also be problematised: if health is defined as a lifestyle choice, then lack of health or loss of health is redefined as careless, irresponsible and even negligent.

#### **7.4 Stories of the body. Conclusion**

Our need to be the same as *and* different from others is a key dynamic in the lives of the research participants. They created their understandings of their sexuality and their HIV identities in relation to aloneness/togetherness, and within/without. This is particularly clear in relation to issues of sexuality and HIV as they are located so clearly at the cusp of the boundaries we draw between self and other, self and world, public and private. Plummer (1995) argues that stories about the body have a social resonance and this is particularly true in relation to HIV which holds such social and collective as well as individual significance. By its very nature and the nature of its transmission, HIV emphasises the contingency of the boundaries between self and other. It is a virus carried in body fluids which flow deep within the self; in the bloodstream, the lymphatic system and it is also carried in the sexual fluids which flow between self and other. Since the early 1980s HIV has been held in society; as a health promotion problem; as an actual or at least potential epidemic; as a collective fear held about particular groups and communities; as a historically located disease. HIV is located in time; the lifespan of the HIV positive individual and the changing nature of the virus and our responses to it in the last twenty five years. Each of these threads of meaning are inter-related and mutually influence one another.

I undertook this research at a significant time in the history of HIV. Anti-retroviral therapy has been available to HIV positive people in the UK since the mid 1990s and has impacted enormously on the lives of HIV positive people and the ways in which HIV is collectively and culturally understood. 'Fateful moments' as described by Heaphy (Weeks & Holland, 1996, 1998) in relation to diagnosis hold different potential meanings post-anti-retroviral therapy. A 'Fateful Moment' might now be a blood result which indicates a need to start anti-retroviral therapy; a blood result which indicates the development of drug resistance; a need for a changed combination which might involve debilitating side effects; the development of visible side effects to the medication which makes a person visibly HIV positive and so on. Anti-

retroviral therapy creates a whole new set of potential and shifting identities and dialectics: on therapy; not on therapy; ill from side effects to the medication; on one's first, second, third or maybe last combination; able to adhere to the medication regime; unable to adhere which would carry punitive implications and so on. Identity is problematised in relation to sex/sexuality and in relation to illness; anti-retroviral therapy only accentuates and further complicates those issues.

The participants developed different Explanatory Models of anti-retroviral therapy and these understandings would shift and change at different times. For some participants, anti-retroviral therapy was entirely positive, life giving and life affirming; for others, it was a burden; a regime to be adhered to, a daily reminder of the virus, something toxic that brought its own sickness. Each participant needed to locate themselves in relation to anti-retroviral therapy and this in turn would create different understandings about other aspects of their lives and their understandings of themselves in relation to time. We see the meanings that we already know and this is true of the way in which the participants shaped their stories in terms of their Explanatory Models of anti-retroviral therapy to create a narrative which can be shared with others and which gives some coherency to experience.

Anti-retroviral therapy has had tangible medical advantages and has changed the social understanding of HIV; no longer a terminal illness, it is now understood as a chronic condition which might present problems with living but rarely presents issues of dying. The HIV positive individual is regarded as holding a responsibility to 'live well' rather than 'die well'. The responsibility of managing a body which is always at least potentially sick and which always presents a potential risk presents a long term challenge post anti-retroviral therapy. The potential of a 'healthist' discourse both to liberate and repress (Crossley, 2000 a&b) is more apparent and presents a far more complex challenge to individuals living with the virus. Participants had to manage paradox as a daily reality; how to live with a life threatening condition but at the same time manage their lives and an uncertain future; how to take

medication which might well make them feel more sick than the condition for which they took it in the first place.

Kleinman's (1980) idea of Explanatory Models is evidenced in how participants told their stories and seems to be key to a sense of coping. Those participants who were able to create Explanatory Models, or narratives, which had a sense of coherence, even if the participant themselves recognised their contingency, were more able to understand themselves in relation to their HIV status and were as a result more resilient. Thus the narratives themselves had a therapeutic aspect. When a participant's Explanatory Model was undermined or threatened, their ability to cope and sense of identity was similarly problematised. This piece of research is itself an attempt both by participants and by myself as researcher to create an individual and social Explanatory Model of HIV post-anti-retroviral therapy and of being gay in the context of HIV. The dynamic between illness as social construction and lived experience is highlighted in the research as particularly problematic; how we make sense of feeling ill when the social discourse no longer allows for such a definition, or, conversely, to understand ourselves as well when the discourse available to us is one of illness.

## **7.5 - STORIES OF NEED / STORIES OF SERVICES**

Need is constructed within the dialectic which creates an individual into a service user and thence creates a service for that user. This section considers ways in which this dialectic can better reflect the uncertainty and paradox of community, relationship, identity and health as described above. Participants created a particular relationship between how they lived their lives, what they needed in their lives and the relationships they created with services and professionals. In this section I interweave theoretical concepts with the concrete provision of services and in doing so am conscious of my own position as a practitioner in this field, carrying my own narrative of service provision.

Anderson et al. (2000) argue that health and social care research, including HIV research, defines need in terms of people's demands for services and the empirical research considered in the literature review highlights this limitation. This research, in contrast, moves from a consideration of subjectivity and meaning-making to a consideration of the relationships individuals create with services and what role these services can play in assisting individuals in forming and performing narratives of self. The relationship between individual, 'need' and the service designed to meet this need is complex.

### **7.51 - New ways of conceptualising need**

In this section I draw on the data analysis to consider the implications for gay HIV positive men in urban and rural areas and the services whose remit it is to support these individuals. I have examined the relationship between lived experience and service provision, thus creating a link between the questions of subjectivity and the pragmatic question of how we might improve services.

The principle conclusion drawn from the data is that a mechanistic construction of need follows an assumed urban model which may not hold for all men in an urban setting, nor for men in rural areas. Participants were different and their requirements were different according to their experiences, where they lived, their communities, their identity and the dynamic between all these. Services cannot present a uniform blueprint when catering to diversity.

Gay HIV positive men are faced with new psycho-social dilemmas in relation to the virus including unpredictability of outcome as well as the complexity and burden of the current treatment; they engage in a constant process of renegotiating their sense of themselves in their world. To define 'need' within this context requires flexibility and creativity at all levels but will enable us to build a clearer idea of what these groups of people require from services in order to live their lives as fully as possible. In order to define need we have to take into account the lived reality of people's lives, including an understanding of community and spatial context, their networks of relationships, their sense of identity and the ways in which they understand their health. It is clear when

this far richer picture is painted of men's lives, that the services which men require in rural areas will be different from those which are more suitable and sustainable for men in urban areas. Urban space gives access to multiple discourses and the possibility of multiple identities whereas rural space has more restrictions, less choice and more emphasis on privacy within a smaller, closed community. Men living in urban areas have access to a clearly identified and identifiable political and collective voice and many (though not all) experience a desire to be part of that, whereas their rural counterparts have far less of a sense of community and collective voice. If services become homogenised and centralised they will no longer be created from, and may therefore no longer serve the interests of, the communities to which they owe their existence. We need to look for ways of maintaining local, small scale responsiveness and diversity with national standards of quality.

### **7.52 - Responding to need**

Both the existing literature and my research data clearly demonstrate that living with HIV is far more than a medical state and that the changes which HIV has undergone place more emphasis on the psychological and social discourses, as opposed to a purely medical discourse. Men who are faced with the possibility or the reality of improved and stable good health need to find a way of incorporating HIV into their lives, when its status as an 'illness' and therefore their identity as an 'ill person' may be called into question. A purely medical discourse and response fails to address questions of meaning and identity. This, potentially, leaves patients with a troubling gap and it is this space which poses a new and exciting challenge to services.

### **Responsibility / control**

We must be careful, however, to ensure that changes which are intended to liberate, 'empower' and enable, do not in reality oppress and overburden. 'Healthism' (Crawford, 1980); a discourse which promotes individual responsibility and action for health, both repoliticises health by giving the individual greater freedom and choice over how the body is conceptualised

and cared for, whilst paradoxically, depoliticising it by making health an individual responsibility. The growth of self-care and self-help discourses can on the one hand hold the potential to challenge both medical hegemony and more traditional 'doing for' support services but on the other can further burden the patient with a sense of responsibility for being sick in the first place and a burden of living healthily, which may be beyond their capacity to cope (Baistow, 1995). If services impose a discourse of empowerment on people who are not able to realise those opportunities, then we further exclude and 'disempower'. The dialectic within which both services and service users are located is between the concept of the individual as victim of external forces beyond his control and the individual as responsible for constructing a sense of self-efficacy and control over his life.

To a greater or lesser extent participants wished to maintain or reclaim some level of control over how their illness was understood and treated. The way in which that was negotiated depended on the service, the service user and the context of their interaction. In a world which is increasingly fragmented and in which expertise is increasingly pluralised, there may be, for some people, points in their lives when they wish to re-invest professionals (in the absence of the priest) with unquestionable expertise which they can trust; there is both scepticism and hope held in an uneasy balance. Service users hold a great deal more power, although the extent to which that power is felt, desired and able to be exercised will vary. Services in both urban and rural areas need to be able to hold and respond to this shifting and ambiguous picture and further research is needed to identify and highlight examples of 'best practice' both in the UK and abroad.

