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HIV generations? Generational discourse in interviews with Australian general practitioners and their HIV positive gay male patients

Abstract

The introduction of highly active antiretroviral therapy (HAART) is typically represented as a turning point in the social and medical history of HIV/AIDS, leading to a conceptual division into pre- and post-HAART eras. This paper explores how generational discourse is produced in interviews with general practitioners (GPs) and their HIV positive gay male patients in making sense of this moment and related changes in the Australian HIV epidemic. A theme of ‘HIV generations’ was identified in in-depth interviews with GPs who have HIV medication prescribing rights (based in Sydney, Adelaide and rural-coastal New South Wales) and the HIV positive gay men who attend their practices. In a closer analysis, generational discourse was identified across the interviews with GPs, characterising pre- and post-HAART HIV generations through three main features: treatment histories, socioeconomic status, and modes of survivorship. While generational discourse was less common in the accounts of HIV positive gay men, many of their examples wove together two narrative forms – ‘a different time’ and ‘difference today’ – suggesting that concepts of time and inequity are deeply embedded in these men’s understandings of the HIV experience. Our analysis indicates that generational concepts play a significant role in shaping both professional and ‘lay’ understandings of changes and patterns in the HIV epidemic.
**Introduction**

The introduction of highly active antiretroviral therapy (HAART) in 1996-1997 comprised access to new classes and combinations of medications as well as new diagnostic technologies for measuring viral load, which together were found to reduce viral replication and prevent progression to AIDS-related illness and death (eg. Detels, Munoz, McFarlane, Kingsley, Margolick, Giorgi et al., 1998). The success of this approach (hereafter abbreviated to the term ‘HAART’) has led to this period being typically represented as a turning point in the global HIV pandemic. This paper explores how the social and medical history of HIV/AIDS is conceptually divided into pre- and post-HAART eras in the expression of ‘generational discourse’ in interviews with general practitioners (GPs) and their HIV positive gay male patients. The concept of ‘generation’ is used in everyday language to distinguish people or objects on the basis of a time factor such as date of birth (eg. ‘Generation X’) or stage of development (eg. ‘this new generation technology’). However, our approach does not limit the notion of HIV generations to factors associated with age or time. Rather, we are interested in exploring the diverse meanings behind the generational discourse evident in these interviews, following on from a brief review of how the pre- and post-HAART eras are characterised in the research literature.

**Background**

Around three-quarters of the estimated seventeen thousand people living with HIV (PLHIV) in Australia are currently taking HAART (Grierson, Thorpe, & Pitts, 2006; NCHECR, 2008). GPs have played a central role in the response to the HIV epidemic in Australia (Kidd, 1997), and PLHIV are known to visit their primary doctor regularly (Grierson et al., 2006). As in other developed nations, the transformation of HIV from a terminal to a ‘chronic’ illness following the introduction of HAART simplified the treatment and management of HIV in some people, particularly those diagnosed recently (Hoy & Lewin, 2004). However, the expanding range of medications also generated more complexity in terms of potential interactions and side effects alongside multi-drug-resistance, the long-term effects of treatment toxicities and new health issues associated with ageing (eg. Baer & Roberts, 2002). As Wong and Ussher have observed, while death rates may have reduced in the post-HAART era, quality of life has not improved for all since: ‘people are continuing to be confronted by,
and therefore positioned as, having to make sense of complex issues embedded in living with a
disease for which there is no cure’ (2008: 127).

