

WHISPERS AND CLOSED DOORS:



THE EXPERIENCES OF GAY MEN LIVING LONG-TERM WITH HIV

ALISON WELLS

2008



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Ministerial Foreword

The number of cases of HIV is rising in Scotland. This rise is particularly apparent in Men who have Sex with Men. This report provides a very informative insight into the difficulties faced by those living with HIV not only physically but mentally, emotionally and financially.

In recent years there have been vast advances in medical science. We know that early diagnosis and treatment is key to preventing the spread of HIV and that those who are diagnosed and treated early can now expect a near normal life expectancy. While this is extremely positive, we cannot be complacent. There is no cure for HIV and the side effects of anti-retroviral therapy can be difficult to manage. It is therefore essential that the experiences of those detailed in this report and its learning are used alongside the wider evidence to develop our policy on HIV for the future.

We also have a responsibility in Scotland to challenge the stigma and discrimination that is associated with HIV. While we recognise that attitudes can not be changed overnight, this will be a focus of our work for the foreseeable future. This however is not only a challenge for the Scottish Government but for other statutory and voluntary organisations.

The report highlights the very crucial work undertaken by voluntary organisations in providing support to those living with HIV and their families. It is essential that voluntary and statutory support continue. I shall ensure that we continue our strong links with those voluntary organisations providing this support to help them to continue their excellent work.

A handwritten signature in black ink that reads "Shona Robison". The signature is written in a cursive, flowing style.

Shona Robison MSP
Minister for Public Health

Executive Summary

Whispers and Closed Doors: The experiences of gay men living long -term with HIV

Alison Wells

Introduction

People diagnosed with HIV before 1996 lived in a climate of death and expected to die. Today, however the situation is different with HIV now classified as a chronic illness (Siegal & Lekas, 2002). HIV remains an important issue which particularly affects gay men. This research aimed to develop a deeper understanding of what it was like to live with HIV at a time when there was no cure or treatment for the virus and how that lived experience may have changed following the introduction of effective treatments. These experiences may have implications and ramifications in terms of their current ability to adapt to life with HIV.

Method

Seven gay men who had been living with HIV for at least 12 years were recruited across Lothian, Scotland. The men aged in range from 41-56 years old (mean 47 years), years diagnosed 12-19 (mean 15.5 years).

Findings

There were five main themes that emerged from this research.

Being positive

Being HIV positive also meant coming out for most of the men. For many receiving the diagnosis of HIV was a turning point in their lives where they went from being strong, confident, employed, with full social lives to experiencing a period of coming to terms with, what was at that time, a terminal diagnosis. Most had experienced stigma associated with their diagnosis, which at times had led to being subjected to direct abuse.

Living with HIV

The men appeared to cope with their diagnosis in similar ways, initially denial, isolation and uncertainty about the future. Over many years they have moved to accepting their HIV using humour, goal setting, altruism, as well as maladaptive mechanisms, for example, excessive alcohol consumption. A fighting attitude also appeared important and when one was not adopted this meant death. Although the length of time the men utilised a coping mechanism varied. A range of emotions were linked to the virus, including anger, fear, feeling worthless, guilty, or empty.

Managing holistic health needs

Each of the men had physical and mental health experiences due to their HIV but the magnitude and severity has differed between men. A significant part of managing life

with HIV is the use of medications to manage the condition. However taking medication is not an easy 'cure' for HIV, indeed there still is no cure, and the medication regimes could lead to difficult side effects. For some men there was still a strong sense of uncertainty in their long term health particularly given their reliance on medication for which the long term impact is still not fully known.

The men agreed that living with HIV presented more mental challenges than physical ones and depression was an issue for all of the men. Most of the men also talked about suicide, either their personal ideation or experience of others successfully committing suicide as a result of HIV. All of the men talked about their efforts to keep mentally well, demonstrating an understanding and acceptance of their mental health and knowledge of what to do about it, although not all of the treatment options were adaptive. The men talked about having to deal with feelings of worthlessness, guilt, depression, loss and uncertainty.

Coming to terms with loss

Finding meaning in HIV/AIDS including making sense of death and dying, as well as other losses, is needed in order to successfully adapt to living with HIV. All of the men noted a loss or a change of self to some degree and described significant loss of material possessions or income. The sense of loss experienced by the men was at times overwhelming especially when the men talked about the loss of their

partners. The literature post-HAART did not mention death or loss but referred to adjustment and adaptation to a life with HIV. People who have lived long-term with HIV have experienced loss and, at some point, accepted the loss as part of their future. Long term treatments also signified the loss of the certainty of death, and the introduction of a new but uncertain sense of future.

Psychosocial Needs

The psychosocial issues the men described during this piece of research concerned money, work, housing and relationships. They talked about issues they had experienced and how they had gone about resolving them, including the use of support services. The breadth of issues or needs served to highlight the extent of the impact of living with HIV across all of their lives. This added to the sense of hopelessness some of the men felt because they were not able to rebuild the lives they had before their HIV diagnoses or they were aware that they would not ever achieve what they thought they would have done prior to diagnosis. All of the men (except for Euan and Gary) talked about how they had, or had not, benefited from the support centers and why they were so beneficial.