One of the particular challenges of conceptualising need for HIV positive gay men in rural areas is the absence of a collective voice or community and in the absence of clear alternative discourses, the medical discourse was more powerful than it was for the men in London. Rural culture and relationships are lived more traditionally and hierarchically and are less open to change, challenge and diversification. This culture affects the ways in which gay HIV positive men are able to develop their own sense of what they need and the



ways in which they are able to articulate that need. A politically strong identity was a less available and less desired discourse for the rural participants. It may be that rural services need to create strategies to enable gay men to draw on the strength of a collective voice or perhaps simply to promote ways of information sharing and support within a less politically activist population. Both medical and psycho-social support services in rural areas were more likely to have a 'doing for' culture which may be appropriate for the very ill but can perpetuate a sense of helplessness. On the other hand, the healthist discourse generally adopted by London services promotes individualism and responsibility which is appropriate for men who are able to take those opportunities but risks alienating those who are unable to cope. Services for HIV positive men in all areas need to balance 'doing for' services for the sick and dying with a healthist discourse for those who can look to their future. They also need more carefully to consider what support frameworks people will need in order to create a coherent sense of meaning for themselves as gay and HIV+; to form relationships with others which are fulfilling and sustaining and to be able to make choices in relation to treatment, lifestyle and so on.

### **7.53 - Men living in rural areas: conclusions and recommendations**

The recommendations for services made below draw on the expectations of services as laid out in Department of Health literature (see chapter 3) and the stated requirements as expressed by the research participants. There are several components to the National Strategy and the Toolkit for Commissioners discussed earlier which relate to the results of this research study in terms of the needs of HIV positive gay men living in rural areas:

- The need for partnership working without losing sight of local need
- The relation between health, poverty, social exclusion and stigma
- The implications of losing ring-fenced funding for HIV services
- The need to keep the service users' voices at the centre of policy and service development and provision

It is important to emphasise that the recommendations for services made here are tentative only. If services are to be fully responsive to individuals, they will incorporate more creativity and diversity than could be included here.

### **Narratives of inclusion/exclusion: experience of services in rural areas**

There are continuities as well as points of significant difference in terms of the support requirements of HIV positive gay men whatever their area of residence. Differences in space and community mean that the ways in which these requirements are met may need to be different. The results demonstrate that, on the whole, gay positive men living in urban areas felt reasonably well catered for in terms of a choice of accessible and appropriate services. Men in rural areas, however, did not always feel that they had the support they needed. The Department of Health makes a specific connection between social exclusion and health need; the National Sexual Health and HIV Strategy states as its two main aims to improve the health and social care of people living with HIV and to reduce the stigma associated with HIV. Gay positive men living in rural areas by definition are socially excluded in terms of access to health services and living with a stigmatised condition. The loss of ring-fenced funding may pose a particular threat to these men. Rural services need to take up the challenge of assisting gay HIV+ men in creating narratives of meaning from within the dialectic inside/outside, belonging/not belonging.

### **Narratives of meaning/meaninglessness: gay HIV+ men in rural areas**

The National Strategy states that services benefit from a relationship of negotiation and dialogue with service users. Each individual will construct a unique meaning system around their illness and services can work constructively within that meaning system. Services therefore need to consider where an individual places HIV in their lives and how this may change over time according to different circumstances. Responsive services are aware of the importance of an individual's sense of control over their life, body and relationships; their own identity and the role of hope and a sense of the future. HIV positive service users need to establish a sense of 'fit' and

coherence in their lives and services can assist individuals in altering their understanding and coping strategies to incorporate HIV in a meaningful way.

Services may assist individuals in their process of meaning-making by offering them a range of different discourses with which to frame their illness, for example through discussion and contact with other HIV positive individuals. The NHS plan (2000) specifically states that public service users, not providers, need to be the focus of policy and service provision by matching services more closely to people's lives. Patient and user forums and similar measures to promote the voice of service users are vital in terms of providing people with an opportunity to frame their experience in discussing different aspects of their situation which are important to them. User forums and a powerful user voice give other positive men alternative discourses to that provided by their clinic doctor. In rural areas this may need to be set up differently and have a different remit given that fewer men in rural areas have a politicised identity. User forums in these areas would need to be sensitive to local need and may need to have a remit which emphasises support and information dissemination. Such forums would also have to be particularly sensitive to the smaller size of the community being served and issues regarding confidentiality.

Defining oneself as a gay man involves both a personal act of affirmation and a collective, political statement. If someone defines themselves as gay, that label will have a particular meaning for them and will have a particular impact on their world, and one may reinforce or undermine the other. Sexual identity is both a matter of describing oneself and one's world, and being described. Identity politics are powerful points of resistance to traditional sexual attitudes but the research data demonstrates that, for a sense of community to form, there has to be a large number of people in the same situation in a geographically concentrated area (see also Weeks in Harwood et al., 1993). Constructing and maintaining a gay identity in a rural space is a different process and carries different meanings (Smith & Mancoske, 1997). Establishing a gay identity is harder in a rural area. We establish our identity through the construction of our own stories, and the stories we tell both draw

on and influence the stories of others around us which altogether form the collective story of the community in which we live.

In a postmodern world, the individual constructing themselves amidst a plurality of choices is pitted against the more traditional security and political efficacy of community bonds. Theoretically at least, Queer theory allows us to celebrate our infinite potential, both within ourselves as individuals, and our collective potential for infinite diversity (Nicholson & Seidman, 1995). This is an uncomfortable, unsafe, but potentially liberating. On the other hand, there still exist the politically efficacious and personally affirming ties of identity politics which strengthen community bonds. The participants in both urban and rural areas looked for some sense of community, of belonging, of shared experience to balance, and to affirm the identity choices available to them.

### **Creating community narratives in rural areas: the role of services**

Gay HIV positive men living in any area benefit from a choice of support services and this will be harder to provide in a rural area of low prevalence and will entail greater travelling time and distance. Gay men in rural areas may miss a sense of community and shared experience with other people in the same position. Rather than adhering to the support group model which can work well in an urban setting, rural services may need to be more creative about facilitating links between service users who may live some distance apart. Services in such areas can develop strategies to cope with the transport needs of service users, such as volunteer drivers, increased mileage rates for Motability cars, car shares etc. Modern technology can eclipse distances in a way which can benefit positive gay men in rural areas and services could consider the benefits of chat sites on the internet, telephone meetings etc. which could allow men who may live in an isolated area to make helpful links. This also may alleviate anxieties about confidentiality which some men may experience. For example, the website for Positive Vision Surrey/UK includes support links, information about HIV, STDs, opportunistic infections, neurological problems, a chatroom, safer sex information and advice, and further links to different local and national organisations. Such

measures will facilitate gay HIV+ men living in rural areas to create narratives of meaning in relation to self and other.

Gay positive men need access to information about safer sex, medication, side effects, safer drug use, benefits, employment etc. In urban settings this will be easier as most individuals are able to visit an HIV service for information. Gay men in rural areas may be more dependent on accurate, up-to-date, comprehensive information from their clinic and for those men who do not access any other service, the clinic may be an invaluable source of peer information.

Again, voluntary organisations can play a valuable role in facilitating links between different individuals, perhaps a mentoring scheme for people who are newly diagnosed or first considering treatment etc. The clinic has a responsibility to facilitate accessing information and it may be that useful partnership working could take place within clinics with hospital staff and voluntary agencies. Clinics could hold legal and welfare rights surgeries, complementary therapies, information links and adherence support. The toolkit following the National Strategy specifically states that voluntary sector organisations are well placed to deliver social care and health promotion services and that it would be beneficial for the voluntary sector to work in partnership in an integrated way with clinic and surgery based services. Voluntary sector services also have a unique insight into local need and the views of local users. The Toolkit recommends that they should therefore be involved in local commissioning and planning. Several of the rural participants reported that their clinic was not 'user friendly' both in terms of its culture and in terms of practicalities such as opening hours. Voluntary agencies may usefully develop a training and educative function in relation to medical services as well as a role in training the users of services themselves about what is available and what service standards they should expect.

## **Telling/not telling within multiple identities**

In rural areas, gay HIV+ men may not disclose their sexuality or status to their friends, families or to sexual partners. Thus their relationships with professionals may be their only opportunity to define themselves in an act of disclosure. In addition, the discourse of professionals may be the only discourse available to these men in creating a narrative of self.

Confidentiality may be of great concern to any HIV positive individual but those gay men living in rural areas were part of a more closed community in which information can spread rapidly amongst the entire community, so the implications for breaches of confidentiality could be greater. Certainly disclosure carried a considerably higher risk for the rural participants. Services in rural areas need to balance these concerns with the importance of forging links between different HIV positive individuals, bearing in mind that they will be drawing on a small pool of gay men both for service users, volunteers, employees and management committee members. Services in all, but particularly rural, areas could write into their policies a procedure for coping with the same individuals occupying a number of different roles within an organisation and ensuring that those who access a service for support are also enabled to take an active role in running the organisation without jeopardising that support.

## **Creating a narrative of an (uncertain) future**

The difficulty of moving beyond a victim mentality was a concern for some of the urban participants, but was a more pervasive difficulty in rural areas. Rural services need to consider the different discourses available to their service users to frame their experience and work at energising the service and fostering a sense of hope and future. This can be done by encouraging men to take an active role in identifying and accessing support and in running the service as a whole. Organising outside speakers and making links with different services can help to energise a service that has become stagnant

and provide a choice of narrative positions. Changing a culture can be painful and slow but HIV is a changing phenomenon and services need to reflect those changes. Within this, however, services have to acknowledge the difficulty for men to face the prospect of a prolonged future when for years they may have lived with a short prognosis. It is also important to remember and give a place to the men who are still ill and dying as a result of HIV. Services need to be able to hold several discourses concurrently – a discourse of self-responsibility and future for those whose health is good and a discourse of palliation for those who are ill and dying.