Social research has contributed a great deal to the characterisation of the pre- and post-HAART eras.
For example, Sydney gay men were shown to acquire a new optimism about the effectiveness of HIV
treatments after the introduction of HAART (Knox, Van de Ven, Prestage, Crawford, Grulich, &
Kippax, 2001). Research also indicated that some of the ways that HIV community and identity were
previously understood also began to change, with only 54% of the participants in an Australian cohort
study who were diagnosed post-HAART reporting that they felt part of an HIV positive community,
compared with 80% of those diagnosed pre-HAART (Rawstorne, Prestage, Grierson, Song, Grulich,
& Kippax, 2005: 598). The authors suggest this could be due to PLHIV having less need to engage
with HIV positive community over time (because they are feeling well), or to the more recently
diagnosed group having always felt less engaged, perhaps evidence of the ‘post-AIDS’ subjectivity
described by Dowsett & McInnes (1996). For those diagnosed pre-HAART, successful responses to
HAART were shown to have often led to a physical renewal – sometimes described as ‘the “Lazarus
phenomena”’ (Thompson, 2003) – inspiring a concurrent revival in social roles and interpersonal
relationships (Brashers, Neidig, Cardillo, Dobbs, Russell, & Haas, 1999). Other hypothesised
characteristics of the post-HAART era include a more ‘integrated’ HIV positive identity, due at least
in part to the ‘increased orientation to the future’ made possible by effective medications
(Baumgartner, 2007: 928). However, the widespread uptake of medical technologies such as antibody
and viral load testing that accompanied HAART are also seen as contributing to a ‘responsibilisation’
of individual PLHIV in the monitoring and management of their own health (Race, 2001).

The introduction of HAART has been shown to have had a major impact on the health professionals
who care for PLHIV. Prior to the introduction of HAART, research on the HIV workforce was mainly
focused on their attitudes towards HIV and homosexuality (eg. Horsman & Sheeran, 1995) and their
high rates of burnout (eg. Bennett & Kelaher, 1994). However, as so many of the social and structural
features of HIV care have changed post-HAART, this research has little applicability today. As one
Australian doctor was quoted as saying: ‘We have lived through one of the great revolutions in medicine’ (Yallop, Lowth, Fitzgerald, Reid, & Morelli, 2002: 434). Several new outcomes of this ‘turning point in the HIV/AIDS situation’ (Lowth, Yallop, Reid, & et al., 1999: 31) have been identified including a shift in the models of HIV care from dying to living, a greater focus on medication compliance and a need to support positive patients’ in ‘reinventing life’. In a later paper, the same authors describe a transformation in professional roles: HIV doctors becoming more central in their role as medication prescribers, and others such as nurses shifting from acute care to less challenging roles including medication dispensing (Yallop et al., 2002). Rosengarten et al (2004) have observed that in the post-HAART era many HIV doctors feel torn between their dual responsibilities for prescribing effective drugs and preventing the harms they can cause. The ambivalence that arises in response to these tensions has also been identified in the post-HAART Australian community-based HIV media, contributing to a persistent representation of HIV medicine as volatile and unpredictable (Newman, Persson, & Ellard, 2006).

A large majority of PLHIV in Australia today are gay men (NCHECR, 2008), many of whom live in the inner suburbs of our largest capital cities. Contrary to the international research on homophobia among health care professionals (eg. Plummer, 1995), many Australian PLHIV live within the reach of gay-friendly medical practices in which sexuality and HIV are constituted as everyday and non-stigmatised aspects of the clinical encounter. This is by no means a happy accident since the political history of the AIDS epidemic in Australia (as in many other developed nations) is closely tied to the rise of queer politics and advocacy movements, with one outcome of the pre-HAART response to HIV being a continuing partnership between medicine, research organisations, government and affected communities (Kippax & Race, 2003). Many of the GPs who have worked in the HIV sector long-term are also gay men themselves and engaged with gay communities in complex ways (Newman, Kippax, Mao, Saltman, & Kidd, 2008). Although there is little research specifically exploring the experiences of gay doctors in Australia, one post-HAART study of a group of doctors involved in HIV care reported that sexual orientation was the most important ‘shared value’ in the relationship between doctors and patients in this setting (Lawlor & Braunack-Mayer, 2004). Because
of these close connections, any shifts and changes in HIV medicine have both shaped and been shaped by the practices and meanings inherent to urban gay cultures. Grierson and Smith (2005) have gone so far as to identify generational differences between those gay men who came out before, during or ‘post’ the AIDS crisis in Australia. While this particular typology focuses on the advent of the HIV epidemic rather than HAART, similar distinctions could possibly be observed in the cohort of GPs who provide HIV care in Australia today, depending on when they entered this area of special interest. However, there has been no research to date that explores how the notion of pre- and post-HAART eras shapes the accounts of the doctors and patients affected by the HIV epidemic in Australia. This paper addresses this gap.

