

This article was downloaded by: [Glasgow Caledonian University]

On: 13 January 2012, At: 04:44

Publisher: Routledge

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



## Psychology & Health

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/gpsh20>

### Understanding the impact of HIV diagnosis amongst gay men in Scotland: An interpretative phenomenological analysis

Paul Flowers<sup>a</sup>, Mark McGregor Davis<sup>b</sup>, Michael Larkin<sup>c</sup>,  
Stephanie Church<sup>a</sup> & Claire Marriott<sup>d</sup>

<sup>a</sup> Department of Psychology, Glasgow Caledonian University, Cowcaddens Road, Glasgow, G4 0BA, UK

<sup>b</sup> Department of Sociology, Monash University, Melbourne, VIC, Australia

<sup>c</sup> School of Psychology, Birmingham University, Birmingham, UK

<sup>d</sup> Maggies Cancer Care, Oxford, UK

Available online: 21 Jun 2011

To cite this article: Paul Flowers, Mark McGregor Davis, Michael Larkin, Stephanie Church & Claire Marriott (2011): Understanding the impact of HIV diagnosis amongst gay men in Scotland: An interpretative phenomenological analysis, *Psychology & Health*, 26:10, 1378-1391

To link to this article: <http://dx.doi.org/10.1080/08870446.2010.551213>

PLEASE SCROLL DOWN FOR ARTICLE

Full terms and conditions of use: <http://www.tandfonline.com/page/terms-and-conditions>

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae, and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings,

demand, or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.

## Understanding the impact of HIV diagnosis amongst gay men in Scotland: An interpretative phenomenological analysis

Paul Flowers<sup>a\*</sup>, Mark McGregor Davis<sup>b</sup>, Michael Larkin<sup>c</sup>, Stephanie Church<sup>a</sup> and Claire Marriott<sup>d</sup>

<sup>a</sup>Department of Psychology, Glasgow Caledonian University, Cowcaddens Road, Glasgow G4 0BA, UK; <sup>b</sup>Department of Sociology, Monash University, Melbourne, VIC, Australia; <sup>c</sup>School of Psychology, Birmingham University, Birmingham, UK; <sup>d</sup>Maggies Cancer Care, Oxford, UK

(Received 27 July 2010; final version received 22 December 2010)

**Objectives:** Although a wide literature details the psychological impact of human immunodeficiency virus (HIV) diagnosis, it predates the introduction of effective treatment for HIV (i.e. anti-retroviral therapies, ARTs). This article explores the psychological impact of HIV diagnosis in post-ART accounts. This is important, given the recent policy developments which focus upon increasing HIV testing and thus diagnoses.

**Design:** This study presents a qualitative exploration of the experiential accounts of HIV-positive gay men living in Scotland. A total of 14 HIV-positive gay men took part in open-ended interviews.

**Methods:** Interpretative phenomenological analysis was employed to identify recurrent themes across the interviews.

**Results:** Our analysis focuses upon the participants' struggles in adjusting to their HIV status. Diagnosis was a deeply shocking and unexpected experience. Stigma and fear of prejudice dominated their accounts. HIV was understood, variously, as a shameful, fatal and life-changing condition. Overall, within these accounts there was little sense of HIV normalisation.

**Conclusions:** In Scotland, where HIV prevalence is low, and where no accessible HIV-positive sub-culture exists, there is on-going psychological distress and morbidity amongst gay men testing HIV positive. As HIV-related policy increasingly focuses on increasing rates of antibody testing, there is a need to reduce the psychosocial costs associated with HIV-positive diagnoses.

**Keywords:** HIV; diagnosis; gay men; chronic illness; medicalisation; IPA

### Introduction

Recent changes in the management of the human immunodeficiency virus (HIV) epidemic in the UK are drawing renewed attention to the psychosocial needs of people diagnosed with HIV. Green and Smith (2004) reviewed the impact of anti-retroviral therapies (ARTs) upon the psychosocial and health care needs of HIV-positive people in the UK. They suggested that HIV had been transformed

---

\*Corresponding author. Email: P.Flowers@gcu.ac.uk

from a 'fatal disease' to a 'chronic manageable infection'. These overarching changes are reflected within both recent policy developments and corresponding shifts in epidemiology. In terms of policy, in the UK and many other countries, increasing the uptake of HIV testing and reducing the levels of undiagnosed HIV infection have become key priorities. In Scotland, for example, reducing undiagnosed infection represents one of the HIV Action Plan's (2009) three overarching aims. Moreover, NHS Quality Improvement Standards (NHS QIS, 2010) relating to HIV are currently being developed and emphasis is given to increase the testing in at-risk populations. In England, similar guidelines from the National Institute for Health and Clinical Excellence (NICE, 2010) are being constructed. These changes build upon other policy documents such as the 'UK national guidelines for HIV testing 2008' (British HIV Association, British Association of Sexual Health and HIV, British Infection Society, 2008) and the Scottish Government HIV testing policy which highlighted a change from opt-in testing, to routine, opt-out testing in GUM clinics (Scottish Executive, 2005). Increases in HIV incidence among gay men have also been reported and gay men remain the group most at risk of acquiring HIV in both Scotland (Health Protection Scotland, 2008) and across the rest of the UK (Health Protection Agency, 2008). As of June 2010, 48% of people being diagnosed with HIV within the UK were gay men (Health Protection Agency, 2010). Recent work from Scotland highlights that between 1995 and 2005, there were increases in HIV testing over time, yet there were also enduring, relatively low, testing levels when compared to other international studies of gay men (Williamson, Flowers, Knussen, & Hart, 2009). In an earlier study addressing the barriers to HIV testing, Flowers, Knussen, and Church (2003) reported the results of a cross-sectional survey of gay men in the central belt of Scotland ( $n = 803$ ). They found that the most important factor in explaining variance in testing behaviours was the perceived psychological drawbacks of testing HIV positive.