Discussion

Uncertainty is uniform for all people now living with HIV. Long-term survivors moved from a certainty of death to uncertainty. Those more recently sero-converted moved into a

culture of uncertainty, although hopeful uncertainty, because of advances in medication, treatment options and knowledge of the virus are being made all of the time. This research has shown that there continues to be physical and psychological consequences of living with HIV long-term. Issues of uncertainty about the future, the need for psychosocial support and the barriers posed by stigma continue to be enduring features of living with HIV long-term and pose an ongoing challenge to policy makers and service providers to offer responsive services that continue to meet these complex needs.

There are a number of clinical and service implications that have arisen from this research. Many of these implications are relevant for men who have lived with HIV short or long-term.

- The support needs for men living with HIV are complex and must be addressed holistically.
- Coming to terms with the diagnosis of HIV may also be accompanied by coming to terms with disclosing sexual orientation to others.
- Holistic and long-term consideration of psychosocial needs is essential as current estimates of how long a man living with HIV may require additional support are inadequate and indicate that such needs have been likely underestimated.
- Sharing the experience of those living with HIV long-term may promote prevention.
- The long term socioeconomic impacts of living with HIV need to be considered. Living with HIV long-term may lead to increased need as some men may have spent or used resources when they reasonably thought they were going to die, and now face economic hardship.
- Addressing issues of loss is important. The level of loss experienced by this group is extensive. This may have clinical implications and demonstrate barriers to treatments in a population with a high morbidity of mental health problems.
- Economic and physical consequences of HIV are a barrier to engaging with services.
- Support from positive peers is valuable and should be resourced.
- Daily life offers continuing adjustment and transitions. Managing daily life under the HAART regime can be difficult and have a negative impact on quality of life and there is no fixed period of adjustment in living with HIV long-term

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1 Introduction

At the beginning of the HIV pandemic many gay men could not comprehend its magnitude. For years they had fought to be free in their sexual expression and it was hard to believe that this sexual freedom could have such negative implications. The virus set the gay liberation movement (indeed sexual liberation) back substantially as sex became highly associated with danger and fear. Gay men began to fear bodily fluids and avoid sexual encounters altogether (Shernoff, 2006). From the moment scientists identified HIV and AIDS, public responses of fear, denial, stigma and discrimination have accompanied it. Discrimination spread rapidly, fuelling anxiety and prejudice towards the groups most affected, that is, gay men in general and those living with HIV or AIDS. HIV and AIDS are therefore as much about social phenomena as they are about biological and medical concerns (Avert, 2007).

People diagnosed with HIV before 1996 lived in a climate of death and expected to die. Today, however the situation is different. Investigators from Denmark estimated an individual diagnosed with HIV aged 25 could now expect to survive until they were 64, compared to 76 years of age for the HIV-negative control group (Lohse, Hansen & Pedersen, 2007). Following the introduction of Highly Active AntiRetroviral Therapy (HAART) in 1996, the number of people dying every year in the UK radically declined and now remains stable with approximately 500 people dying per year due to HIV (Weatherburn, Keogh, Dodds, et al., 2007). HAART can lead to individuals achieving an undetectable viral load and sustaining a CD4 count above 200. HIV is therefore now classified as a chronic illness (Siegal & Lekas, 2002).

HIV remains an important issue which particularly affects gay men. The number of new infections of HIV is still increasing in Scotland. In Lothian, approximately one new HIV diagnosis in gay men is given each week. About 80% of all domestically acquired HIV infections occur as a consequence of sex between men (Weatherburn et al., 2007) and about half of all Scottish gay men reported having unprotected anal intercourse in the last year (Vital Statistics, 2007; Hickson et al., 2007). According to a sex survey carried out in the UK, 4.3% of all Scottish gay men are living with HIV (7.3% of all Lothian based gay men) (Vital Statistics, 2007). Approximately 70% of those living with HIV in Scotland were male, aged between 35-44 (Weatherburn et al., 2007).

There is still no cure for HIV but there are now effective treatments which enable people living with HIV today to expect a near-normal life expectancy. However, it remains unclear what this actually means in light of the potential HIV sequelae highlighted above? There is relatively little written about people living long term with HIV, specifically gay men, the population still seeing the greatest increases in HIV prevalence. With measures of HIV efficacy concentrating on medical measures, could it be assumed that living long term with HIV is a success when

the quality of that life is not questioned? Successfully adapting to HAART is not the only predictor of adaptation to HIV as there are also complex psychological sequelae and psychosocial needs which are experienced in everyday life with the virus (Green & Smith, 2004).

Research has indicated that gay men are reporting less consideration of safer sex for a variety of complex psychological reasons, including the fact that media messages often promote the idea that drug treatments are 'the cure' for HIV/AIDS (Dilley, Woods & McFarland, 1997), therefore posing a real threat to the safe sex message. These individuals are often unaware of the impact that the new drug regimes can have. There are severe stressors associated with complicated drug regimes, side effects of the medication, unknown long term efficacy and safety of drugs, and the financial consequences of long-term reliance on the medications. Issues of drug failure and drug resistance complicate the ability to predict sustained response (Brashers et al., 1999).