Methods
The Primary Health Care Project on HIV and Depression, from which this study is drawn, employed quantitative and qualitative methods to measure rates of depression among gay men with and without HIV and to describe how depression is understood, identified and treated by GPs and their gay male patients. The scope was broad ranging to address the complexity of social factors associated with depression in gay men, including those arising from the experience of living with HIV. The methodology has been described elsewhere (eg. Mao, Kidd, Rogers, Andrews, Newman, Booth et al., 2009; Newman, Kippax, Mao, Rogers, Saltman, & Kidd, 2008), but information relevant to this paper is provided here. Ethics approval was granted by the Royal Australian College of General Practitioners and ratified by the Human Research Ethics Committees of participating universities.

In-depth interviews were first conducted with 16 GPs with HIV medication prescribing rights between August and December 2006. Participants were based in seven general practices across Sydney, Adelaide and a rural-coastal city in New South Wales and included 14 men and two women. The number of years each had been working in HIV medicine ranged from two to 24. (GPs were not asked to disclose their age, sexuality or HIV status.) This sample represents a large proportion of the GP workforce currently providing care to gay men and HIV positive men in those locations. The second component of the study comprised a survey of all of the male patients attending these practices over a
two week period, from which we identified a sub-set to invite into interviews as the final component of the study. Men were invited if they had: 1) agreed to be contacted; 2) identified as ‘currently suffering from depression’ at the time of the survey; 3) measured above 4 on the PHQ9 self-screening tool for depressive disorders, and; 4) identified as gay, homosexual, queer or bisexual. Forty interviews were conducted between February and May 2008: 26 in Sydney and 14 in Adelaide. The rest of this paper is focused on the 17 HIV positive participants.

A majority (11) of the HIV positive gay men we interviewed had been diagnosed since 2000, well into what we are calling the ‘post-HAART era’ (1996-2008), with the remainder (6) diagnosed in the ‘pre-HAART era’ (1984-1995). Almost all were born in Australia and had an Anglo-Celtic background. All identified as gay or homosexual, however three had been in heterosexual relationships previously and one was currently living with his wife, which is an important reminder of the fluidity of sexual identity categories. More than half were aged in their forties but ages ranged from 32 to 72. HIV positive men who were aged younger than 32 proved difficult to recruit into interviews. We were unable to address this since our study methodology restricted us to recruiting through the cohort of survey respondents. Around half of the participants were living by themselves and two thirds were single. Most were employed full (7) or part-time (4), earning a wide range of incomes, up to $4,000 per week gross. However, seven of the men were on limited incomes of less than $400 per week including two unemployed (one receiving Jobseekers Allowance and the other living on savings), and three on the Disability Support Pension only.

Both sets of interviews were semi-structured, with participants asked a range of open-ended questions relating to their clinical and personal experiences of the diagnosis and management of depression, with a particular focus on issues relating to HIV and sexuality. Participants were encouraged to explore related issues as broadly as they wished. The research team was satisfied that sufficient interviews were conducted with both groups to achieve data saturation. Analysis involved the identification of recurrent themes across the data set, following the principles of thematic analysis (Braun & Clarke, 2006). Transcripts were firstly coded broadly by the primary researcher (CN) using
NVivo software. Codes were then collated into potential themes and reviewed in an iterative manner, so as new themes emerged, earlier transcripts were re-examined and the coding framework refined. Emerging themes were discussed, revised and refined among the project team. It is important to note that while the original study aims were focused on the issue of depression, we were also interested in exploring broader issues around HIV, sexuality and subjectivity. So once the main coding framework was complete, a more focused round of coding was carried out by CN arising from our particular interest in the theme of ‘HIV generations’, identified in both the ‘doctor’ and ‘patient’ interviews. In writing this paper, our analysis extended beyond the level of theme to consider how our textual examples were constitutive of ‘discourse’. By this, we mean that each example of generational discourse is understood as embedded within a complex series of social relations between language, subjectivity, culture and power, in line with a Foucauldian interpretation of discourse as ‘practices that systematically form the objects of which they speak’ (Foucault, 1972: 49). A similar interpretation of the notion of discourse is found in Holt and Stephenson’s (2006) analysis of ‘psychological discourse’ in group discussions with HIV positive gay men. We hope our analysis is equally as revealing of the productive capacity of (generational) discourse in this setting.