Thus in Scotland, more gay men are testing for HIV than ever before and more men are testing HIV positive. However, with the national and international intensification of policy aiming to further reduce undiagnosed infection and promote the increased frequency of HIV testing, it is important to understand the impact of such diagnoses. Equally increased patient numbers and improvements within HIV care have changed the nature of routine HIV service provision; intensive pre-test counselling is now the exception not the rule, and medical markers and drug management are the focus of doctor-patient interactions (Rosengarten, Imrie, Flowers, Davis, & Hart, 2004).

In contrast to this increasingly *public health* approach to managing HIV, the current study seeks to idiographically explore the impact of HIV diagnosis in-depth. To do this, it utilises interpretative phenomenological analysis (IPA, see Smith, Flowers, & Larkin, 2009) as a means to explore the psychological aspects of HIV diagnosis.

### Data collection

Fourteen HIV-positive gay men were recruited through advertising in the gay press, the positive press and through leafleting gay bars and clubs. The participants' ages ranged from 22 to 54, with a mean age of 36. All were diagnosed after the introduction of ART between 1997 and 2003 at around the time that testing policy

began to change. Average age at diagnosis was 29. Average time since diagnosis was 4 years. All participants were white, and represented a range of professional and working-class backgrounds. The majority of participants lived in major Scottish cities. The interviews were conducted between 2003 and 2005.

Interviews were conducted by the first author in either the university, the participant's home or a charity office setting. The interviews addressed various aspects of the lived experience of gay men with HIV including testing, diagnosis and treatment, mental health and wellbeing, family life and relationships and sexual practices. The interview style consisted of a dynamic of reflection, followed by further questioning relating to what the participant had just said. Throughout the interview, the talk flowed from initially general accounts of experience, to very detailed, retrospective accounts of specific thoughts and feelings. Thus, although the content of each interview depended upon what the participant brought to the interview, the interview style was consistent across interviews. The interviewer's role was to establish rapport and actively manage the interaction to elicit first person detailed accounts of specific events. As with all qualitative research, there was variability in the depth and richness of the data collected within the interviews; this is reflected in the choices of extracts used below. Ethical approval for the study was granted by Glasgow Caledonian University. All participants consented to their interviews being used for analysis and publication with pseudonyms used to protect their identity.

### **Approach**

We employed IPA to explore people's accounts of their experiences. IPA is an established method in clinical, health and social psychology, which provides a stance and protocol for the analysis of experiential qualitative data (Reid, Flowers, & Larkin, 2005; Smith & Osborne, 2003; Smith et al., 2009). It has been used several times before to address sensitive and under-explored topic areas such as sexual health (e.g. Flowers, Duncan, & Knussen, 2003; Flowers, Smith, Sheeran, & Beail, 1997; Flowers et al., 2006), wherein its participant-led focus facilitates the emergence of novel and useful insights. It requires a detailed, rigorous and systematic engagement with each participant's interview transcript, employing inductive and iterative processes of reading, exploring, coding, reflecting, interrogating, integrating and, eventually, thematising. The analyst aims to identify patterns of meaning (themes) in the participant's experiential claims and concerns, and to situate these in the context of wider structures, narratives or life stories (Larkin, Clifton, & Watts, 2006). In IPA, the final analytic account aims to reflect the shared understandings of the experience in question, whilst also giving some sense of individual variation (in terms of particular participants' experiences) within the data set.

Unusually for IPA, a team approach to analysis was adopted to promote the credibility of the analysis and theoretical nuance. Initially, PF and SC separately coded each interview, PF manually and SC using NVivo software. We found that the former approach lends itself to nuanced, language-focused interpretation, whilst the latter promotes more rigorous, descriptive, thematic analysis (both essential for good IPA). They then met on several occasions to discuss, challenge and revise their coding to develop both their respective and joint analyses. The process was one of continuously independently checking and verifying each other's analytic insights.

We found that the differing perspectives of the two primary analysts, in terms of PF being a gay man very familiar with the effects of HIV, and SC being a heterosexual woman with little experience of the HIV sector, enhanced the analytic process; assumptions and prior knowledge were constantly questioned from both perspectives. Analysis was structured around the six key stages of IPA: repeated reading; exploratory coding; identifying emergent themes; looking for patterns and connections across emergent themes; looking for recurrent themes (across transcripts) and looking for patterns and connections across recurrent themes (for an in-depth, step-by-step account illustrating the process, see Smith et al., 2009).

### Analysis

In order to understand the accounts of being diagnosed HIV-positive, it is necessary to situate them in the context of the participants' lives. An 'illness' trajectory, or narrative runs through many of the interviews. This traces the history of the participants' HIV-related experiences from HIV-antibody testing, through diagnosis, and for many, to eventual anti-retroviral treatment. Therefore, an overarching HIV-narrative structures our analytic account here. This narrative resonates with the public health, or biomedical perspective, as it presents what could be described as a patient pathway, but it also reveals what the former perspectives obscure: the temporal and psychological aspects of identity work and stigma management. The analysis is illustrated through the use of three key recurrent themes: 'Crisis, loss and challenges', 'Integrating HIV and experiencing a sense of damaged identity' and 'Adjustment and assimilation'.