### **Different communities in rural areas: implications for services**

There was an urban and rural difference in the way in which relationships were constructed and this included family relationships, friendships and sexual partnerships. Rural participants were more likely to be in touch with their families and regard them as an important part of their network and indeed in many cases family ties had kept them in the area or had been instrumental in an individual's decision to move back to his place of birth. Services in rural areas need to be aware of the role of families in a person's care and provide appropriate support where necessary. This might involve facilitating links between different families to break down the isolation which can be experienced, particularly with a stigmatised condition. Again, because of possible concerns with confidentiality and potential transport difficulties, it may be that telephone links and one to one meetings may be more appropriate than a support group model, although support groups can be helpful in breaking down stigma. If families are to play an important part in a positive man's care, they need to be given the appropriate information and support in order to do this effectively. A systems model in working with rural gay men which would place the individual in the context of his formal and informal networks, may be helpful in identifying his sources of support. Appropriate carer and family support might include telephone support, 1:1 networking, home visits, hospital visits, counselling, respite, advocacy, complementary therapies and information. Families will be challenged in

creating a new family narrative which incorporates an understanding of gay sexuality and HIV.

Rural participants were more likely to include heterosexual men and women in their friendship networks, perhaps because there are fewer gay men on which to draw for friendship and perhaps also because neighbourhood networks are tighter in a rural area. Services in rural areas again need to be aware of the support and information needs of the individual's friendship network. Information aimed at all members of the population is important in terms of breaking down the walls of silence and stigma and rural services may have to work particularly hard at integrating themselves in all aspects of the community – local churches, youth clubs, community centres, schools, police etc. The promotion of information aimed at all sectors of the population which is mentioned in the strategy would be particularly helpful in rural areas. Such measures would help to create new community narratives.

Sexual relationships in rural areas were constructed along more traditional 'heterosexual' lines and casual sex tended only to take place in cruising grounds rather than in pubs or clubs. This has important implications for outreach and HIV prevention work. Again it will be particularly important for rural services to foster positive working relationships with the police in order to ensure the safety and confidentiality of men using the cruising grounds. Men using cruising grounds may not be accessing other services so outreach work should include HIV specific support and information for men who are or who may be positive rather than simply HIV prevention work. HIV services in rural areas may also need to consider couples counselling to ensure that again the positive person's system is taken into account. The results of the research demonstrate that the position of HIV within the relationship (i.e. where each partner positioned the virus in terms of its importance in their lives and in the relationships) was salient in terms of coping and relationship counselling may enable partners to take a complementary approach to dealing with the virus in their lives. Services need to deconstruct the gay / straight HIV+/HIV- dialectics to appreciate the unique ways in which individuals will live and experience their sexuality.



## **Creating quality services which incorporate difference**

Gay positive men in both urban and rural areas were concerned to receive a quality service. In an urban setting, it is easier for an individual to check with his peers and compare his service with that of others. It is also easier for him to be supported by his peers and by other services in making a complaint. Rural areas are generally less challenging of traditional hierarchies and social norms which makes it harder for those who do need to challenge the quality of the service they are being offered. Services in rural areas need to consider how to evaluate services, to facilitate feedback from service users and how to tailor services accordingly, through the development of patient forums, user-led groups etc. This is particularly important in areas where there may not be a choice of services and so service users are not able to vote 'with their feet'. National standards have a role here but it is vital that quality standards are not translated as unified services. Rural services need to be qualitatively different given the qualitative differences of life in the areas they serve but positive men in those areas can be given an assurance that the overall quality of their service is nationally set and measured.

## **Sexual narratives in rural areas: implications for services**

There was a difference between the urban and rural participants in the way sexual difficulties were articulated. The urban participants termed it 'sexual dysfunction'; a clinical condition to be treated pharmaceutically and/or with sexual counselling. The rural participants described a lack of interest in sex and did not discuss it with their doctors or HIV services. Services need to be aware of a difficulty in discussing sexual matters and services in rural areas need to give service users explicit 'permission' to discuss sexual concerns. Again, information about sexual dysfunction and HIV may help to promote discussion about this issue. This may need to be raised as a standard question in clinic appointments and accessible written information should be circulated about sexual dysfunction and how it can be treated. We should beware of interpreting sexual dysfunction as only a physical problem or only

an emotional issue by developing a range of approaches to facilitate discussion and support in this area. This will involve both therapeutic and clinical approaches and will require close working links between outreach workers, medical staff, psychologists and counselling services. Services will thus incorporate both sexual narratives and the narrative of HIV, and the uncomfortable space between the two where one is often undermined by the other.

### **The clinic as the dominant discourse in rural areas**

It was striking that the perception of several of the urban participants of rural life and rural experience was not the same as the perceptions of the rural participants themselves. It is heartening that access to medication and treatment seemed to be of the same standard whatever the person's area of residence, although there was a difference in terms of the perceived attitudes of doctors in urban and rural areas. It was apparent from the data, however, that individuals living in rural as well as urban areas wished to be heard by their clinic doctor, to be appreciated holistically and to feel they had choice and jurisdiction over their treatment. Again, if there is less choice available, it is perhaps even more important for service users in rural areas to be able to trust the treatment provided by their clinic doctor. National standards of care should include not only pharmaceutical care but also the psycho-social support offered by clinic staff and the 'culture' of care which should include a holistic approach and patient involvement. The development of patient and user forums within clinics may help to facilitate this and medical staff may need to be aware that some patients will not be accessing any other service in relation to their HIV. Increased dialogue between clinics and voluntary organisations may facilitate opportunities for information sharing and both formal and informal group and peer support. These measures would encourage a diversity of discourses available to individuals.

## **The challenge for rural services: narrative diversity in areas of low prevalence**

HIV is a changing and fluctuating condition, in the way it is experienced by individuals, in the way medical treatment has extended the anticipated prognosis of patients and in the level of health that people are expected to experience. The most appropriate services will be those which operate flexibly and responsively in an environment where on the one hand, people are living longer and more healthily, and on the other people will still have periods of ill health and others are still dying as a result of HIV. It is important that services remain responsive to the role of HIV medication in people's lives as this can play an even more prominent role in an individual's experience than the virus itself. Service users need to consider how medication will fit into their lives, changes in identity when starting, changing or stopping medication, and may benefit from 'informal' peer information exchange about medication issues and support when starting a new regime. This flexibility of response presents a particular challenge to rural services which will have fewer resources than larger urban services. Small, time limited discussion groups on topics raised by service users, short information sheets on particular topics, outside speakers, partnership working with other agencies and use of the internet are all realistic and feasible ways in which small rural services can respond to the changing and diverse needs of their users. These measures would provide service users with a number of different narrative discourses.

### **7.54 - Resourcing services**

The ending of ring fenced funding for HIV services has important implications and has given rise to heightened anxieties about how services can be resourced and funded. This should not, however, be regarded as an automatic stumbling block as the recommendations I have outlined rely on creative facilitation of communication between service users and between professionals; a facilitation which has neither major financial nor personnel implications. Rather it demands a process of 'freeing up' what has perhaps

become a rather rigid and narrow means of providing services. There is a rich pool of volunteers, both HIV positive themselves or concerned about issues of HIV who could be used to implement these new developments with a paid professional from within the clinic and/or from a voluntary organisation acting in a co-ordination/training/support role.

It should be emphasised again that the suggestions and recommendations provided here are in no way intended to be prescriptive. Rather they are tools intended to create new potentialities for gay positive men living in different areas, new narrative discourses which have the potential to 'free up' and diversify. The challenge for urban services, on the other hand, takes place within a field which already is diverse but inherent within this diversity are discourses which seem to carry a moral and oppressive force.

#### **7.55 - Men living in urban areas: conclusions and recommendations**

Men living in urban areas have the luxury of a choice of services but there is always a danger that choice can degenerate into fragmentation. Services in urban areas need to build on the best of partnership and collaborative working whilst allowing individual services to retain their own particular character. Positive gay men in urban areas are anxious that mergers will create large faceless bureaucracies out of HIV agencies which were born out of political ideals and the traumatic experiences of the early days of the epidemic. Whilst there is a need for streamlining and efficiency, it is important that agencies remain small scale and personalised at the coal face.

The other danger of choice is the difficulty of good information dissemination. There is a need for clear written information about what is available where and when so people can make informed choices about which services they access. Although the National AIDS Manual gives very comprehensive information, its size can be rather forbidding and it is vital that this is complemented by clear information given by individual agencies about their own and other organisations. Increased partnership and collaborative working should facilitate appropriate cross referrals.

Gay positive men living in London are such a diverse group that it is almost impossible to generalise at all. Services will need to bear in mind the heterogeneity and mobility of their user base – most gay positive men in London were not born in London, will move frequently to different areas of London, and also many men who use the London scene or London HIV services do not live in London but travel to the capital to access these services. This requires urban services to be particularly flexible in terms of their funding base so that they can have as loose a catchment area as possible.