Whilst the prospects for living with HIV as a chronic illness have risen, social and emotional challenges in living with HIV remain. A significant number of people continue to hold stigmatising attitudes to those who are living with HIV (Herek, Capitano & Wildaman, 2002). Along with those stigmatising attitudes come a range of difficulties in daily life that can lead to constant challenges to overall wellbeing. These challenges include living with noxious symptoms, side effects from treatments, but also include periods of disability, unemployment, isolation from social networks and impoverishment (Fleishman, Sherbourne, Crystal et al., 2000). A range of social and relationship issues have been cited in the literature as a consequence of HIV. For example, sexual dysfunction (Catalan, Meadows & Douzenis, 2000), work and finances (Siegal & Lekas, 2002), social relationships (Brashers et al., 1999) and sexual relationships (Fleishman et al., 2000). Such challenges in living with HIV can lead to increased levels of anxiety and depression (Fleishman et al., 2000).

People living with HIV are more likely to experience a range of mental health problems (NAM, 2005) and are likely to suffer significant psychological distress (Cohen, Hoffman, Cromwell et al., 2002). The psychosocial consequences of HIV have been well documented (Zich & Temoshok, 1987; Catalan et al., 1992; Brashers, Neid, Cardillo, Dobbs, Russel & Haas, 1999; Barroso & Powell-Cope, 2000; Siegal & Lekas, 2002; Flowers & Church, 2006). For example, people living with HIV have a higher prevalence of clinical depression (10-15% compared to 2-5% for the general population) (Dilley, Ochitill, Perl & Volberding, 1985; Ciesla & Roberts, 2001), there is an increased prevalence of suicidal ideation and attempts (Carrico, Johnson, Morin et al., 2007), anxiety is commonly experienced particularly fear of death (85% compared to 64% in people not living with HIV) (Kalichman & Sikkema, 1994) and bi-polar disorder is more prevalent (Carter, 2005).

Medical measures of HIV treatment efficacy are frequently prioritised over psychosocial and sociocultural issues (Green & Smith, 2004). A recent study postulated that three-quarters of people with HIV reported poor mental and physical health. They concluded by suggesting that more focus should be on mental well-being, employment advice and combating stigma and discrimination (Harding & Molloy, 2007; Harding & Sherr, 2007). Brashers et al. (1999) found that psychosocial issues impacted on the quality of life of people with the virus. Therefore it would appear that successful adaptation to living with HIV should not just be based on medical efficacy alone.

Brashers et al. (1999) stated that work needs to continue in this area to understand the experiences of people living with HIV. Telford, Kralik and Kock (2006) in their research regarding adjustment to illness urged healthcare professionals to listen to the stories people tell. This study is a first step to fill that gap by exploring the experience of gay men who have been living with HIV long term¹.

This research aimed to develop a deeper understanding of what it was like to live with HIV at a time when there was no cure or treatment for the virus and how that lived experience may have changed following the introduction of effective treatments. These experiences may have implications and ramifications in terms of their current ability to adapt to life with HIV.

¹ Long term for this piece of work is defined as men who were diagnosed before the availability for ART, therefore men who have been living with the virus for 12+ years.

2 Method

Seven gay men who had been living with HIV for at least 12 years were recruited through a variety of voluntary and NHS settings across Lothian, Scotland. The men aged in range from 41-56 years old (mean 47 years), years diagnosed 12-19 (mean 15.5 years) and all lived in East Central Scotland. All participants are described using pseudonyms.

Each interview was transcribed verbatim. An idiographic approach to analysis was employed, that is, one transcript was analysed in detail before moving onto the next (Smith, 2003) and each man's transcript was coded in isolation. Once codes and themes were established for each individual, the transcripts were then considered as a group considering the similarities and differences between the men. A qualitative methodology was utilised for this research. Data was analysed using Interpretative Phenomenological Analysis (IPA) (Smith, 1995, 2003).

Ethical approval was granted for this study by Lothian Regional Ethics Committee (LREC) in February 2007.

3 Findings

Here we describe the experiences of gay men living long-term with HIV around five central themes of the journey into HIV, which was often associated with also having to come out as gay, living with HIV, managing the holistic health needs associated with HIV, coming to terms with loss and psychosocial needs.

3.1 *Being positive*

Being diagnosed with HIV has a complex psychosocial sequelae especially at diagnosis and considering revival, including change in financial circumstance, issues surrounding work, housing, support, relationships and uncertainty. All of the men talked about what their lives were like before they were diagnosed with HIV. For many receiving the diagnosis of HIV was a turning point in their lives where they went from being strong, confident, employed, with full social lives to experiencing a period of coming to terms with, what was at that time, a terminal diagnosis.

I find it really difficult to explain to you because my life went from having everything to just nothing in a year. (Frank)

Brian, Duncan, Euan and Gary mentioned how they had first heard about the HIV virus through the media before they were living with it, or indeed, anyone they knew was. Gary and Brian were critical of the media portrayal.

When they first advertised it on the television saying 'don't die of ignorance', and this was how they advertised it, you know if you caught the virus it was through your own ignorance. Maybe sometimes it was ignorance but if someone was raped, for example, that was not ignorance. (Brian)

Brian and Euan believed alcohol had been involved in their becoming infected with the virus.