### HIV diagnosis: Crisis, loss and challenges

One recurring theme of the narratives was that HIV diagnosis had led to unwelcome and problematic changes in identity. In contrast to the clarity and certainty associated with the linear, biomedical, patient pathway associated with the effective medical management of HIV, the participants of this study found HIV diagnosis, and the related notion of prognosis, to be full of uncertainty, and both unsettling and confusing. As Alex said 'you're getting all these mixed messages about, all the eighties media stuff, thinking: well that's it that's my life over; but on the other hand there's all the optimistic stuff around having a long fulfilled life'. Alex goes on to demonstrate the profound sense of identity crisis associated with the period immediately following diagnosis itself. In explaining the magnitude of this crisis, he draws upon a range of visible identities and symbols, each important because of the significance they have to an imagined onlooker. In this way, he introduces the idea that, although HIV status is an embodied and thus individual reality, its significance is often relational (for similar findings in other UK populations, see Jarman, Walsh, & De Lacey, 2005; Rhodes & Cusick, 2000):

All I can say is for those weeks after I found out, I felt as if I had a huge neon sign above my head saying 'HIV', and it's as if I woke up and found that I was black, when I'd always thought I was white, is the only way I can explain it. [...] You were really having to get used to yourself with this new identity. (Alex)

For all the participants, the period surrounding diagnosis was associated with an intense period of crisis; feelings of anxiety, paranoia and distress were common.

Jack, for example, describes how he tried to manage his identity crisis, without telling any significant others of his HIV status:

R: I think that was really because in lots of ways I didn't know who I was at that time, in the early days of being diagnosed and coming to terms with it, I couldn't stop thinking about it . . . I had to go through a process of finding out or finding myself again, and whilst I was around people that knew me well, I found it really, really exhausting because, well maybe they couldn't tell but I was paranoid that they would know that something was wrong, so I was constantly trying to be as near to how I imagined myself to being without HIV so . . . that in itself made it even more impossible, because the more you try to stop thinking about something, then the harder it becomes. . .

I: And these are your close friends are you thinking about?

R: Close friends, family, anybody, even new people that I'd meet; I just felt that I couldn't, I suppose I felt quite, quite worthless because I didn't have the, [sighs] I felt like I'd lost something, I just found everything so tiring, I didn't have anything to give, I didn't feel that I had anything worthwhile to kind of contribute, I don't know, I was just kind of like shell shocked I suppose. (Jack)

In this extract – where Jack captures many aspects of the identity crises described by his fellow participants – the reader will detect a strong resonance with other phenomenological literature on the experience of living with embodied changes in general (e.g. see Burton, 2000 – on stroke), and living with stigma in particular (see, e.g. Knight, Wykes, & Hayward, 2003 – on psychosis). As with Alex, above, there is a palpable sense of the struggle to articulate the magnitude of the identity confusion. Jack's account is evocative of the entrapment in cyclical and ruminative thinking which will be familiar to many professionals working with people in psychological distress. It also reveals his attempts to claim back ('I'd lost something. . .') and perform ('I was constantly trying to be as near to how I imagined myself to being without HIV') a pre-diagnosis version of himself. It is a tangibly distressing account.

Alongside this crisis of identity, feelings of loss and grief were also sometimes reported. For Denis, this related to ideas of grief, or mourning, for the part of himself that had died during diagnosis:

R: I grieved first of all, I had a period of grief, because it was just as if I'd suffered a loss, a part of me had died I think, um that lasted for a couple of months I think.

I: So when you said: grief and mourning, what were you grieving?

R: It was, it's hard to, to describe, but I just felt as if part of me died, I don't know what that was.

I: Aye because you said it's hard to describe it, but have a go. . .

R: I don't know, maybe a kind of loss of innocence, and the fact that I was going to have to, this was going to be such a major event, something that's going to be hanging over me and that I'm going to have to deal with in almost everything I do every day, which it is. Every morning I woke up I thought oh . . . I'd wake up and think: oh it's a nice day, oh my god I'm HIV-positive and I would be down again, but that would only last till like I said a couple of months.

I: So you said about the sense of, the sense of grief was the word you used about the loss of. . . innocence.

R: Yeah it's feeling unhappy that I was, had this horrible thing that was hanging over me that I was very different, had this like big label on my forehead.

I: What do you mean by that?

R: A sort of biohazard symbol, you know, like I'm dangerous, I'm different, that's how it felt, I felt very isolated because of a . . . of a sort of clinical condition. (Denis)

Again, the stigmatising aspect of diagnosis is evoked, this time with the added element of 'embodied dangerousness', which is denoted by the 'biohazard symbol'.

Here, HIV diagnosis is understood to be distorting and corrupting, but also taking or stealing, some sense of the person being diagnosed. The 'self-dialogue' that we see in these accounts is also related to a potential rejection of the new person created by diagnosis. In this way, suicidal ideation and self-abandonment were also sometimes reported. Thus, Jack describes the absence of himself in his life:

I: You just said you wanted to lie on the floor and dissolve, can you tell me more about that feeling?

R: Just the feeling that, a feeling of unreality, a feeling of not being attached to anything anymore, feeling very strange, like I had no control over anything anymore, like that I didn't know what was going to happen and . . . I just wanted to give up and collapse and just have everything over with and that would be the end, and I wouldn't have to think about anything and . . .

I: So what was dissolved?