On the whole, London-based HIV services have placed increasing emphasis on living healthily with the virus and making choices for the future and this reflects the new reality of many men's lives post-anti-retroviral therapy. There needs, however, to be an understanding that this discourse is not appropriate for everyone; men who are sick and dying as a result of the virus may well need the 'doing-for' services which have existed in the past. There are psycho-social as well as physiological issues which may prevent men from framing their lives through a discourse of individual responsibility and empowerment. HIV services need to work alongside palliative care services and mental health services to ensure that those for whom anti-retroviral therapy has not been successful still receive appropriate medical and psycho-social intervention.

Whilst services in rural areas have to rise to challenge of facilitating a range and diversity of narrative discourses within a heteronormative culture of low prevalence, the challenge for urban services is to retain heterogeneity whilst ensuring this does not fragment into meaningless chaos.

### **7.5 – Stories of services. Conclusion**

The difficulties the participants experienced centred on holding paradox and contradiction – when one framework of ideas was contradicted by another and gave rise to uncertainty about what was 'reality'. Participants struggled with

seemingly mutually contradictory versions of 'reality' and some made almost arbitrary decisions about what they would choose as their reality, based on what frameworks or models the people around them were using, or maybe what seemed to be most functional for them.

This is a particularly post-modern project – participants chose their own reality more or less consciously in a world of flux and competing realities. We need to do this in order to feel ontologically secure – the self is seen as a project for which the individual is responsible and the complexities of this process is one of the pressures of modern life. One of the principle dilemmas of living in the modern world is unification versus fragmentation: how do I cope with maintaining a coherent sense of who I am in the midst of competing discourses about how I should be? (Giddens, 1991). The primary threat with which we grapple as a day-to-day physical reality is the threat of meaninglessness and participants created meaning for themselves about their sexual identity and their illness by adopting some discourses of identity and of the body and avoiding others.

It may be easier to die in a rural area as a result of HIV but it is difficult to live positively. Conversely, it is easier to be healthy in London as HIV positive but harder to die. Services for HIV positive men in all areas need to hold the tension between 'doing for' services for the sick and dying and a discourse of healthism, individual control and choice for those who are more able to look to their future. We must guard against a dynamic of passivism which can be created between service users who have constructed an identity of sickness and service providers, anxious to help, who perpetuate a sense of helplessness. On the other hand, we must guard against losing the experience of those who face fundamental obstacles as a result of physical ill health, psychological or social pressures. A healthist discourse can promote choice and control but can be an overwhelming and ostracising burden for someone who is struggling to survive.

We learn through the experience of those around us. Gay positive men and organisations serving them based in rural areas face a particular challenge of

the isolation of low prevalence. Rural services need to foster ways in which these men can create and hold a collective voice which may not be politically activist but will be collectively supportive.

HIV is not about to go away, but its lived reality is changing and will continue to change whilst also staying the same. In both urban and rural areas, gay positive men and their support services need to learn and integrate the lessons of the past whilst moving into the future with an openness to change. In recent years we have experienced a pluralisation of choice of ways to live our lives. We are now faced with ethical questions about the legitimate limits of individual choice and with the challenge of constructing our own identity. We are living in a world of increased uncertainty in which the old legal and moral absolutisms are fading but the alternatives, which each individual needs to arrive at for themselves, have yet to be worked out. HIV brings up issues of boundaries, which separate people from each other, and identities, which merge them. Living with HIV is a crisis of opportunity; providing us with the means to appreciate the uncertainties but also the possibilities which can give us new meanings. HIV connects this search for meaning with our relationships with others.

## **7.6 - STORIES OF STORIES**

In this final section I weave together the idea of narrative meaning in relation to space, relationships, identity and health to create a meta-analysis of the narratives themselves within the narrative of this research.

### **7.61 - Telling stories**

Narrative meaning is created in the telling of stories: they comment on experience without splitting off from it. Narrative, like HIV, treads the space between self and other, individual and collective. Narrativising experience is to perform the self and to blur the boundaries between the one who tells and the one who hears. Similarly, narrative research articulates the space between participants, researcher and reader and control over meaning is not clearly held by any one person (Mattingly, 1988, p289).

Ricoeur (in Wood, 1993) describes emplotment as incorporating two understandings of time: an open and indefinite succession of events (and then?...and then?...) *and* integration, culmination and closure (a beginning, middle and end). The framework holding the participants' stories and the story of this research are arbitrary and contingent; they are all stories 'in process'.

### **7.62 - Listening to stories**

This web of stories incorporates:

- The participants' narrative as recorded in the interview
- The narrative of the research project as a whole
- My narrative which forms part of my role as listener, reader and writer
- The narrative of each reader (which will also include myself as the researcher and the participants)

Reading the narrative is an act both of completion and creation. It connects this story to a multiplicity of others beyond the research itself.

The act of reading the narrative is a crucial stage in the whole process; not only do you as reader create the narrative in the act of reading, but you also



read yourself into the narrative. The act of reading takes place at multiple levels in research: the participants become their own readers as they read their transcripts and the finished piece of work; I 'read' their narratives in the context of the interview; they read what I have heard and written and the you the reader read yourself through this multiplicity of other readings.

### **7.63 - Stories of meaning**

We search for meaning and identity through narrative. My research constructs a new narrative of meaning through the hearing and recounting again of the individual narratives of gay men living with HIV. The self is actually created through the stories we tell about ourselves, these explain who we are both to others and to ourselves (Kelly & Dickinson, 1997, p276). To ask what I am in abstraction from self-interpretation makes no sense. Our lives themselves can be assimilated into a story and are understood both to ourselves and others through the reflexive stories we tell about ourselves.

The participants both tell their stories and create their own meaning constructions from their experiences. Through narrative we come in contact with participants as people engaged in the process of interpreting themselves and thus we can gain an understanding of how such accounts constitute rather than simply reflect the realities of the social world.

Participants are engaged in a process of structuring and restructuring their world views as a result of remembering, disclosing and living through the reverberations of 'telling'. The writing and the reading of this study is a snapshot moment of that continuing and evolving process. The multiple layers of living, telling, writing, and reading our lives are an integral part of what it means to make meaning and they create a potential space where the boundaries between oneself as knower and the other as known are relaxed.

We only exist in relation to the other: the concept that we shape our reality through the telling of it creates the potential for new understanding.

#### **7.64 - Stories in society**

Individual understandings are socially, historically and politically constructed. In turn, our individual understandings shape social, historical and political discourse. This research is located within a specific historical, cultural and political context which affects how it is spoken, written and read. Narrative forestalls a split between individual and society (Fischer-Rosenthal in Chamberlayne et al., 2000) – it is a way of being within and without, of treading that space. Because narrative is situated in the spaces between self and world, change and continuity, the individual and collective, it articulates these spaces without imposing rigid distinctions.

We appropriate existing discourses to describe ourselves in a process which is unique, shifting and contingent. There are a number of dominant, competing, conflicting and shifting discourses of HIV and participants positioned themselves in specifically individual ways in relation to these public narratives.

Narrative serves a collective as well as an individual function, both the narratives we tell about ourselves and the communities which feed and are fed by this process. Our stories allow us to construct a narrative identity at a historically collective as well as at an individual level. The necessity of a reader/listener in narrative gives us a sense of self in relation to others. Narratives play out the interrelationship between collective memory and myth on the one hand and individual experience on the other. They emphasise both the diversity of social experience and how each individual story builds on a common culture.

## 7.65 - Ethical stories

Narrative is a means through which we assess and judge ourselves, our lives and our relationships. So the stories people tell not only offer a window into subjective experience, but also have an ethical or moral function as the means through which we question, judge or validate our values, behaviour and beliefs.

Healthism is a particularly prevalent postmodern narrative. This imperative towards a reflexive concern with life, self and the body is resulting in a wide resurgence of interest in moral, political and ethical issues. Like many dilemmas in our world, it is the dilemma of choice, of plenty and of relative freedom and prosperity. Yet the expectation that we should live self-consciously is potentially yet another burden: 'the necessity to narrativise our lives in a vocabulary of interiority. The self that is liberated is obliged to live its life tied to the project of its own identity' (Rose, 1990, p254). There is a 'moral imperative' inherent in polyphonic narratives which require a commitment to shaping oneself as a human being. It might be that the expectation to take personal responsibility for the meaning of illness is experienced as an extra burden and the shade of differentiation between personal choice as liberation and personal responsibility as oppression is nebulous. The individual taking of responsibility and power is very close to the apportioning of individual blame. Similarly, a focus on the political, social, economic and cultural factors in health and illness threaten to assign the ill person a powerless victim status. Frank's (1998) evaluation of stories of illness in relation to the care of the self moves towards a synthesis of these different possibilities. He asks if personal narratives liberate the speech of the ill from social resistance or if they are simply a gentle form of compelling this speech. He suggests that reflection of what sort of stories we want our lives to be and what sort of stories we want to avoid are the core of any personal ethics. The ethical is animated by power

and power is imposed through ethics. He resists imposing a divide between technologies of the self and the practices used in the care of the self.

This tension between personal choice as liberation and personal responsibility as oppression is evident in the research data. Participants experienced this differently but for most there was at least some belief that taking charge of one's life and 'living well' was a current moral imperative.