**GP accounts of ‘HIV generations’**

Generational discourse was apparent throughout the interviews that we conducted with GPs. For example, many of the GPs made reference to the introduction of HAART as transforming HIV from a fatal disease to a chronic condition:

> I guess the battle before 1995 was whether you lived or died. And whether you could sustain immune function. Whether a new drug would come out in time to rescue somebody ... If someone’s got a viable regime and they take it, then they’re basically fine. So now the issues are more social issues, economic issues, side effect issues. Not that many people complained about AIDS, even AIDS wasting, when they were still alive. But now, of course, body image problems and things like that are much more of a hassle. (Rural-Coastal GP [2], 16 years in HIV medicine)
So it went from being a presumed death sentence in the eighties and early nineties. That was the worst time for me, we had five hundred deaths in a few years in this practice. And that’s when everybody left medicine and HIV and whatever. And then in ’96, ’97 when effective treatment came in, many people were brought back from the brink of death. And then it was a grieving for how they’d misplanned their future. (Sydney GP [8], 23 years in HIV medicine)

In both accounts, a chronological shift is identified between the early years of high mortality and a post-HAART revival of possibility. An interesting aspect of the second extract is that this GP weaves in a narrative about his own emotional experience of being so closely involved in the epidemic from the early days. This suggests that for many of these doctors, both personal and professional experiences have shaped how they talk about the impact of generational change on their clinical work.

Another aspect of generational discourse evident in these interviews was a focus on differences between men diagnosed at different stages in the epidemic:

I think there are differences in those that are now being diagnosed [with HIV] and are living with what is seen to be a more chronic and manageable illness and not being given such a bleak prognosis from the very start, to those that have been living with this for a lot longer. And who have had to go through the evolution of change and uncertainty with HIV. You know, they’ve had to live through the uncertainty of treatments, sometimes, or very frequently less optimal treatments in terms of how we deal with it now, having gone through burnt out drugs, so their treatment options have become limited as a result of that early management. The physical changes that have taken place, the body changes to, you know, the fat redistribution loss. (Adelaide GP [1], 6 years in HIV medicine)

This GP is particularly concerned about those men who have lived through several different periods of HIV medicine, with many literally embodying their long treatment histories in the form of treatment resistance or side effects such as lipoatrophy and lipodystrophy.
Generational discourse is often applied in a more complex manner here than simply dividing time into pre- and post-HAART eras. For example, the following GP account envisions different groups of positive gay men living at various historical moments:

[I]t’s gone through different phases. So, I mean, there was a lot of issues around mortality in the early days. And then there was a period where there was a lot of depression [related to] uncertainty of future. As new treatments came in but we didn’t know whether they were going to be effective or not. Now there is probably more diversity in terms of the kind of factors because different people are doing differently. There are people that are failing and getting sick and dying. There are people whose response to therapy is not clear. Then there are people who are probably, they’re not well enough to work or have been out of the workforce for a while and have difficulty getting retrained or getting reintegrated. So with work being such an important identity for people, that can be a factor. Or people who thought they were going to die and are now living, and doing reasonably well but financially are not very well. (Sydney GP [10], 21 years in HIV medicine)

So from this perspective, positive gay men include a group who lived through an era of high mortality, another through an era of great uncertainty, and finally in the present, a multiplicity of groups organised according to differences in their present day medical and social concerns.

A recurring concept within the generational discourse produced by GPs related to social and economic disadvantage:

Because they hadn’t planned for their future because they were expecting to die, and now suddenly we’re saying, “You’re going to live and we don’t know how long for.” And they were well again and it was, “Well, go and get a job and think about a mortgage and all that kind of stuff.” And it was kind of like, “Well, now I’m behind the eight ball and I just let everything slide because I was going to die.” And we copped a lot of anger for that. It was on one hand, “Thanks Doc,” not that we invented the drugs but like, “You gave me the combination that saved my life.” And “But now I’m fucking pissed off because how am I ever going to afford a harbour apartment?” [laughs] (Sydney GP [8], 23 years in HIV medicine)
This quote animates the HIV positive patient with a sense of anger against the medical establishment for the personal consequences of treatment histories, setting up an interesting dynamic in which this GP cohort itself becomes implicated in the constitution of generational differences in the HIV epidemic in Australia.