R: Well me as a person but all the problems around being me would just, wouldn't be there anymore and that would be, that would be it. But yeah, I just wanted to be dead, I didn't want to be here. I didn't know how I was, I didn't know who I was, I didn't, I felt like I was in a really, really, really awful movie that you would see on channel 5 really late at night, that you'd think: oh this is just really tacky and awful, and it's so dramatic and so terrible and then you think: well this is happening to me, I mean you can't get your head around it and all the feelings and everything it's just . . . a bit too much. (Jack)

Jack's account again reflects intense distress as he articulates thoughts of self-destruction. In this respect, HIV diagnosis presents an ontological crisis for the self. Much has been made of the notion of HIV-infection as a chronic manageable condition. ART has changed the prognosis of most of those who are HIV infected, and is often held to have reduced the negative psychosocial aspects of living with HIV. However, Jack's account strongly resembles the stories of HIV diagnosis documented in the stages of the epidemic which precede the advent of ART. For example, working in the early 1990s, and before ART, Roth and Nelson (1994, p. 161) characterised AIDS-related losses as threats to ' . . . ontological health', in the sense that the basis of social existence and identity was undermined. The resemblance is even established reflexively, by Jack himself ('I felt like I was in really, really, really awful movie that you see on Channel 5 late at night'). Culturally then, as well as scientifically, it is understood that the narrative is supposed to have moved on. These 'terrible' feelings seem 'tacky' and 'awful,' because they resonate with a '[melo]dramatic' historical narrative, rather than the current, prevalent narrative, which discounts the possibility of serious psychosocial consequences and focuses upon the effectiveness and increasing simplicity of ART. On the contrary, Jack's account, and others like it, suggests that whilst the medical management of HIV infection has radically improved, the psychosocial concerns endure or are reshaped in light of the contemporary situation.

### **HIV diagnosis: Integrating HIV with self and experiencing a sense of damaged identity**

The relevance of HIV to identity was understood to change across time. Following the diagnostic identity crisis, there was usually a partial sense of identity adjustment, or assimilation; although this was understood as fragile and problematic. Across these participants, a generational pattern was visible. Younger participants (and thus those more recently diagnosed such as Jack, Alexander and Denis) appeared

to describe a slightly easier adjustment to HIV diagnosis than the older participants (who tended to have been diagnosed for longer, such as John, Lee and Andy). The younger participants were sometimes able to offer a sense of regaining some of what the process of HIV diagnosis had removed. Yet for others, particularly those in receipt of benefits and those with on-going health problems, there was little sense of adjustment, or identity reclamation:

R: I thought I could come out of this without being hurt, but the hurt's never gone away, it's still there. But I'll be honest enough to sit here and say that I can laugh and joke with you and have fun and, but deep down inside I'm not happy at all. If you really, really want the truth, I'm really fucked off.

I: You've said that about anger doesn't capture it.

R: There's nothing on this planet that would ever capture how I feel inside.

I: Can you try and...

R: It's like a... it's like someone cutting my skin, so deep you can't reach to the bottom, and the pain just keeps oozing and oozing and oozing out, never stops, that's how it feels: not nice.

I: And when you say it never stops?

R: Well it's with you 24 hours a day. I'm not sure what the next thing's going to be, I haven't even with my body, I know for a fact that things will deteriorate – I'm getting older and I've been on my regime [ART] for seven years, I'll be on my eighth year in January of next year, I've then got to face new challenges by going to reviews for the DLA, this that and the other and I'm really not interested, I couldn't care less, really don't want to know. I just, it's all negative thinking but I just, that's how I feel.[...] I, I can't even bring myself to tears anymore because... it's... every day it's with you, you can't get away from it, it's like I feel like I'm in a tin box, and I can't lift the lid off, or I'm in a fish tank and you lot are out on the other side. Yeah cause you're boxed in you don't have anything in common with people, you, you feel removed away from... like you're not in the work place anymore so therefore you don't get involved in the daily routine or the daily activities what's going on in the world. (Lee)

Lee's powerful metaphorical language (the skin is a barrier; he is trapped in a tin box, then contained, for display, in a fish tank) echoes other participants' concerns with isolation, exclusion and constraint. There is a sharp distinction between Lee's perceptions of the wider world of work and other people, and his own world, where he is struggling with disability living allowance, and the effects of his medication.

For all participants, clinic visits, dental visits, starting ART, changing drug regimes, status disclosure, starting new relationships, the commercial gay scene and interactions with others more broadly, could re-emphasise the importance of HIV and lead to episodic identity difficulties. The salience of HIV in the eyes of others relates directly to stigma. Here, John outlines how an illness episode necessitated contact with his biological family and an ensuing sense of rejection:

R: Yeah I haven't seen any of my family since my parents died, I'm not allowed to see my nieces or nephews since my parents died, I wouldn't even know who they are.

I: And this is all because of...?

R: Because I'm gay and because I'm HIV-positive, mainly because I'm HIV-positive, you know so that's hard for me to deal with, even at this moment [yeah] you know, and when I had my brain haemorrhage, and the hospital had to get in touch with my brother, and the response that I got from him was 'we don't want to know. Just when he dies put him in a bin bag and burn him', and the hospital social worker had to tell me that. (John)

The relational impact of HIV diagnosis was often severe – either in terms of the changed perceptions of others (as with John's account here), or in the *fear* of the changed perceptions of others, as we have seen already in the material describing

various forms of imagined visual stigmata (e.g., the biohazard symbol, the neon sign). For some of the older participants, whose appearances really had changed, due to lipodystrophy (the fat-redistributing side effects of ART particularly associated with the first wave of effective drug regimes available) this was further exacerbated. The management of an HIV identity became a real concern. In the extract from Andy, below, we see a distressing and embodied enactment of the identity issues outlined earlier. It is almost as if Alex's 'neon sign' has been manifested in the facial and bodily disfigurement associated with lipodystrophy:

R: I was like, wouldn't come out my house because to me it was so evident, what I had, even though it wouldn't be evident other people, in my head, if they looked at me, I would direct everything to that place where I had lipodystrophy and turn everything round to having lipodystrophy. So, lipodystrophy ruled my world at that point.