### **7.66 - The changing story of this research**

Stories are not static. Over the years it has taken to carry out this research, the stories of HIV and gay sexuality have changed, yet also stayed the same. The story of HIV has increasingly become a healthiest discourse of 'Living Well' and a project of that name based in London is currently flourishing. The government have made changes to incapacity benefit to encourage people to go back to work and this will undoubtedly affect those with HIV. I work in a London-based hospice where approximately 50% of our in- and day care patients at any one time are HIV+. Fewer of these patients require palliative care, although some certainly are in need of palliation, but increasingly individuals present with problems of living: mental health difficulties, substance misuse, housing and financial difficulties, problems with anti-retroviral therapy. Many of these individuals in addition struggle with their sense of self and how they can live a life which is meaningful for them. Their struggle is with the areas of living explored in this study: with their sense of space and community; their relationships with others; their understanding of themselves; their understanding of their physical selves as HIV+ and their relationships with professional services.

The story of gay sexuality has also changed and yet stayed the same. During the course of writing this research, the Civil Partnerships Act 2005 has accorded legal, social and cultural status and recognition to same sex couples. This new legal discourse provides gay partnerships with a new legitimacy. Like many legal changes, this both is a result of and also now changes the social discourse of homosexuality. On the other hand, during the

journey of this research, gay men have been targeted by nail bombers, the Catholic church has continued to ostracise its (active) gay members and 'gay' is accepted teenage slang for 'lame', 'useless' and 'no good'.

### **7.6 Stories of stories. Conclusion**

Stories are told in space and in community, for ourselves and in relationship. Stories are told through words and inscribed on our bodies. We create our stories out of what is available to us in our time, space and history. We make choices about what sort of story we tell and to whom we tell it; stories have a narrator and an audience, including those stories which we tell to ourselves. In telling me their stories, the participants were creating a narrative of their lives which they were in part telling to themselves; in part to me as an individual and as researcher, and in part to an intended audience of (invisible and potential) readers. This single piece of research is multi-vocal and this chorus of voices joins the other many voices in the field in this deeply personal and deeply social enterprise. The content of the individual stories, and the content of the research holds significance but this also has to be considered alongside the fact that the participants, and myself as researcher, are involved in a social and cultural process of story telling which leads us to tell this particular story at this moment. And you, the reader, bring your own story and this too is part of a social and cultural story which will lead you to read this and to bring a certain constellation of meanings to what you read. We are telling the story of our time, true for this moment, and deserving to be told with passion because it is about real embodied, breathing lives, but the stories will change and from it will emerge different stories born from these:

'We experience our bodies and our feelings, as well as our behaviours and talk. And everywhere we go, we are charged with telling stories and making meaning – giving sense to ourselves and the world around us. And the meanings we invoke and the worlds we craft mesh and flow, but remain emergent: never fixed, always indeterminate, ceaselessly contested. Change is ubiquitous: we are always becoming, never arriving; and the social order heaves as a

vast negotiated web of dialogue and conversation. So-called social science is not cut off from this activity but is itself very much a part of it: it is simply an occasion of more systematic reflection and story-telling upon the world' (Plummer, 1995, p20)

The participants' stories were a continuum 'and...and' as well as having a coherence of a beginning middle and end. Similarly, this research forms part of a continuum of research narrative as well as having its own coherence. This research also has a specific historical context, located within an academic milieu which grapples with a postmodern 'life politics' of fragmentation, discontinuity and contradiction. As with issues of identity we struggle with limiting ourselves on the one hand and chaos on the other and the participants, myself as researcher and you as reader will make pragmatic and even arbitrary decisions to foreclose in order to make sense out of possibility. The dilemma of the participants' stories and my dilemma as researcher is how to remain open to possibility without falling into chaos; if we foreclose, we limit and if we open fully to the infinity of meaning then it all becomes meaningless. We create stories as fictional representations of the complexities of lived meaning in order to create and convey sense from chaos, yet, at the same time these stories are painfully, passionately, vividly real.

Any story can be both radical and conservative and this is also true of participants' individual stories as well as the story of the research as a whole. The data demonstrates that the participants held an unresolved tension between what Plummer (1995) terms 'modernist stories' and a postmodern fragmentation and contingency. I suggest that such a tension is also inherent in this research. On the one hand the participants used pre-existing cultural stories of Coming Out, of illness with HIV etc. as pegs on which to hang their experience. At the same time, there was always a sense that their own unique story was far more than the language in which, at that moment, they were choosing to frame it. Similarly, this research uses pre-existing social and cultural frameworks of meaning and at the same time struggles to emerge into

something new. We need the 'modernist conventions' (Plummer, 1995) as launchpads into a new multivocality:

'Some stories work so well because they fit into the major rituals of story telling...Their ultimate pragmatic function is to make the world safe for us, to keep the threat and terror of life at bay. Even seemingly radical stories...take on conservative functions once they assume traditional narrative forms' (Plummer, 1995, p177).

A clear narrative flow provides order and it is from *within* this order that a postmodern ambiguity can emerge and be expressed:

'Stories are often, if not usually, conservative and preservative – tapping into the dominant world view...But...stories can also be radical in their implications' (ibid, p178)

The dialectical oppositions for gay men living with HIV have become more complex, more pronounced, more challenging. The participants in this research continue to negotiate these spaces and this research also places itself in the space between. Your challenge as reader is to consider your own position – different from mine or from the men presented here; your own unique, shifting, contingent 'fiction' of meaning-making. Thank you.

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## APPENDIX 1

### PROFILE OF SERVICE PROVISION IN YORKSHIRE & LONDON

#### Services in North East England

This information is taken from The National AIDS Manual which gives comprehensive information of services available in each area of the country. This information covers North Yorkshire including York, East Riding of Yorkshire including Hull, Doncaster, Wakefield, Barnsley, Sheffield, Rotherham, Kirklees, Calderdale, Bradford and Leeds. I did not interview men from all of these areas but the men I did interview were reasonably able to access all of these services and several did travel out of their immediate area for their services. This information was accurate at the time of the research, but clearly in a rapidly changing field it will quickly date. For example, at the time I was gathering this information from NAM, I was aware that PAL (Pennine AIDS Link) the main voluntary organisation available in Bradford for people with HIV, had been closed down, and at the time of my research there was no equivalent organisation available in the area.

I have given details only about the services for positive gay men rather than for Africans or Intravenous Drug Users, or for health promotion as this constituted my research population. Also, when organisation had different branches across the area, I have counted the organisation as 1.

Services providing complementary therapies: 6

Organisations providing services some specifically targeting gay men: 9

GUM Clinics/HIV testing centres: 25

Helplines: 21

Hospices/respite care: 27

Gay organisations: 8

Self-help HIV/AIDS groups: 3

Support groups: 14

In this next section I again use NAM to give a profile of the services available in each of the regional centres which most of my research participants would have been able to access most easily. Again, I am only including services which exclusively or partially target gay HIV positive men, rather than services which primarily work in HIV prevention or who target different groups affected by HIV.

### **Services in Leeds**

#### □ Leeds City Council

HIV Sexual Health and Drug Unit acts as an information and referral point to the full range of council services for people affected by HIV/AIDS

#### □ Leeds Community & Mental Health Services NHS Trust

This service has a nutrition and dietetic department which gives information regarding HIV nutrition issues

#### □ Leeds Daybreak Trust

Is a charity which makes grants to people living in financial need who are living with HIV/AIDS and to their partners, family and carers.

#### □ Leeds Lesbian and Gay Switchboard

Gives advice and information about local groups and services and offers counselling

#### □ Leeds Health Authority

Co-ordination of HIV work within the health service; responsibility to work jointly with other statutory and voluntary agencies in Leeds.

#### └ The Leeds Hospital NHS Trust

Leeds General Infirmary GUM Department provides general GUM services, HIV testing including same day testing, designated HIV Clinic, an HIV

pharmacy service, inpatient care, Counselling and support services provided by health advisors and a social worker.

Palliative Care Team provides care for, among others, people affected by HIV/AIDS

- St Gemma's Hospice

Provides care for, among others, people affected by HIV/AIDS

- St James' & Seacroft University Hospitals NHS Trust

Provides HIV testing including same day testing, HIV related care and counselling services, including dietetic and physiotherapy services and access to social workers, facilities for day care and in-patient treatment

- Terrence Higgins Trust Yorkshire

Provides drop-in sessions including a gay men's drop-in, information, support, advice, complementary therapies, counselling and information drop-in

- Wheatfields Hospice

Provides care for, among others, people affected by HIV/AIDS

- Yorkshire MESMAC

Provides a social group for gay men, as well developing as a number of other non HIV-specific projects with a campaigning and health promotion remit

### **Services in Bradford**

- Bradford Council

HIV & Sexual Health Unit provides counselling and advice

- Bradford Friend

Provides information, support and befriending

- Bradford Hospitals NHS Trust



St Luke's Hospital Department of GU Medicine for Sexual Health provides an HIV Clinic, access to counselling, health advice and HIV testing (results available in one week)

Palliative Care Team provides palliative care for, among others, people affected by HIV/AIDS

- Bradford Lesbian and Gay Switchboard

Advice and information about local groups and services

- Pennine AIDS Link

Provides a community support service (practical and emotional support, advice, financial assistance and home visits), drop-in and complementary therapies

- Yorkshire MESMAC

A sexual health organisation for gay men and men who have sex with men

### **Services in Halifax**

- Calderdale Council Social Services Department

Social Services for adults affected by HIV/AIDS

- Calderdale Health Care NHS Trust

Calderdale Centre for Sexual Health provides a clinic, HIV testing (results available within 1 week), inpatient care

- Calderdale & Kirklees HIV/AIDS Link (CKHAL)

Support and information on HIV/AIDS. Counselling, complementary therapies, practical assistance, advice

## **Services in Wakefield**

- **Begin Living and Learning with HIV**

Offers care and support services to individuals infected with or directly affected by HIV/AIDS, including befriending support, complementary therapies, financial assistance, support group for positive people, information and resources, access to the internet

- **Pinderfields & Pontefract Hospitals NHS Trust**

Clayton Hospital GUM Department provides clinics including an HIV clinic, HIV testing (result available within 3 days), outpatient reviews, access to specialist health advice, inpatient care, palliative care

- **Wakefield Hospice**

Offers care for, among others, people affected by HIV/AIDS

- **Wakefield & Pontefract Community Health NHS Trust**

A comprehensive counselling service for anyone affected by HIV/AIDS, support for carers, home visits possible.