...me, personally, I was drunk...so the chances are that's how I got the virus, through stupidity and down right ignorance and being totally plastered. (Brian)

All of the men, except for Euan, talked about their experience of disclosing their HIV status and the anger, anxiety and tension they felt as a result of disclosure. Adam, Brian and Callum disclosed their sexuality and HIV status together. They were in denial about their sexuality and overtly portrayed a heterosexual lifestyle whilst covertly leading a

homosexual life. Some men found support for having disclosed both their sexuality and HIV status, others did not. Some remembered their families finding the acceptance of their sexuality was more problematic than their HIV status.

They [parents] took it upon themselves, were they to blame type of thing... they didn't want to believe it, that their sons were gay. That seemed to be more of a problem than the fact that they had the virus. I know that sounds crazy...but the fact that they were gay, that seemed to be more embarrassing. (Brian)

All of the men except for Euan had felt the stigma that was attached to HIV now as well as earlier in the pandemic.

Stigma is a killer, a big one...there is still stigma there, still whispers and closed doors. (Adam)

For Callum, Duncan and Frank this stigma resulted in experiencing direct abuse, and even for those not directly subject to abuse there was an awareness of the potential for being abused in relation to their HIV status. Most of the men believed that stigma, whilst still having a significant impact on their lives, was not as prevalent today as it was when they were first diagnosed. For Frank this lack of stigma also indicates a lack of awareness of just how difficult it can be to live with HIV.

But the youth of today they haven't got the same conception of how destructive and how horrible it is...that bothers me. HIV now is not like, kids today have unprotected sex and think you're mad, HIV is nothing to them now, well until they get it. (Frank)

3.2 Living with HIV

The men appeared to cope with their diagnosis in similar ways, initially denial, isolation and uncertainty about the future. Over many years they have moved to accepting their HIV using humour, goal setting, altruism, as well as maladaptive mechanisms. A fighting attitude also appeared important and when one was not adopted this meant death. Although the length of time the men utilised a coping mechanism varied. A range of emotions were linked to the virus, including anger, fear, feeling worthless, guilty, or empty.

Denial was experienced by all of the men particularly after diagnosis but was used for differing periods of time for each of the men. Courtney et al. (1998) discovered that individuals could stay in this period for 6 months to 5 years. Reeves et al. (1999) report a transition period that people go through in order to move from denial to acceptance. A similar period appeared to be evident for the

men because they were unsure of when they moved from denial to acceptance or how it came about. Gary reported being in denial for 9 years and Duncan and Callum reported similar lengths of time before they started to accept their HIV.

I basically went into denial about it for a long, long time, um, um, I actually got to the point that I convinced myself that I didn't have it cos I was ok, you know. (Gary)

All of the men, except for Duncan, talked about isolation to some degree due to living with HIV. This might have been out of necessity because of the unwanted side effects of medication.

So I'm staying in more and doing more things on my own because when I am like that I want to be on my own than if I don't feel like it. So I'm reading a lot, um, starting to go for longer walks with the dog, but everything's solitary. (Euan)

When the men were diagnosed with HIV there was no effective treatment although some treatments were being used to combat specific opportunistic infections, so all the men needed to come to terms with having a terminal illness. All of the men expressed uncertainty about their futures although they all now accepted their continued lives with HIV. All of the men experienced the introduction of effective treatment for HIV so have had to change their outlook from certain death to probable life. Making the transition from living life day by day, to building a future was a difficult challenge fraught with uncertainties.

...and now I'm thinking I've got to re-build all that now, I've got to make new friends, (sigh) and think about a future. I think I don't want to do that anymore, well I do, but I think what's the point. (Frank)

This new sense of future and improved outlook could still feel uncertain, bringing a sense that you still cannot know what your long term prospects are with HIV.

...you don't know how long it'll last. (Adam)

For some men there seemed to have been steps they had gone through in order to trust in a future.

I think my first goal was to see the millennium or was it my 40th, which came first my 40th or the millennium. I was 32, 33 and I thought, if I live till I'm 40 then that will be pretty much a goal and then it was the millennium and then I was still here and things have just carried on. (Frank)

The men found a range of ways to cope with daily life with HIV. Humour, altruism and goal setting were cited by some of the men as ways to cope with HIV.

I know it will obviously, it will get the better of me at some point, but I am going to give it everything that I possibly can. Hence the reason for the volunteering, so I can help people in a similar situation. (Brian)

Maladaptive mechanisms were also mentioned by most of the men, including the use of drugs, alcohol, contemplating suicide and running away. Reeves et al. (1999) noted that along with affective coping mechanisms (for example, denial), behavioural ones were also common (for example, excessive drug and alcohol use).

The illness obviously has an impact on me as well, um, I probably and I mean, in the past I've turned to alcohol and...to drugs. (Gary)

Siegal and Lekas (2002) highlighted that in an era of drug-resistant viral strains, the risks of re-infection and co-infection may play a considerable role in shaping people's relationships. All of the men talked about how they live their lives and how this has been shaped by their HIV diagnosis and how their lives had been shaped was different for each man. Adam, Brian, Duncan, Frank and Gary all expressed specific hopes and fears for the future, a common hope being a cure for HIV.