I: What was it about the lipodystrophy that was worrying you?

R: Just because it was HIV. If I had looked like this normally, I wouldn't give a shit. Everything's to do with HIV.

I: Can you explain again. . . . Why did it bother you?

R: How do you mean, why did it bother me? Why would it bother you if you were deformed? Through something which you wanted to hide from everybody? Isn't that kind of stating the obvious? Obviously, if you've got something to hide, and you're wearing it on a badge, and that badge can only be read by certain people, it's going to bother you. [. . .] So, yeah, my whole life at that point, was geared round not looking like I had lipodystrophy. Plus, I was extremely uncomfortable, I had no fat on the bottom of my feet, I had no fat on my arse. in my knees, you know, so I couldn't walk on wooden floors. (Andy)

Here, the sense of transformation is complete: not only is the act of self-presentation made risky and unpredictable by changes in one's own appearance, but one's own embodied experience of oneself has shifted. Moreover, the extract details the salience of status disclosure as a major concern and, in this case, the loss of control regarding knowledge of HIV status which may result from lipodystrophy.

### **HIV diagnosis: Adjustment and assimilation**

Against this backdrop of distress and difficulty, the participants also outlined an emerging sense of adjustment and self-acceptance. Again, within this limited sample, there was a generational pattern; for younger, more recently diagnosed men suffering less from HIV, or the side effects of ART, such adjustment seemed easier. However, acceptance of HIV diagnosis was relational because it depended upon perceptions of acceptance from other people:

R: I think the biggest kind of how thing was, was telling friends and or telling people that I was positive, I think that was probably the biggest practical thing that I did, that enabled me to kind of move on and see . . . and I think it's about having acceptance from people, then you're able to accept yourself as well, if people know about it then, then, then it's easier to kind of feel alright about it yourself and, that that was a big change. (Jack)

Adjustment sometimes related to the idea of being 'allowed' to continue in the role of friend, lover or colleague without HIV 'taking over' as an all-encompassing identity (resonating with the participants' own internal identity struggles). As Alex explains:

I: So what is it about your friends' reactions, when they forget, that amazes you?

R: I think that's wonderful, I love it when they forget [my status], because what that tells me is that they're seeing me as Alexander, and they're seeing me as the same person as I always was, and ok they might think sometimes I've got this virus, but that's just I have like anything anyone could have. My fear was that they would, they would see that neon sign when they looked at me, and they would always treat me with kid gloves and kind of dance around that and maybe, I'm not quite sure how I expected it to manifest itself, but that they would somehow see me as Alexander who was HIV-positive, rather than just Alexander. (Alex)

Jack described a process of eventual identity integration, in which he constructed a new sense of self:

R: Although I've been talking about feeling, you know cut off and I'd felt very detached from the world, I didn't feel that I was alive, I felt really, really strange, I'd never felt like that before. Although I felt all these kind of negative things, at the same time I felt a lot of me was kind of re-affirmed by the diagnosis of things that I'd believed in before I still believed in afterwards, and that gave me a sense of strength somewhere... And it, it was almost like I had to break down every little part of myself and build it back up again so that everything would work better... if that makes, [laughing] if that makes any sense, kind of like rebuilding everything to make the connections a bit better, or some that kind of thing would... a kind of re-evaluation of things I suppose, of sort of getting things back to working order. (Jack)

Thus, the continuity of relationships that existed before HIV diagnosis was important in understanding adjustment to diagnosis. Significant others could look past the label of HIV and give the participant a sense of enduring self, remind them that they were the same persons they always had been. In this way, ART offers a potential means to the reclamation of social and sexual identities. This should be understood as occurring over time, and after the initial crisis period associated with diagnosis. For those who had been both physically and psychologically changed by HIV and ART, this assimilation was more difficult.

The participants also talked about the changes HIV had wrought in positive terms. Again, there was a sense of identity assimilation. Denis, for example, described how diagnosis had made him reappraise his relationships with other people and allowed him to appreciate his life:

R: I think it makes me realise how fragile we are, and how to make the most of every single day, and not to fret, or have huge hopes that you're not going to achieve, make the most of every day, just be good to everyone, because it may be your last day, and hope that everyone will be good to you in return. These are maybe just things that everyone should do in their normal life, but don't... but that's what's being diagnosed as a positive person has done to me, it's really made me value my life and other people's all around me.

I: But can you think of moments where that has happened or...?

R: Everyday, it's just a, it's just a way of life for me now, it's probably because I was such a negative person when I was negative, [laughter] I know isn't that strange? [loud laughter] But it's true. (Denis)

The potential loss of future, or loss of life, was sometimes catalytic in men making positive changes in the present. HIV had changed men's lives and often their attitude to their life. New treatments had given men the optimism to believe that they had healthy years of life in which to fulfil dreams. Diagnosis and changes in lifestyle had given some men a driving impetus they had never had before. Several men reported positive improvements in their attitudes, self and life following their diagnosis. Many men were determined and optimistic about their futures. Some men noted that since responding to the suggestion of adapting a healthier lifestyle,

they now felt healthier than before diagnosis. Others reported a wholeness, honesty or peace following years of uncertainty.