- **Yorkshire MESMAC**

A sexual health organisation for gay men and men who have sex with men

## **Services In York**

- **Gay Switchboard North Yorkshire**

Advice and information about local groups and services

- **North Yorkshire AIDS Action**

Offers a wide range of services (including practical and emotional support) for people living with HIV/AIDS and their carers, family, partners and friends. Community Support Services include befriending, transport, legal advice, information, advocacy, welfare rights advice, complementary therapies and

practical help. North Yorkshire AIDS Memorial Quilt Group also meets regularly. Support groups and networks for people who have tested positive, carers and bereaved carers. Resource Centre and a small welfare fund

- North Yorkshire Health Authority

Responsible for the commissioning of HIV and sexual health services

- St Leonard's Hospice

Offering care for, among others, people affected by HIV/AIDS

- York City Council Social Services Department

First point of contact for people affected by HIV/AIDS requiring social services

- York Health Services NHS Trust

Monkgate Health Centre GUM Department: Provides clinics, HIV Testing (results available within 1 week). A Clinical Nurse Specialist is available who works in acute and community care to set up support treatment for people with HIV living in the community.

Sexual Health Services: Provides an HIV testing service

- Yorkshire MESMAC

A sexual health organisation for gay men and men who have sex with men

It is significant to compare the perception of service choice and diversity presented by these NAM entries and the perception of choice held by the participants living in these areas as outlined in the research data.

### **Services in London**

The information below is again taken from NAM and covers London-wide agencies, i.e. agencies which cover all London Boroughs. The men I interviewed who were living in London would be reasonably able to access all of these services. As with the information about services in the North East,

this information was accurate at the time of the research, but clearly in a rapidly changing field it will quickly date.

Services providing complementary therapies: 38

Faith Communities: 17

Organisations providing services specifically targeting gay men: 41

GUM Clinics/HIV Testing: 37

Helplines: 77

Hospices/respite care: 28

Housing Agencies: 11

Self-help HIV/AIDS Groups: 4(for gay men)

Support Groups: 29

It would be overwhelming to give details of all services across all London Boroughs so I have chosen one only – Camden - in order to give a ‘snapshot’ picture of organisations specific to each London Borough.

### **Services in Camden**

Complementary therapies:

- ❑ Central YMCA Positive Health Scheme
- ❑ Centrepeace
- ❑ Continuum
- ❑ FACTS
- ❑ The Link
- ❑ Royal Free Hampstead NHS Trust

Gay Men’s Services

- ❑ Camden & Islington Community Health Services NHS Trust
- ❑ Mortimer Market Centre GUM Department
- ❑ Chalk Farm Oasis

GUM Clinics/HIV Testing

- ❑ Camden & Islington Community Services NHS Trust Mortimer Market Centre GUM Department

❑ FACTS

- ❑ Royal Free Hampstead NHS Trust

The HIV/AIDS Unit

Ian Charleson Day Centre

The Royal Free Hospital Marlborough Clinic GUM Department

- ❑ University College Hospitals Group

Patrick Manson Unit

Helplines

- ❑ Camden CAB HIV Project

- ❑ Camden Council Social Services HIV Services

- ❑ Royal Free Hampstead NHS Trust, The Ian Charleson Day Centre

Hospices/Respite Care

- ❑ Marie Curie Centre, Edenhall

- ❑ St John's Hospice

Local Authority

- ❑ Camden Council Social Services, HIV Services

Support Groups

- ❑ Centrepeace

- ❑ Chalk Farm Oasis

- ❑ The Link

## **APPENDIX 2**

### **GLOSSARY OF TERMS**

#### **AIDS**

Acquired Immune Deficiency Syndrome

#### **Anti-retroviral therapy/anti-retroviral therapy**

The collective name for a combination of drug treatments aimed at reducing the replication of HIV in a positive person

#### **'Coming Out'**

The term used to describe the process of starting to be open about being gay or lesbian

#### **'Cottages'**

The name given to public toilets which are used for sex between men

#### **'Cruising areas'**

Areas where men look for sexual encounters with other men

#### **HIV**

Human Immuno-deficiency virus

#### **Public sex environments (PSEs)**

Places which are used for sex between men, often common land or heathland or public laybys

## **APPENDIX 3**

### **INFORMATION PACK**

**FOR A**

**COMPARATIVE RESEARCH STUDY  
ON THE  
EFFECTS OF URBAN AND RURAL LIVING  
ON THE  
SUBJECTIVITIES OF MEN WHO IDENTIFY AS  
GAY AND HIV POSITIVE**

***PhD Thesis***

***Katherine Cox  
Brunel University***

'Life is nothing until it is lived; but it is yours to make sense of, and the value of it is nothing else but the sense you choose' (John Paul Sartre)

*'The unity of a human life...is the unity of a narrative quest. We have to work at it' (Weeks, 1995, p31)*

**ARE YOU  
A GAY MAN  
DIAGNOSED AS HIV POSITIVE  
OR  
AS HAVING AIDS  
LIVING IN LONDON OR  
NORTH OR RURAL WEST YORKSHIRE?  
IF SO,  
WOULD YOU LIKE TO TAKE PART IN A  
COMPARATIVE RESEARCH STUDY  
EXPLORING THE  
EFFECTS OF URBAN AND RURAL LIVING  
ON GAY HIV+ MEN?**

IF YOU ARE INTERESTED, PLEASE READ THIS INFORMATION PACK  
AND/OR CONTACT KATHERINE COX DIRECT ON

***Tel: 07775677842***

***e-mail: [katherinevc@netscapeonline.co.uk](mailto:katherinevc@netscapeonline.co.uk)***

***address: PO Box 50, Twickenham, Middx. TW11YB***

***or via one of the link organisations named in this pack***



## **CONTENTS**

- **THE RESEARCH IN A NUTSHELL**
- **HOW MAY THIS RESEARCH BENEFIT THE PARTICIPANTS?**
- **HOW MAY THIS RESEARCH BENEFIT ORGANISATIONS?**
- **WHAT WILL BE THE CIRCUMSTANCES OF AN INDIVIDUAL'S INVOLVEMENT?**

What to do if you're interested

*What's in an interview*

*The first step*

*Taping and transcribing*

*What will the interview be about?*

*What form will it take?*

*Where will it take place?*

*When will it take place?*

*How long will it last?*

*What control do you have over the information you give?*

- **WHAT WILL BE THE CIRCUMSTANCES OF AN ORGANISATION'S INVOLVEMENT?**

*Using information gathered from organisations to provide a context for the interview data*

- **CONFIDENTIALITY**

- **WHAT WILL HAPPEN TO THE RESEARCH AND WHO WILL READ IT?**

□ **WHO AM I AND WHAT IS MY PERSPECTIVE?**

Academic background

*Professional background*

*Personal background*

□ **POWER AND DIFFERENCE**

□ **WHY ONLY RESEARCH GAY MEN?**

□ **HOW IS THIS RESEARCH DIFFERENT FROM EVERYTHING THAT'S BEEN DONE ALREADY?**

□ **ANY QUESTIONS?**

## ***THE RESEARCH IN A NUTSHELL***

What is the research about?

I want to find about how being an HIV positive gay man in a rural and urban environment affects your sense of who you are.

Why am I doing the research?

I am suggesting that living in a rural or urban environment may differently affect your experience of being gay and HIV positive

Why might you want to get involved in the research?

Taking part in the research gives you an opportunity to talk about what your experience has been as an HIV positive gay man. This may give you time to reflect on and give meaning to your own experience as well as reaching a wider audience of readers.

What would getting involved in the research mean?

I want to interview gay HIV positive men living in London and North and rural West Yorkshire. Very broadly I am interested in finding out how

Being a gay man

Being diagnosed as HIV positive

Living in an urban/rural area

Influences the way you feel about yourself

The interview will be at a place and time convenient to you.

What about confidentiality?

- If you prefer, I can contact you through a third party and you can give me a pseudonym
- The tape of your interview will be kept safely and separately from your contact details
- Other arrangements can be made if you do not want the interview to be taped

- All identifying details about you will be removed from the written research and you will receive draft copies to ensure that this has been done to your satisfaction

What control do you have over the process?

- If you don't feel comfortable with or don't wish to talk about a particular issue, that's fine
- You will have access to the pause and stop buttons on the tape recorder
- You can stop the interview and withdraw from the research at any point

What should you do if you're interested?