Accounts of both time and money were often woven together in GPs’ descriptions of the complex relationships between HIV, ageing and mental health:

I’m actually dealing with long term grief at ‘non loss’. Meaning I’ve had to pick up the pieces of one bloke, about three weeks ago, where [a clinician] said to him, “Look, you’re going to be dead when you’re ninety.” And you don’t say that to somebody. It was said in jest, but he’s devastated. Because he’s got to replan his life. What about work? … What about superannuation? What about all these practical things that he didn’t think he’d have to deal with? So I’m dealing with that increasingly about, not only survivor guilt, but survivor anxiety: how they’re going to manage in old age? (Sydney GP [7], 24 years in HIV medicine)

These GPs see a kind of historical misfortune for those pre-HAART men who either spent all their savings when first diagnosed, and/or missed the opportunity to earn money and build up superannuation because of years of illness and disability. These men are represented as now struggling with the prospect of surviving into old age.

Generational discourse was prevalent in these GP accounts, characterising the notion of ‘HIV generations’ through three main features. First, HIV generations are seen as shaped by treatment histories with the pre-HAART generation facing bleak prognoses and critical issues around treatment toxicity and resistance. Post-HAART treatment issues are seen as more focused on minimising the impact of HIV treatments on work and social lives. Second, HIV generations are seen as shaped by socioeconomic status. GPs articulate the notion of a duty of care to those positive gay men who were diagnosed with HIV in the pre-HAART era and given no indication that they might need to think or plan for their futures. Third, HIV generations are seen as shaped by modes of survivorship. That is, PLHIV are characterised as facing both new social and personal challenges since the reinvention of...
HIV as a chronic illness, which inspires the crafting of new forms of identity and practice in order to ‘survive’ in the long term. The main challenges identified here relate to body image, treatment fatigue, social status and survivor guilt/anxiety, but these are represented as issues for many positive men rather than only those diagnosed pre- or post-HAART.

**HIV positive gay men’s accounts of ‘HIV generations’**

Since generational concepts were not directly explored in the interview schedule, it is interesting to note that while generational discourse was common in the GP interviews, it was less so in the gay men’s interviews. However, those passages in which generational concepts were explicit in the ‘lay’ interviews provide an important alternative perspective to the ‘professional’ GP examples. The remainder of this paper therefore examines key extracts from the interviews with six of these men – four diagnosed pre-HAART and two diagnosed post-HAART – following the three features of generational discourse identified in the GP interviews as a way to structure the analysis.

As with the GP examples, the personal and global histories of HIV treatments provided some of the clearest examples of the use of generational discourse in the interviews with positive gay men, particularly those diagnosed in the early years of HIV:

I remember in the early days, when everyone was dying around me, and we had no treatments. This is the eighties. And I was saying, you know, “We will get a drug treatment!” … I had huge faith in medical science. I argued that, in the very early days, amongst my HIV positive colleagues that the market system would deliver us the drug treatments … And I was fairly activist in the early days … [I]t was a ‘war’. But come the moment in 1996 when we did get the combined therapies working, I thought it was appropriate then to declare an armistice. (Nicholas 46, diagnosed in 1984 at age 22)

I didn’t tell my parents I was poz until I was twenty four … [I said,] “I thought I should tell you while I’m still well so you can get used to the concept.” And the thing behind that was that, “Yes, inevitably I am going to get sick.” Now that’s ‘94. Things were very different. Yeah, okay, there were things in clinical trials but … you didn’t know what the fuck you were
going to be getting [or] what the fuck it was going to do to you. But for the guys who were on that it was just like, “Give us anything. Give us hope.” (Miles 38, diagnosed in 1987 at age 17)

Both of these men describe their pre-HAART experiences as shared with a generation who were equally as dependent on ‘the system’ to provide them with treatment options. Nicholas’ story evokes an image of PLHIV as a new pharmaceutical market who were ultimately the victors in an activist war for better treatments. Miles describes a sense of the ‘inevitability’ of his own physical decline, shared with those men who were desperate for pharmaceutical intervention. This sense of both the vulnerability and activism of positive people in the early years were major drivers in the original gay and lesbian community response to HIV, leading to the formation of a range of voluntary home care and support services and the long term professionalisation of an HIV community sector.