## Discussion

These men's HIV narratives are imbued with the notion of the birth of a new self—the 'self with HIV' – and its survival *via* a long and difficult journey. However, the participants also described the intense, on-going psychological distress associated with HIV diagnosis, and the related social adjustments which were required. Critically, the distress associated with diagnosis and the concomitant processes of adjustment are not singular, but are embedded within unfolding temporal, relational and social contexts. In this way, the participants not only describe particular crisis points (such as diagnosis itself) but also subsequent challenging episodes within which they experienced a re-visitation of earlier difficulties. Examples of these include starting ART, managing the acute side effects of ART associated with treatment initiation, managing the long-term side effects of ART, periods of illness, medical visits, developing new relationships, negotiating disclosure events and having time off work. The extant literature resonates with many of the findings presented here concerning the immediate crisis following diagnosis, with pre-ART evidence highlighting diagnosis-associated distress. However, studies have tended to show that distress decreases within 2–10 weeks (Perry et al., 1990). Similarly, Ironson et al. (1990) report that, for people testing positive, intrusive thoughts, clinical levels of anxiety and avoidant responses are usually reported in the week following diagnosis but that within 5 weeks, these returned to normal levels (Ironson et al., 1990). Others have also noted that responses to receiving a positive test result often include denial, anxiety, depression and suicidal ideation (Coates, Moore, & McKusick, 1987; Ostrow et al., 1989) and that the period immediately following diagnosis is a particular point of vulnerability for depression (Ciesla & Roberts, 2001). More recent research not only highlights the on-going distress associated with diagnosis itself, but also the particular importance of how test results are communicated (Anderson et al., 2010; Hult, Maurer, & Moskowitz, 2009).

This study has findings reminiscent of the pre-ART literature which highlighted the psychological needs of those newly diagnosed. But the current study shows that these psychological concerns have new and distinct qualities. Flowers et al. (2001, p. 669) have noted how in the post-ART era, HIV diagnosis has changed from 'death sentence to life sentence'. Similarly, Green and Smith (2005, p. 20) describe such changes as 'a shift from the acute mental health problems associated with dying to the chronic complex problems associated with living'. Building on these perspectives, this study describes episodic distress for most and pervasive distress for some (particularly those living with the side effects of ART itself). This finding reflects the adoption of the IPA methodology, as quantitative methods, even when they are tied to longitudinal designs and are relatively insensitive to episodic phenomena (Tennen, Affleck, Armeli, & Carney, 2000).

In terms of the experience of living with HIV post-ART, the health benefits of ART are clear; reduced morbidity and reduced mortality (Garcia et al., 2004; Gulick et al., 2003; Kaufmann et al., 2003). Equally, however, there have been changes in terms of the emergence of new uncertainties; for example, potential longevity instead of almost certain death, returning to the workplace, potential loss of benefits,

facing an unanticipated future (Brashers et al., 1999), re-engaging with the possibilities of relationships and reinvigorated interest in sex. In addition, the side effects of medication bring further psychological challenges, for example the impact of lipodystrophy (Blanch et al., 2002; Collins, Wagner, & Walmsley, 2000; Kelly, Langdon, & Serpell, 2009) and possible psychiatric side effects of some ART (see, e.g. Arendt, de Nocker, von Giesen, & Nolting, 2007).

Given the impact of ART and that diagnosis no longer equates with poor prognosis, the transferability of evidence from pre- to post-ART should be approached cautiously. For example, acute opportunistic illnesses associated with AIDS and end of life issues are less common. Yet, the participants in this study, diagnosed after the advent of ART, still reported major psychological distress. This article has shown how some of this relates to uncertainty regarding the contemporary health-related meaning of HIV status. In a UK-based survey of HIV-positive men, Harding and Molloy (2008) also show how enduring questions of life expectancy remain central to living with HIV post-ART, irrespective of treatment history.

We have also shown that issues such as HIV-related stigma, fear of discrimination and identity-related distress remain critical to men's experience of, and adjustment to, HIV diagnosis. In this way, although the distress concerning preparation for death has diminished, the psychological and social factors associated with diagnosis seem to have remained, or perhaps have taken on new meaning in the lives of people with HIV. For example, in their review of the impact of ART upon psychological distress in studies of positive people, Siegel and Lekas (2002) found inconclusive evidence regarding changes in the prevalence of psychological distress. Their review shows no clear relationship between the introduction of ART and either increasing, or decreasing, distress associated with living with HIV, though it may be that some of the distressing issues themselves have evolved. More broadly, and in relation to the notion of episodic difficulties, Catalan, Meadows, and Douzenis (2000) review the overall changes in the patterns of mental health problems presented at a London service for positive people. They report that when comparing 1990 (pre-ART) with 1999 (post-ART), there was a decrease in referrals relating to organic brain syndromes and adjustment disorders. However, there were increases in depressive disorders and sexual dysfunction. Similarly, Ciesla and Roberts (2001), in a meta-analytic review of the literature relating to HIV status and depression, report that when comparing HIV-positive subjects to HIV-negative subjects, the frequency of a major depressive disorder was two times higher amongst positive people. They were unable to assess the impact of the introduction of ART upon depression. They conclude that HIV infection was associated with a greater risk for major depressive disorder. All of this research is still relevant, given the double-bind of participants like Jack, who are not only faced with a terribly distressing situation, but also constrained by the prevailing and misplaced assumption that, post-ART, this is not such a terrible event after all.

Critically, stigma plays a central role in shaping people's reactions to diagnosis, both in studies from before and after the introduction of ART (Chesney & Smith, 1999). Stigma is a function of the value and meaning attributed to various kinds of social positions and identities. More broadly, HIV-related stigma has been shown to be associated with anxiety, guilt, depression, isolation, the disruption of family dynamics, emotional and physical violence and difficulties in relationships with health professionals (Chesney & Smith, 1999). These meanings may be attached by the persons who are in those positions, or by those who are outside of them, or both.