- Read the rest of this document which outlines the research in more detail
- Contact me directly on 07775677842, at [katherinevc@netscapeonline.co.uk](mailto:katherinevc@netscapeonline.co.uk) or at PO Box 50, Twickenham, Middx. TW11YB
- Contact one of the link organisations (see following page) who will be able to give you more information and/or contact me on your behalf

At present the organisations are as follows:

LONDON:

Gay Men Fighting AIDS – Carl Burnell 020 7738 6872

London Lighthouse – Adam Wilkinson 020 7792 1200

NORTH YORKSHIRE

MESMAC – Rob Wannerton 01904 620400

York social services department – Jackie Wishart 01904613161 ext.4128

WEST YORKSHIRE

BEGIN – John McKernaghan – 01924 211117

MESMAC – Tony Atkins – 01924 211116

CKHAL – Lesley Dunn or Alan Sherwood – 01422 341764

Links may be made with other organisations as the research progresses

## **HOW MAY THE RESEARCH BENEFIT YOU AS A PARTICIPANT?**

***'I want to be all parts of who I am' (Clausen, 1990)***

It would be impossibly arrogant of me to claim to know how each individual participant will benefit from the research but if I am to argue that it *is* important for you to benefit from your experience, I need to make at least some tentative suggestions as to why this may be to your advantage, For this I draw on personal experience, feedback from my Masters research and other literature.

Personally I find it of immense value to give myself time and space that is separate from the rest of my life to reflect on how I feel with myself, with my world, where I am, who I am etc. Being able to talk about these things with someone who is also separate from my life can both free up and clarify my thoughts. This is not therapy, it is simply time and space away from the rest of my life to reflect with someone else. The agenda I bring as a researcher is minimal and to a large extent you will have the opportunity to talk about what is important to you, because by definition that is 'valid data' for the purposes of this study.

For a lot of us it is important to have a sense that there is some meaning in things which we may find difficult, painful or confusing. Telling your story gives your life the coherency of a narrative. I believe that this helps to protect us from a sense of meaninglessness and chaos.

To produce a narrative is to presuppose a reader, and you will have both me as the 'reader' of your spoken words and the wider readership of the written research. For many of us it is important to create a monument to ourselves, to construct a memory, to put part of ourselves down as a written account and to reach a wider readership with that account.

I will give you a copy of the tape recording of the interview(s) (or a written transcription if you prefer not to be recorded). You may wish to have your own personal record of what you have said and how you feel.

There are many ways in which we can make a difference through and with our lives. We can give money, volunteer, demonstrate, write letters to our MPs etc. If you believe it is important to bear witness to who you are and why, for yourself, for people who may be in a similar situation to you and for professionals whose remit it is to provide appropriate and ethically grounded services, then participating in this study is a way in which you could make a difference.

Why this research may not be of benefit

There may be all sorts of reasons why you may choose not to participate in the research; some I can imagine and some I will not have thought of. If you decide not to participate, it would be really useful for me if you are able to let me know why not. People's silence is as important as people's words; if I don't know why you didn't participate, I will only be able to speculate and I may misinterpret your silence.

***What will be the circumstances of your involvement as a participant?***

What to do if you're interested?

You can 'phone me directly on my mobile (07775677842) leaving a name and contact number and I will 'phone you back. I will not, however, leave a message unless you specifically state that I may do so. Alternatively you can contact me via e-mail ([katherinevc@netscapeonline.co.uk](mailto:katherinevc@netscapeonline.co.uk)), by post at *PO Box 50, Twickenham, Middlesex, TW11YB* or through one of the link organisations named in this pack. If you are still interested in participating, we will arrange to meet.

What's in an interview?

*'The in-depth interview offers the benefit of seeing in its full complexity the world of another. And in collating in-depth interviews and using the insights to be gained from them as well as different kinds of information from other kinds*

*of records, we can come to some understanding of the process by which we got to be the way we are (Yow, 1994, p25)*

### *The first step*

There will be an opportunity for you to ask any questions about the research or to talk about any concerns you may have. You may also wish to meet me before you decide whether or not you want to participate.

### Taping and transcribing

If you agree, I will tape the interview, keep a tape for my records and make a copy for you to keep. This is for a number of reasons. If I know the tape will make an accurate record of what you say, I can concentrate on what you are saying then and there rather than be distracted by taking notes or by trying to remember in order to write it up later, both of which will inevitably mean I will lose a lot of what you say.

I will ask you before we start the interview if you agree to a recording being made. After the interview is ended I will ask you if you agree to me using the information in my research in a way that protects your confidentiality. Only you and I will have access to the tape and I will wipe my copy of the tape once my thesis is complete.

If you are concerned about a tape being kept by me at all, we could make a recording which I then transcribe and return to you. Alternatively, you could take the tape immediately after the interview, I will write up the interview as best I can from memory and written notes, send you the written transcription which you can check against the tape recording and amend accordingly. If you don't want any recording made at all, I will make notes during the interview, write them up afterwards and send them to you to check.

You will have access to the pause and stop buttons on the recorder. We will only start the recording when you are ready to do so and you can pause and stop at any time.



*What will the interview be about?*

Very broadly, I am interested in finding out how

Being a gay man

Being diagnosed as HIV positive

Living in an urban/rural area

Influences the way you feel about yourself.

This means that by definition what is important to you will be relevant to the research.

*What form will it take?*

Rather than asking you lots of questions, the above points are the broad areas which I will hope to cover, but if they don't feel relevant to you we will skip them and if there are other areas which are more significant to your life we will talk about them instead.

*Where will it take place?*

It is important that we meet somewhere which is comfortable for you, private and quiet. I can either meet you at one of the named 'link' organisations or, if you are already known to an organisation, I can visit you at home. If you are contacting me directly and not via an organisation, for yours and my safety I would prefer to meet you at the premises of an organisation. If there is a problem with transport and/or access, please let me know and we will arrange something to suit you.

*When will it take place?*

I will arrange to meet you at a time which is convenient for you.

*How long will it last?*

There is no rigid time limit at all, although it is often useful to stop after about an hour, simply because it is useful to break and to continue at another time.

There are several benefits to meeting on more than one occasion:

- if the interview continues for a long time, you may need a break and continue at another time

- in the break between meetings you may think of new things you want to say
- a lot of how you feel about the research as a whole will depend on how comfortable you feel with me and getting to know me will be a process that takes place over time

What sort of control do you have over the information you give?

As much control as possible. There is absolutely no pressure to answer particular questions and if you don't feel comfortable with or don't wish to talk about a particular issue, that's absolutely fine. If you want information you have given to be altered or removed, that's fine as well. You will have a copy of the interview for you to check and you will see a draft of the thesis before it is submitted.

*How may the research benefit organisations?*

'Is it not an enterprise to know how to and to what extent it might be possible to think differently?' (Foucault)

I hope that my research will give rise to whole range of information about what relationships gay HIV positive men have with themselves and with their world. I believe that this will provide a rich opportunity for organisations to evaluate their service provision in order to provide the most appropriate services for the people in their area. The qualitative nature of the research means that I won't be able to give out neat statistics, definitive answers or clear recommendations. On the other hand, the open nature of the study means that I may well be able to incorporate a particular enquiry which an organisation wishes to pursue.

Funding is always a crucial issue and I believe there is currently a devaluing of funding psycho-social support services. While current mergers have created more logical service provision, cutting back on bureaucracy and needless duplication, it is important that this does not lead to over-

homogenisation and a loss of clarity about the influence of locale on people's experience.

*What are the circumstances of an organisation's involvement?*

There is a link person in several different organisations who can act as a contact for potential research participants and encourage people to become involved in the research. Where possible, I would also like to be able to use a room for interviews, although if an individual is already known to an organisation, I would be happy to visit them at home.

The different organisations I contact are my link to potential participants and they provide a point from which information about the research is distributed.

If a particular or related aspect of the study is of particular interest to an organisation, I am able to highlight this in the research.

Each participating organisation will receive a copy of the thesis once it is completed.

*Using information gathered from organisations to provide a context for the interview data*

Although the core of my research will be the information I gather from individual interviews, I will also need to place this information in a context which takes account of the social, cultural and political issues and factors including the geographical context of service provision. I will use the information I gather from organisations both in the way I implement the research and to construct a framework within which the interview data will be placed.

## Protecting your confidentiality as a participant

I will need to have a contact name for you, but this can be a pseudonym if you prefer. In the research you will be referred to by a pseudonym of your choice.

I will need to have a contact address and 'phone number in order for me to send you the recording of the interview and drafts of my write-up. If you prefer, you can name a third person and I can contact you through them.

I will keep information about you on a link-file system. This means that your interview data will be held in one place and labelled with a number. Your contact details will be held in another place and labelled with a letter. In a third and separate place I will keep a record of which number corresponds with which letter. This means that only I will be able to link your interview information and your contact details. All information will be kept in a locked and secure place.

All identifying information will be removed from my final write-up. When you receive the draft write-up, you will be able to check that I have done this to your satisfaction.

What will happen to the research and who will read it?

It is the fate of many a PhD thesis to sit on the shelf and gather dust. To ensure that this does not happen in this case I will do the following:

- send a copy to everyone who participates
- send a copy to all HIV/AIDS and gay men's organisations in London, North and West Yorkshire
- submit aspects of my work to relevant academic journals, local newsletters concerned with gay and HIV issues, HIV journals and periodicals and the gay press

In this way I hope to target interested individuals, professionals and funding bodies.

Who am I and what is my perspective?

#### Academic background

My undergraduate degree is in English Literature and after a period of employment I completed a combined Diploma in Social Work and Masters in Applied Social Sciences at Brunel University. I am now working full-time towards a doctorate based in the Social Work Department of Brunel University.