Generational discourse was also common in the treatment stories of men diagnosed post-HAART:

[My] way of dealing with [HIV] at the beginning was: “Well, you know what? It’s just like any other disease. It’s manageable.” … That went all right to a point. Until [I started] getting a lot of pressure from my managing director to do stuff … And of course I watched my viral load start to climb very fast. And I got really scared … [In] the HIV support networks, you see guys that have been living long term with HIV. And what confuses me to this very day is how come some of these guys have never had any treatment and they’re fine? How in the hell do they do that? I couldn’t go any longer than three years before I had to have treatment … I’m really at a point right now where I would actually like to take twelve months away from work altogether, just so I could get well. I’ve never felt so unwell in my whole bloody life. (Brad 40, diagnosed in 2000 at age 32).

Brad’s expectations of good health in the post-HAART era are challenged by evidence of a wide variability of treatment experiences, indicating that a post-HAART generation is no longer bound together by a shared treatment trajectory. This may be an obvious outcome of the expansion of HIV medicine, however, Brad’s description of his own ‘differentness’ also tests broader ideas of generational solidarity amongst PLHIV. As someone with no personal experience of living with HIV
before HAART, Brad’s story typifies the individualisation of health and illness in an era of ‘effective’ pharmaceutical responses to HIV.

Stories describing the socioeconomic experiences of these men also commonly drew upon generational discourse:

I left work, and I went on sickness benefits for twelve months … [T]hen I got a payout with some money and stupidly, you know, instead of being sensible with the money, I just went and blew it on a sports car [because I] thought, “Well, there’s no purpose in saving.” And I stopped my superannuation because I thought, “Well, I’m going to die at some stage.” Because most of my friends around me who had become HIV had died or were becoming sick and dying. It was at that time where people were just dropping off like flies, you know? … And it’s really hard to understand that, “Why am I still here after twenty three years? And yet these people that were really healthy people, have been taken before me.” … And people often say to me, “You’re so lucky that you’re still here.” Whereas I don’t feel that I’m lucky … I feel like I’m a forty eight year old man that has an eighty year old body … I didn’t want my life to be like this, being on a pension and being stuck at home and not being able to do anything. (Nate 48, diagnosed in 1985 at age 25)

Nate’s extract contrasts his pre-HAART financial decisions with his post-HAART experiences of illness, disability, poverty, isolation and loneliness. He paints a picture of what successful HIV therapy has meant for him: a longer life, but one in which quality of life is not what he would have hoped for himself. For Nate, being part of a generation who survived against the odds is little to celebrate when understood in the context of the numbers (including friends and colleagues) who did not survive, and the difficult realities of his life today.

While neither year of diagnosis nor age was a consistent factor in the financial success or otherwise of the positive men who took part in this study, generational discourse did shape their accounts of post-HAART socioeconomic outcomes:
These are the fears that you have. The fears that you’re going to get sick. You’re not going to be able to work. No one’s going to be able to love you. You’re going to end up on welfare in one of those bloody horrible suicide tower arrangements … I would think, “Oh my God!” you know? “Is this my lot in life now?” … I can only imagine what it must be like for guys that are on welfare that have such a limited income … I mean, they get a hundred and fifty bucks a week. And a quarter of that goes to their, say their accommodation. And then they’ve got to pay their bills and their food. You know, and their medications. I don’t know how they do it … I was going to all those HIV support groups … To meet people and connect with other HIV positive people. And that was really good at the start. I don’t feel that I need that now …

[While] HIV [used to be] a death sentence, it’s no longer the case. And so there’s been a shift in thinking. And I’m one of these ones that’s saying, “Well, we’re not just living with HIV now, we’re living and working with HIV.” And … what I really need now is support in terms of how to work with HIV.  (Brad 40, diagnosed in 2000 at age 32).

Brad contrasts his own life experiences against those of a group of positive men who he perceives as trapped in a cycle of welfare dependence. While he doesn’t specifically identify those men as a pre-HAART generation, a ‘new’ generation of post-HAART positive men are being imagined here, typified by a ‘shift in thinking’ and the need to find new ways to balance competing work and health priorities.