In this study, stigma is important both as ‘felt’ and ‘enacted’ (Scambler, 2004). In terms of felt stigma, much of the stigma ‘work’ reported here related to the internal worlds of the participants (the imaginary signs and symbols that disclosed their HIV status to others). However, enacted stigma also emerged as important with incidents of HIV-related abuse being reported by a few of the participants. Recent research highlights the context specificity of psychological distress associated with HIV stigma, for example, Stutterheim et al. (2009) highlight the centrality of interactions with both family and health care workers as key vulnerable contexts and areas for intervention.

Within this particular sample there was also a tangible sense of divergent illness trajectories according to the length of time since diagnosis, with a trend for older participants to report more significant difficulties with living with HIV. This may relate to the time frame of the study, in that some of the older generation had experienced HIV-related illness, and had taken particularly toxic, early-generation ART (Andy, Lee, John). Given subsequent improvements in ART regimes and the decreased prevalence of HIV-related illness associated with early detection and corresponding earlier treatment initiation (UK guidelines increasingly recommend starting treatments sooner than later), it may be that these findings relate to the specificity of the sample. It is important to remember that the design and aim of qualitative studies such as this does not enable robust comparative analysis and although the interplay of the idiographic with patterns across groups (e.g. here – age and generational effects) is worthy of reporting, the resulting hypotheses/research questions need to be addressed through the use of different research methods.

In conclusion, the biomedical model of HIV management sustains the view that HIV is ‘normalised’ (DeCock & Johnson, 1998), in as much as there is accessible (at least in the West) diagnosis and treatment. However, our research indicates that, from a psychological perspective, there is little evidence of ‘normalisation’ as such, and strong indications of changing psychological and social morbidity related to HIV infection. As policy and service provision increasingly move towards a biomedical and public health approach, for example, in the drive to reduce undiagnosed HIV infection through increased rates of HIV testing, it is crucial that the individual and their psychological and social needs are not forgotten or eclipsed by the brilliance of effective treatment for HIV.

## References

- Anderson, M., Elam, G., Gerver, S., Solarin, I., Fenton, K., & Easterbrook, P. (2010). “It took a piece of me”: Initial responses to a positive HIV diagnosis by Caribbean people in the UK. *AIDS Care*, *22*, 1493–1498.
- Arendt, G., de Nocker, D., von Giesen, H., & Nolting, T. (2007). Neuropsychiatric side effects of efavirenz therapy. *Expert Opinion on Drug Safety*, *6*, 147–154.
- Blanch, J., Rousaud, A., Martínez, E., De Lazzari, E., Peri, J.M., Milinkovic, A., . . . , Gatell, J.M. (2002). Impact of lipodystrophy on the quality of life of HIV-1-infected patients. *Journal of Acquired Immune Deficiency Syndromes*, *31*, 404–407.
- Brashers, D., Neidig, J.L., Cardillo, L.W., Dobbs, L.K., Russell, J.A., & Haas, S.M. (1999). ‘In an important way, I did die’: Uncertainty and revival in persons living with HIV or AIDS. *AIDS Care*, *11*, 201–209.

- British HIV Association, British Association of Sexual Health and HIV, British Infection Society. (2008). *UK national guidelines for HIV testing 2008*. London: British HIV Association.
- Burton, C.R. (2000). Living with stroke a phenomenological study. *Journal of Advanced Nursing*, 32, 301–309.
- Catalan, J., Meadows, J., & Douzenis, A. (2000). The changing pattern of mental health problems in HIV infection: The view from London. *AIDS Care*, 12, 333–341.
- Chesney, M.A., & Smith, A.W. (1999). Critical delays in HIV testing and care: The potential role of stigma. *American Behavioural Scientist*, 42, 1162–1174.
- Ciesla, J., & Roberts, J. (2001). Meta-analysis of the relationship between HIV infection and risk for depressive disorders. *American Journal of Psychiatry*, 158, 725–730.
- Coates, T., Moore, S., & McKusick, L. (1987). Behavioral consequences of AIDS antibody testing among gay men. *Journal of American Medical Association*, 258, 1889.
- Collins, E., Wagner, C., & Walmsley, M. (2000). Psychosocial impact of the lipodystrophy syndrome in HIV infection. *AIDS Reader*, 10, 546–551.
- DeCock, K., & Johnson, A. (1998). From exceptionalism to normalisation: A reappraisal of attitudes and practice around HIV testing. *British Medical Journal*, 316, 290–293.
- Flowers, P., Duncan, B., & Knussen, C. (2001). Re-appraising HIV testing amongst Scottish gay men: The impact of new treatments. *Journal of Health Psychology*, 6, 665–679.
- Flowers, P., Duncan, B., & Knussen, C. (2003). Re-appraising HIV testing: An exploration of the psychosocial costs and benefits associated with learning one's HIV status in a purposive sample of Scottish gay men. *British Journal of Health Psychology*, 2, 179–194.
- Flowers, P., Knussen, C., & Church, S. (2003). Psychosocial factors associated with HIV testing amongst Scottish gay men. *Psychology and Health*, 18, 739–752.
- Flowers, P., Davis, M., Hart, G., Rosengarten, M., Frankis, J., & Imrie, J. (2006). Diagnosis and stigma and Identity amongst HIV positive Black Africans living in the UK. *Psychology and Health*, 21, 109–122.
- Garcia, F., De Lazzari, E., Plana, M., Castro, P., Mestre, G., & Nomdedeu, M. (2004). Long-term CD4+ T-cell response to highly active antiretroviral therapy according to baseline CD4+ T-cell count. *Journal of Acquired Immune Deficiency Syndrome*, 36, 702–713.
- Green, G., & Smith, R. (2004). The psychosocial and health care needs of HIV positive people in the UK: A review. *HIV Medicine*, 5, 5–46.
- Gulick, R., Meibohm, A., Havlir, D., Eron, J., Mosley, A., & Chodakewitz, J. (2003). Six-year follow-up of HIV-1-infected adults in a clinical trial of antiretroviral therapy with indinavir, zidovudine, and lamivudine. *AIDS*, 17, 2345–2349.
- Harding, R., & Molloy, T. (2008). Positive futures? The impact of HIV infection on achieving health, wealth and future planning. *AIDS Care*, 20, 565–570.
- Health Protection Agency. (2008). *HIV in the United Kingdom: 2008 report*. London: Health Protection Agency.
- Health Protection Agency. (2010). Retrieved from [http://www.hpa.org.uk/web/HPAwebFile/HPAweb\\_C/1237970242135](http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1237970242135)
- Health Protection Scotland. (2008). HIV infection and AIDS: Quarterly report to 30 September 2008/HIV prevalence among non-injecting drug using heterosexuals, injecting drug users (IDUs), and men who have sex with men (MSM) who undergo attributable HIV testing in Scotland: 2007 update/Unlinked anonymous HIV testing of genito-urinary medicine clinic attendees in Glasgow: Data to 2007. *HPS Weekly Reports*, 42, 403–416.
- HIV Action Plan. (2009). Retrieved from <http://www.scotland.gov.uk/Resource/Doc/293178/0090440.pdf>
- Hult, J.R., Maurer, S.A., & Moskowitz, J.T. (2009). “I’m sorry, you’re positive”: A qualitative study of individual experiences of testing positive for HIV. *AIDS Care*, 21, 185–188.
- Ironson, G., La Perriere, A., Antoni, M., O’Hearn, P., Scheniderman, N., Klimas, N., & Fletcher, M.A. (1990). Changes in immune and psychological measures as a function of