My Masters dissertation was a piece of qualitative research on the impact of multiple bereavement as a result of HIV/AIDS which I carried out at The Terrence Higgins Trust.

#### Professional background

I have worked in a voluntary and paid capacity with different groups of people in a number of different settings, both statutory and voluntary. I have been a volunteer buddy for a person living with HIV in London and between December 1997 and December 1998 I was the Community Support Services Co-ordinator for North Yorkshire AIDS Action.

#### Personal background

I have known a number of people who have been diagnosed HIV positive and who have died as a result of an AIDS-related condition. My professional involvement has been fuelled by a belief that people living with HIV must be treated with fairness, respect, equity, justice and care. I find the issues surrounding the virus of importance intellectually, professionally and personally because they touch so closely on questions of who we are with ourselves, with each other, in time and space.

I have lived and worked in both London and North Yorkshire and have been struck by the way in which issues of space may influence our sense of who we are. I want to find out more about how where people live may affect their sense of who they are as gay and as HIV positive.

## Power and difference

One of the main questions which anyone doing research has to grapple with is 'What gives me the right to carry out this research?' Personally, I don't think it's a question of rights. I am doing this research because I feel it will be of benefit to the people who participate, and on a wider scale I believe it can contribute towards better understanding and improved service provision.

By definition someone who carries out research is in a powerful position in relation to the research participants. My intention is to equalise this relationship as much as possible by ensuring that I do the following:

- obtaining your informed consent before you participate
- making the format of the interview open; you will be free to talk about what is important to you
- being clear throughout about my position in relation to the research
- giving you a choice over how the interview is recorded
- giving you control over the information you give
- if you disagree with what I say and we are unable to reach an agreement, I will fully record those differences in my final write-up

Being a woman who has not undergone an HIV antibody test, I am in a position of difference in relation to the people I am asking to participate in the research. I don't think this is necessarily a good or bad thing, but I think that it is important to think about its possible effect on the research:

- some people may not feel comfortable speaking to me about their experience and may choose not to participate. On the other hand others may feel more comfortable talking to someone who is more separate
- I will not be able to draw on direct personal experience to understand what people are telling me. I can guard against misunderstanding by using the participants' own words and by sending them drafts of my final write-up for checking and review. I also think that being different encourages me to enter imaginatively into people's lives without personal assumptions of a shared or similar experience.

Why only research gay men?

I want to be absolutely clear that in choosing to confine this study to HIV positive gay men, I am in no way denying or denigrating the experience of other people such as gay men who are untested or who have tested negative, or other HIV positive individuals. I have decided to focus this study because I believe the relationship of being gay to being HIV positive is quite distinctive in this country and this in turn affects the person's relationship with the virus and the impact on their identity. Similar studies focusing on the experience of other groups of people are also needed.

It must also be acknowledged that most of the people who participate in the research will be people who are willing and able to discuss their situation with an outsider and this will have an impact on the type of information that is collected.

I hope to make contacts with potential participants through 'snowballing', i.e. individual participants talking about the research to friends and acquaintances, as well as through links with different organisations.

How is this research different from everything that has been done already?

The problem of researching anything to do with HIV is that there is a mountain of already existing research material. This research adds to and is different from this existing body of work. I explicitly compare urban and rural experience. To date there has been very little research on the experience of gay HIV positive men in rural areas and no studies which compares this with urban experience. There has been no research which takes a broad definition of subjectivity and looks at how where someone you live may affect how you see yourself as gay and as HIV positive.

Any questions?

If you have any comments or questions about the research, I would be very pleased to hear from you, whether or not you decide to participate. If you have decided that you would like to participate, or if you want to find out more, please call me on 07775677842 or contact me via one of the organisations named in this pack.

Finally, thank you for taking the time to read this.

Katherine Cox  
May 2000



## APPENDIX 4

### INTERVIEW PACK

#### CHECKLIST FOR INTERVIEWS

##### *On initial contact:*

Have you received an information pack?

Do you want to meet before the interview?

Venue

Date and time

Take their name, address, contact number

How did you hear about the research?

Do you have any questions at this point?

Write to confirm telephone call, send map of venue if necessary

Open file with interviewee number

##### *Prior to interview:*

Check tape recorder and batteries

Check venue's OK

'Phone day before to confirm

Go through schedule

Take:

Tape recorder

Several tapes – ready to label as soon as removed from the player

Mains lead

Spare batteries

Earphones

Notebook and pencil

Details of interviewee

Interview schedule

Checklist

Camera

Spare information pack

*At interview:*

Before beginning:

Thank you for coming

Name, pseudonym, contact arrangements

Any questions at this point?

Check received an information pack

Consent to taping

Confidentiality

Format of interview, areas to cover, able to take a break, stop etc.

*At end of interview*

Thank you

Arrange a further meeting if required – date, time, venue

Explain re sending a copy of the tape

Any comments about the process of the interview

*After the interview*

Remove tabs from the tape

Label each tape with interviewee number and tape number

Write down impressions, comments, feelings, hunches

Copy tape: main copy, copy I use, copy to participant – label all tapes

File: tapes, comments, contact details

Write with copy of tape, confirmation of next meeting if relevant, thanks

## ***EDITING SHEET***

Interviewee number:

Date of interview

Place of interview

Number of tapes used

Number of interview

## ***INTERVIEW COVER SHEET***

Interviewee's pseudonym

Interviewee number

Personal information

Short biography

My comments

## ***INTERVIEWEE CONTACT SHEET***

Name

Interviewee number

Address

Telephone number

## ***INTERVIEW DATA SHEET***

Complete with a tick and the date completed

Interviewee number  
Introductory 'phone call  
Contact sheet completed  
Confirmatory letter  
Preliminary visit  
Interview number  
Date  
Total time  
Number of tapes  
Tapes labelled  
Cover sheet completed  
Thank you letter written  
Tapes sent to interviewee  
Transcript completed  
Any problems  
Any special considerations  
Comments

## **INTERVIEW SCHEDULE**

### **Areas I need to go over at the beginning:**

Confidentiality

Taping

Consent

Name/pseudonym/contact arrangements

Check they received a pack

Any queries, comments

Options to alter, withhold information, withdraw

Option to stop or pause the tape

Format of the interview, areas to cover, able to stop, take a break etc.

### **Initial biographical information**

What would you like me to call you during the interview?

What pseudonym would you like to be referred by when I write up the research

How old are you?

How would you describe your ethnicity?

Where were you born?

Where have you lived and where are you currently living?

When and where were you diagnosed?

### **Gay subjectivity:**

**I'm interested in finding out what part your sexuality plays in your life**

#### *History*

When did you decide/know that you were gay?

How did that feel for you?

How did that affect your relationships with the people around you?

#### Geography:

**In what ways might where you were living have affected your sense of yourself as a gay man?**

## Relationships

Who have you told about being gay?

How did the different processes of coming out affect your relationships with the people around you?

In what ways might where you were living have affected this process?

## Gay 'community'

**What do you think about the term gay community? What is your sense of the gay community?**

In what ways is defining yourself as gay important to you?

In what ways, if any, is it problematic?

## Wider social world

What has been your experience of homophobia?

## Being HIV+

***I'm interested in finding out what an HIV+ diagnosis has meant for you***

## Pre-diagnosis

When did you think you might be positive?

How did that feel?

How did that affect your relationships?

When did you decide to get tested?

What influenced that decision?

## Diagnosis and post-diagnosis

Where did you receive your test?

How do you think where you lived may have affected your experience of being tested?

How did you feel when the test was positive?

How did that affect your relationships?

What happened and how did you feel in the initial weeks and months following your diagnosis?



In what ways do you think where you lived may have affected that reaction?

*Sense of self*

How would you describe HIV and being HIV positive?

What part does HIV play in your life?

How have you felt since your diagnosis: physically, mentally emotionally, spiritually, and how have these aspects of your life changed for you?

How have these changes affected your sense of identity, of who you are

What is your sense of your own health?

What are other people's sense of your health?

How has being positive affected your body image?

How do you think the way you understand HIV affected your choices around how to cope with being positive?

What have you drawn on to reach that understanding?

In what ways has HIV changed your life?

How does HIV make sense (or not) in your life?

In what ways is defining yourself as HIV positive important to you

In what ways is it problematic?

In what ways does HIV help/hinder you from being the sort of person you want to be and living the sort of life you want to live?

*Relationships*

How have these changes affected your relationships with other people?

How have these changes been affected by where you have been living?

Tell me about your relationship (or non-relationship) with medical services, alternative/complementary health care, professional support services – social services, voluntary organisations etc.; and your informal support networks

How have all of these and your experience of them been affected by where you live?

Do you think and, if so, in what ways do you think that HIV is different from other medical conditions?

What sort of reactions have you had from others about HIV?

How has this affected your own understanding of HIV?

Wider society

How does HIV in your opinion make sense (or not) in society

How do your material circumstances affect how you cope with being HIV positive e.g. economic position, employment position, housing situation etc.

### **Misc. questions**

How do you see your future

What are the benefits of living where you do?

What are the disadvantages of living where you do?

Tell me about a typical day for you at the moment

Tell me about the good things, the bad things, in your life

### **Areas to cover at the end**

Check the spelling of any names or words

Arrangements for another meeting / sending tape

Feedback about the process

Thanks!

Please pass on my details to anyone else who might be interested in participating