I have seen so much change in technology and you know how you can get treated and what have you, so who knows what the next 10 years will bring. I don't think it'll be eradicated but, in the Western world, who knows. It certainly is improving a great deal. (Duncan)

3.3 Managing holistic health needs

HIV is a virus which has an ongoing physical effect therefore all of the men had been in contact with physical health services for initial testing, subsequent monitoring of their HIV and regarding medication. Living with HIV also has a psychological effect and all of the men talked about their mental health. Each of the men had physical and mental health experiences due to their HIV but the magnitude and severity has differed between men. Other than the initial ill health at diagnosis, Adam, Brian, Duncan and Gary have kept relatively well compared to Frank and Euan who have had numerous hospital admissions, and for Euan, being told to 'expect the worse' more than once. Here we describe how these men managed this multiplicity of physical and mental health needs arising from living long-term with HIV.

3.3.1 Physical Health

All of the men talked about their physical health whilst living with HIV. Adam, Duncan, Euan and Frank talked about the providers of their health care which were generally positive and collaborative.

I've been really lucky with two [Doctors] who have used me as their case study and they just haven't let me go. They've phoned me at home, met me at the drop of a hat. (Euan)

A significant part of managing life with HIV is the use of medications to manage the condition. However taking medication is not an easy 'cure' for HIV, indeed there still is no cure, and the medication regimes can be problematic. Most of the men talked about medication and how when HAART was introduced there was a positive change in the health of themselves and for many of their peers.

It was good to see people recover and begin to look well, put on weight and you know, it was quite nice not to have to go to funerals all the time. (Duncan)

Adam, Brian, Callum, Duncan and Frank talked about the search for the right combination of medication and all of the men, except Gary, talked about unwanted side-effects of the medication. The experiences of all of the men demonstrated that in order to live with HIV you need to take HAART but this comes at a high cost, that is, side effects of the medication which can be extremely difficult to tolerate, the search for the right combination and the high level of adherence needed to avoid developing drug resistance.

...the medication I was on was muck so I stayed where I was for a year and then I took ill again. I was taking medication and it wasn't working so I tried another one, then another one...it was like my time had come up, I got this pill and it gave me such a boost. (Adam)

...you get tired, I'm really, really tired. I'm tired of the pills, of the diarrhoea, or the vomiting. (Euan)

Duncan talked about the uncertainty of his good health and wondered if it would last. He also believed that people living with HIV have self-interest in their medical care which is not seen in many other illnesses. Brian and Duncan expressed concern about the long-term effects of taking HAART considering it is relatively new, untested, medication.

The thing is you don't know, what's 20 years of these drugs doing to my body, all of the side effects, will all the organs need to be

transplanted because everything fails over the years, the liver etc, etc. (Duncan)

There was an expectation that the introduction of HAART would affect all health problems related to HIV. Physically the results are excellent because people are living but considering psychological state and quality of life issues, the effects have not been as significant.

3.3.2 Mental Health

Catalan et al. (1992) suggested that as “AIDS becomes a more manageable disease there will be diminished need for acute mental health services and a greater need for interventions supporting individuals in adjusting long-term to chronic illness related psychosocial stressors”. This would still involve higher levels of anxiety, depression and suicidal ideation compared to the general population which could indicate an unmet need. The men agreed that living with HIV presented more mental challenges than physical ones and depression was an issue for all of the men and was particularly problematic for Callum.

The biggest, biggest, I think the depression is the biggest, biggest hurdle, or pain, the depression is worse than being HIV positive, the depression that has come along with it or has come along with it because it effects your whole being, it paralyses you, well it paralyses me, I feel paralysed. (Callum)

Most of the men also talked about suicide, either their personal ideation or experience of others successfully committing suicide as a result of HIV.

When I'm in a real depression, dark, I'm paralyzed and that's when I have thoughts of suicide. (Callum)

All of the men talked about keeping mentally well, demonstrating an understanding and acceptance of their mental health and knowledge of what to do about it, although not all of the treatment options were adaptive.

I don't go out that much now but what I've been trying to do these past few years is eh, cos I've had a lot of counseling and lots of, you know, you must get out you must you know. (Frank)

All of the men agreed that in order live with HIV you have to have a fighting attitude and not give in. Most of the men stated that they had decided to live, therefore implying that if one does not have a fighting attitude and decide to live with HIV they would die.

I'm a fighter, yeah I believe I will fight, I won't give into anything, I wouldn't even stay in bed if I have the flu, I just won't lie down.
(Callum)

As the men spoke of their experiences of living with HIV a range of emotions were present including anger, guilt, frustration and sadness. There was a limited presence of positive emotions. All of the men had experienced anger, they appeared to be angry at the losses they experienced due to living with HIV, their lost status, money, contentment and acceptance, and in return felt stigmatised, excluded and had to cope with mental and physical illness.

I would not like this on anyone. When I hear people say it was a blessing, well not that, but out of the flames a phoenix will rise, or whatever it is, that it's made them a better person, I just think god, I would rather be the way I was before than of had to have lived with this thing and have gone through the last 16 years. I would not wish it on anyone because it effects every, every, facet of my life. Relationships, family, well there is not a time I do think about it and I don't try to, I don't deliberately think of it, but it's there.
(Callum)

The men also said they felt worthless and useless (all except Brian and Callum) which would have been a difficult place for men to be when they were used to being providers, strong and vital men. Adam, Brian, Callum, Duncan and Gary also stated they had felt fearful or worried at times whilst living with HIV, mainly due to the uncertainty the diagnosis brought into their lives.