- anticipation and reaction to news of HIV-1 antibody status. *Psychosomatic Medicine*, *52*, 247–270.
- Jarman, M., Walsh, S., & De Lacey, G. (2005). Keeping safe, keeping connected: A qualitative study of HIV-positive women's experiences of partner relationships. *Psychology and Health*, *20*, 533–551.
- Kaufmann, G., Perrin, L., Pantaleo, G., Opravil, M., Furrer, H., & Telenti, A. (2003). CD4 T-lymphocyte recovery in individuals with advanced HIV-1 infection receiving potent antiretroviral therapy for 4 years: The Swiss HIV Cohort Study. *Archives of Internal Medicine*, *163*, 2187–2195.
- Kelly, J., Langdon, D., & Serpell, L. (2009). The phenomenology of body image in men living with HIV. *AIDS Care*, *21*, 1560–1567.
- Knight, M., Wykes, T., & Hayward, P. (2003). 'People don't understand': An investigation of schizophrenia using Interpretative Phenomenological Analysis (IPA). *Journal of Mental Health*, *12*, 209–222.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*, 102–120.
- NHS QIS. (2010). Retrieved from <http://www.nhsqis.org/nhsqis/6968.html>
- NICE. (2010). Retrieved from <http://www.nice.org.uk/nicemedia/pdf/HIVMSMFinalScope.pdf>.
- Ostrow, D., Monjan, A., Joseph, J., VanRaden, M., Fox, R., Kingsley, L., . . . , Phair, J. (1989). HIV-related symptoms and psychological functioning in a cohort of homosexual men. *American Journal of Psychiatry*, *146*, 737–742.
- Perry, S., Jacobsberg, L., Fishman, B., Weiler, P., Gold, J., & Frances, A. (1990). Psychological responses to serological testing for HIV. *AIDS*, *4*, 145–152.
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, *18*, 20–23.
- Rhodes, T., & Cusick, L. (2000). Love and intimacy in relationship risk management: HIV positive people and their sexual partners. *Sociology of Health and Illness*, *22*, 1–26.
- Rosengarten, M., Imrie, J., Flowers, P., Davis, M., & Hart, G.J. (2004). After the Euphoria: HIV medical technologies from the perspective of London-based clinicians. *Sociology of Health & Illness*, *26*, 575–596.
- Roth, N., & Nelson, M. (1997). HIV diagnosis rituals and HIV identity narratives. *AIDS Care*, *9*, 161–180.
- Scambler, G. (2004). Re-framing stigma: Felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Social Theory & Health*, *2*, 29–46.
- Scottish Executive (2005). *Respect and responsibility: Strategy and action plan for improving sexual health*. Edinburgh: Scottish Executive.
- Siegel, K., & Lekas, H. (2002). AIDS as a chronic illness: Psychosocial implications. *AIDS*, *16*, S69–S76.
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Method and application*. London: Sage.
- Smith, J.A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). Thousand Oaks, CA: Sage Publications.
- Stutterheim, S., Pryor, J.N., Bos, A., Hoogendijk, R., Muris, P., & Schaalma, H. (2009). HIV-related stigma and psychological distress: The harmful effects of specific stigma manifestations in various social settings. *AIDS*, *23*, 2353–2357.
- Tennen, H., Affleck, G., Armeli, S., & Carney, M. (2000). A daily process approach to coping: Linking theory, research, and practice. *American Psychologist*, *55*, 626–636.
- Williamson, L.M., Flowers, P., Knussen, C., & Hart, G.J. (2009). HIV testing trends among gay men in Scotland, UK (1996–2005): Implications for HIV testing policies and prevention. *Sexually transmitted infections*, *85*, 487–488.