...it was just such a horrific time, so much happened in such a short time, horrific stuff. I could talk to you for hours about the horrible things. And er, it was just a, just a, the most, the most, horrible time in my life, I would never be able to explain how I felt.
(Frank)

Guilt arose in a number of places for some of the men (Adam, Duncan, Euan and Gary). Gary felt guilty for, he believes, infecting his partner with HIV. This guilt made his acceptance of his diagnosis more difficult.

It is a terrible thing to carry around, a terrible thing to carry about. That really does push your self-esteem down and down. You don't feel worthy of other people and I think that's why you end up feeling pretty apologetic about things and over compensating for things. That's what I've felt but maybe that is just me, I don't know, I don't know. (Gary)

Duncan fondly remembered when he had adjusted to a HAART combination so felt well but there was no pressure to return to work, also because of medication other people were also not ill or dying.

I do miss those days, after my health began to improve, I was on Incapacity and got Housing Benefit, but having the time to go out and enjoy the cinema, and go for trips out and have my health and well-being and free time, being able to sit in a cafe. (Duncan)

3.4 Coming to terms with loss

Finding meaning in HIV/AIDS including making sense of death and dying, as well as other losses, is needed in order to successfully adapt to living with HIV (Barroso & Powell-Cope, 1999). All of the men (except for Brian) noted a loss or a change of self to some degree.

There's parts I can't remember, um, and so many times I've thought I wish I was the person I was pre-HIV, or pre-being told I was HIV positive. (Callum)

I just came from being this very strong, confident person to becoming this, I'm becoming quite emotional now, just becoming what you see now, this mess. Just, just, it was just horrible. (Frank)

Callum, Duncan, Frank and Gary talked about their loss of material possessions and status as a result of their HIV diagnosis. Some men, such as Gary, may have found it easier to talk about material losses than talking about the loss of life.

I don't think I would be in the situation I am in today if I hadn't have been infected with HIV. I think I'd be, I'd have my mortgage paid off and I would still be sitting in my 2 bedroom flat in [a desirable part of Edinburgh]. (Gary)

Being diagnosed with HIV when all of the men involved with this study were (pre-1996) meant there was an expectation of death. All of the men, except Gary, talked about death and they had believed that being diagnosed with HIV meant dying.

...and they [friends] just thought I was going to die, I thought I was going to die. (Euan)

Four of the men had experienced the death of a partner and their partner's were probably the person who had infected them, so they were experiencing their deaths whilst living with the same virus. Callum, Duncan, Euan and Frank found that deaths of friends and family members who were not living with HIV affected them greatly. This was possibly because they lived in a sub-culture where death was accepted but they found it difficult to tolerate the thought that death was everywhere not just in the community of people living with, or affected by, HIV.

Is it worth getting close because I was losing so many friends at one time. I'd go to Milestone and it would be she's gone, he's gone, he's really ill. I would think who's next, is it my turn next. It hits you like that. (Adam)

Frank had considered an assisted death, Brian and Callum had arranged and paid for their funerals and Euan had noticed that when he has been told that he might die he started to prepare for this eventuality. This active planning for death might represent a way to find a sense of control over what feels like an uncontrollable circumstance.

You start cleaning, you start seeing yourself doing things like cleaning out, [my partner] did it, [my best friend] did it, and I was half way through doing it before I realised what I was doing. You go through all your photographs and you throw out all your rubbish because you know people are going to go through your stuff and what you want them to find is the quality...I've done that a couple of times. (Euan)

The men had experienced a lot of death so had attended a lot of funerals. Adam, Callum, Duncan and Frank had difficult experiences, which perhaps mirrored the difficulty the men had in life.

As I say most of my friends funerals were ... farces. All the gay friends were not invited to the funerals, they would have private family funerals they would be like get rid of us and pretend it never happened. So for us the grieving process couldn't happen. (Frank)

During the interviews the amount of loss was at times overwhelming especially when the men talked about the loss of their partners. The literature post-HAART does not mention death or loss but referred to adjustment and adaptation to a life with HIV. People who have lived long-term with HIV have experienced loss and, at some point, accepted the loss as part of their future. Revival also signified the loss of the certainty of death, and the introduction of a new but uncertain sense of future.

Euan talked at length about the death of his best friend and partner, in particular, and his comments also reflected another consequence of death, the loss of a future and the loss of growing old together.

He [partner] said please don't let me go to hospital...I was supposed to be getting ready to take him into hospital for a blood transfusion and at this time I was really tired. I phoned up [the hospital] and said I cannot do this any more, I can't take care of him on my own anymore, he's starting to, there's nothing of him and I can hardly lift him because he is a dead weight...So he was fast sleep and I thought, sod it, I really need to shut my

eyes. I lay on top of the bed and cuddled him and when I woke up he was dead. I was just worried he heard me and gave up. (Euan)

3.5 Psychosocial Needs

The psychosocial issues the men described during this piece of research concerned money, work, housing and relationships. They talked about issues they had experienced and how they had gone about resolving them, including the use of support services. The breadth of issues or needs served to highlight the extent of the impact of living with HIV across all of their lives.

All of the men talked about issues relating to their finances, work and housing. They had all experienced a dramatic change in their financial circumstances due to living with HIV moving from being financially viable to critical, at certain points during the time they had lived with HIV.

I took all of the money out of my pension, I thought what's the point I'm not going to live anyway so I might as well have that money. (Duncan)

So I had a really good life, I had my own business, my own house, everything. I sold it all..., I just went absolutely mad and spent all my money like you would. I went on lots of nice holidays and spent money on my friends. (Frank)

This added to the sense of hopelessness some of the men felt because they were not able to re-build the lives they had before their HIV diagnoses or they were aware that they would not ever achieved what they thought they would have done prior to diagnosis.

Now I have to think may be 10 years out of employment there, that's my pension so do I have to do old age and poverty, or think of some other options now to pay my way? It is also thinking am I going to do this for the rest of my life, am I going to go back to college and pick up where I was? I have no idea now. (Duncan)

Siegal & Lekas (2002) noted that many infected individuals benefiting from HAART cautiously considered returning to work to improve their finances, become more socially integrated, feel more productive and to contend with boredom. There was uncertainty on how they would cope with work, confronting stigma in the work place and also how they might not feel able to return to work but public perceptions force them to so they aren't perceived as malingering. Duncan had returned to full-time employment, Gary was working part-time, Adam and Brian volunteered for HIV agencies and Callum was undertaking a course in order to return to paid work.

As discussed above, all of the men had to stop work either directly or indirectly because of HIV. The transition from working to living on benefits was difficult from a financial perspective but also considering the men's sense of worth. For many, work did not just provide financial rewards but a social structure and a sense of worth. Gary in particular mentioned enjoying work for the social, as well as financial, benefits.

Work is important to me and that is one aspect of my life that I really miss and that is the social interaction when you work. It is not just about the rewards you get in your pocket it is about the rewards you get from seeing people on a daily basis and you begin to like and know and trust. I've always found I've got on well with the people at my work, and I've always found it a great way of making friends. (Gary)

There are a small number of support centers in central Scotland within the NHS but most are in the voluntary sector. All of the men (except for Euan and Gary) talked about how they had, or had not, benefited from the support centers and why they were so beneficial. Brian noted that his mother still used a support center which he found comforting.

Once you had HIV that was it, you were labeled, you know, you know, you were on your way to the closest crematorium, book your space type thing. Whereas the reason why support centers are so important, so you can bring people in and make them feel at ease, especially family members and, well for me, my own parents. (Brian)

All of the men talked about their relationships with family members, friendships and sexual relationships, and they had all experienced starting new relationships. The men were upfront about their diagnosis to potential new partners. It appeared that if it was considered that sex might happen then disclosing their HIV status was essential, although difficult.

If it looks like sex is on the agenda I would tell them right away I was positive, letting them know. But then if you turned away and you turned back the chances are the fire exit door is swinging and their drink is left at the bar. (Brian)

Fear of entering into a new relationship because of concerns of burdening the partner with care-giving responsibilities was discussed by Siegal & Lekas (2002). Adam and Gary talked about over compensating with new partners to make up for their HIV.

I took an awful lot of crap and I am probably still guilty of that to a certain extent ... I over compensate for having HIV. You know I do a wee bit more because I think why would someone be with you because you have HIV, that sort of thought. (Gary)

All of the men accessed support services for themselves and their families, the success of this contact varied between the men. Relationships were an issue for all of the men and choosing when to disclose to a new sexual partner particularly. The men were honest and upfront about their status but knew this was often welcomed with fear, indeed, they appeared to expect it.

4 Discussion

This research aimed to develop a deeper understanding of what it is like for gay men to live with HIV long-term. Currently there is no literature available focusing on gay men (or indeed any population) who have lived for a long period with HIV. Literature often focuses on the initial period of adjustment just after diagnosis with little of long term survivors. These findings relate to gay men who had lived with HIV for a period of at least 12 years, but are likely to be relevant to men who have lived with HIV for period of time that are less than this also.

This research presented five key themes to describe the experiences of these gay men living with HIV long-term, these were around the experience of coming to terms with being positive and being gay, finding ways to live with HIV, managing holistic health needs (including mental and physical health needs), coming to terms with different aspects of loss and the broad range of psychosocial needs. The needs of gay men living long-term with HIV appeared to be in line with those present for other populations, except with a more chronic presentation. That is, living long term with HIV resulted in fatigue, uncertainty, issues about emotional investment regarding potential friends and lovers. Indeed, the men involved with this study appeared to all present with a chronic level low mood and was likely to increase their psychosocial need.

There may be a number of reasons that gay men living long-term with HIV have enduring needs. The specific role of stigma in influencing daily life with HIV came through clearly in this research. For this group of men stigma is two fold, being experienced both on the grounds of sexuality (Hickson et al., 2007) and in relation to their HIV status (King 1989). In part as a consequence of this sense of double stigma comes significant isolation, which the men in this study described and the literature supports (Green, 1993, Hart, Fitzpatrick, McLean, Dawson & Boulton, 1990, Miller, 2003; Vital Statistics, 2007). In their metasynthesis of qualitative research on living with HIV, Barosso & Powell-Cope (2000) highlighted that one of the main themes was dealing with stigma. Herek (1999) noted that AIDS stigma was universal, and it is noted in almost every piece of psychosocial research relating to HIV/AIDS (Siegal & Kraus, 1991; DeCock & Johnson, 1998; Fleishman et al., 2000; Flowers & Church, 2006; Carrico et al., 2007).

Finding a way to address this isolation presents a challenge for services, particularly as forming connected relationships helps reduce alienation and separation from others which is thought to be part of the process of successfully living with HIV (Barroso & Powell-Cope, 2000). Other positive consequences for reducing social isolation for HIV positive men include the positive relationship with improved mental health (Hays, Turner & Coates, 1992;

Kalichman & Sikkema, 1994) and facilitating the process of coming to terms with an HIV diagnosis (Leserman et al., 1992; Reeves et al., 1999).

Despite the case made both in this research and the literature about the importance of addressing social isolation, Weatherburn et al. (2007) found that support services were often seen as secondary to treatment and care budgets. This focus on medical provision would appear to have resulted in psychosocial consequences which are unmet considering the high prevalence of depression, suicidal ideation, isolation and this population's use of other maladaptive coping mechanisms.

It has been suggested that psychological distress associated with an HIV diagnosis lasts for a period of time. The length of this period has been cited to last in the literature has varied from 2-10 weeks (Siegal & Lekas, 2002) up to 5 years (Courtney, Merriam & Reeves 1998). The men in this study did not fit either of these time periods, for most the psychological distress was still evident at least 12 years after being diagnosed. Even considering that some of the men probably had pre-morbid psychological issues, the periods of time cited in the literature appears too short. Acceptance of the diagnosis might occur on two levels, that is, a philosophical acceptance occurs relatively quickly but the full emotional implications appear to take much longer than anticipated.

Uncertainty is uniform for all people now living with HIV. Long-term survivors moved from a certainty of death to uncertainty. Those more recently sero-converted moved into a culture of uncertainty, although hopeful uncertainty, because of advances in medication, treatment options and knowledge of the virus are being made all of the time. This research has shown that there continues to be physical and psychological consequences of living with HIV long-term. Issues of uncertainty about the future, the need for psychosocial support and the barriers posed by stigma continue to be enduring features of living with HIV long-term and pose an ongoing challenge to policy makers and service providers to offer responsive services that continue to meet these complex needs.

4.1 Implications

Finally we present a number of clinical and service implications that have arisen from this research. Many of these implications are relevant for men who have lived with HIV short or long-term.

- The support needs for men living with HIV are complex and must be addressed holistically, offering medical support, psychological support and appropriate social support.
- Coming to terms with the diagnosis of HIV may also be accompanied by coming to terms with disclosing sexual orientation to others. This requires

specific sensitivity and support as either disclosure may result in experience of stigma or reduction in social networks.

- Holistic and long-term consideration of psychosocial needs is essential. This research indicates that our current estimates of how long a man living with HIV may require additional support are inadequate and indicate that such needs have been likely underestimated.
- Sharing the experience of those living with HIV long-term may promote prevention. Studies have shown that the rate of new HIV infection is rising and most new infections are seen in the gay male population. The men involved with this research were concerned that HIV was not retaining its 'feared' status.
- The long term socioeconomic impacts of living with HIV need to be considered. The impact of isolation, poor housing, low socioeconomic status, no close supportive relationships could all add to a depressive presentation but equally just be seen as part of life for an HIV+ individual. Living with HIV long-term may lead to increased need as some men may have spent or used resources when they reasonably thought they were going to die, and now face economic hardship.
- Addressing issues of loss is important. The level of loss experienced by this group is extensive. This may have clinical implications and demonstrate barriers to treatments in a population with a high morbidity of mental health problems. An individual who has been living with HIV for a long time must be asked about their affect in clinical settings, not just mental health ones.
- Economic and physical consequences of HIV are a barrier to engaging with services. This research highlighted that living long-term with HIV presents specific barriers to services. Individuals might not be able to attend services because of financial issues or due to the severe side effects of the medication, issues which need to be considered when services are developed.
- Specialist support for returning to employment is required. Research shows that an individual diagnosed with HIV now, if they go onto medication and live a healthy lifestyle, can expect a near normal life span which has implications for working, relationships and living long-term with HIV. Schemes helping long-term survivors stay at work, return to work, negotiate disclosure, coping with stigma and find relationships, for example, are needed. Indeed voluntary agencies work has moved to a more practical focus because the need is there but this is not coordinated on a National level, so some long term survivors will not benefit.

- Support from positive peers is valuable and should be resourced. This research has demonstrated an unmet need for gay men living long term with HIV, support groups for long term survivors might be developed and run by long-term survivors for long-term survivors. Finding a range of options for expressing peer support or experiences is important and needs to include face to face as well as anonymous settings or formats.
- Daily life offers continuing adjustment and transitions. Managing daily life under the HAART regime can be difficult and have a negative impact on quality of life. The impact of side effects and changes in medication in particular mean that there is no fixed period of adjustment in living with HIV long-term. Long term support needs to remain in place to respond to the changing needs and experiences of gay men living long-term with HIV.

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