Our interviews with positive gay men provided many examples of ‘modes of survivorship’, whether those men identified as long term survivors or were still coming to terms with a relatively recent HIV diagnosis. However, as in the GP interviews, we were specifically interested in the complex role of generational discourse in understanding survivorship:

[My partner] died in ‘85. And that’s when they diagnosed me … All the doctors were saying, “You’re going to die, you’re going to die.” And so you wait … [But then] you find, “Oh well, I’m not dying.” … [I]t’s made a world of difference to me to have people [in my life] who are positive … [If you] can find a bit of support and understanding, it counts … [G]ay men, certainly my generation, we’ve often been cut off from families. We’ve sought acceptance
from them and not necessarily gotten it … And what has always surprised me is how many gay men I’ve seen who are really highly accomplished… But they just feel like they’re nothing because they don’t have a six pack. You know, the abdominals and the pecs and the this and the that … And then throw HIV into this equation, where people still don’t deal well with it. Or people who’ve had it for a long time haven’t, you know, are still adjusting to what it means and all the noise around it. All the confusion and talk, and one person thinks this, one person doesn’t think this. One person wants you to fuck them dead without anything and the other person is freaking out because they think you have everything under the sun. And it’s like, “What, who do you listen to? And when do you, how do you find the stillness to just sit in your identity and move on from there?” It’s just, to me, a cocktail for craziness at the moment. (Lucian 44, diagnosed in 1985 at age 21)

The sense of surprise that Lucian describes as accompanying his own survival is poignant in light of the bleak prognoses typically experienced pre-HAART. Lucian identifies the support of other positive people as a central aspect of his capacity to cope with the ongoing challenges of HIV, particularly in the absence of family supports, which he sees as common for gay men of his generation. The body of the HIV positive gay man is located here at the centre of noisy and competing claims on desire, stigma and community, with the notion of generational difference providing yet another complication in the search for a stable identity.

Men diagnosed post-HAART describe similarly ‘noisy’ claims on positive survivorship, despite quite different experiences of diagnosis than the pre-HAART generation:

It’s been a real eye-opener since I’ve seroconverted because I was in one club for so many years, and now I’m in a totally different club … And it’s funny because I’ve experienced the whole gamut of this. I was out before AIDS was even around. In fact I remember coming back from San Francisco on my first trip with newspaper articles saying, “There’s something killing gay young men in the States.” … It was just horrendous. I mean not a week went by that there wasn’t someone I knew really well or just through the scene who was dying … [T]here were friends of mine that were really disappointed with me for seroconverting.
Instead of being supportive they were, “How stupid are you?” I mean I could blame myself for being stupid enough, but to have friends do that was, was tough … I feel a bit like the man who’s got a foot in both doors. You know? I don’t think, a lot of the gay guys that I’ve met who are positive, I’m appalled at their lack of social morality, just in terms of how they [avoid disclosing their HIV status to sexual partners]. So I don’t really identify with them to some extent. But I mean I can’t identify with the negative person really anymore, either, because [I] am positive … So I find myself like caught in-between. (Jean-Paul 49, diagnosed in 2003 at age 44)

Although not HIV positive in the pre-HAART era, Jean-Paul presents his credentials as both a witness to and participant in the scale of loss experienced by a generation of gay men. Emphasising the collective impact of that time serves to further dramatise the conflict he has experienced following his own more recent seroconversion. Not only does Jean-Paul represent that event as moving him from one ‘club’ to another, but he feels unfairly judged by his negative peers for acquiring HIV after so many years of successful prevention. His story suggests that for some gay men, seroconversion in the post-HAART era is accompanied by complex configurations of responsibility and blame. In this extract, the post-HAART seroconverter is located outside of any clear lines of generational connection: a ‘novice’ in a community of survivors, a ‘failure’ in a culture of prevention, a ‘critic’ in the ethical maze of positive sex.

Within the generational discourse identified in these ‘lay’ accounts, we have also observed the recurrence of two distinct yet interconnected narrative forms. Some extracts are dominated by a narrative of ‘a different time’ while others are more closely aligned to a narrative of ‘difference today’. For example, Nicholas’ memory of the ‘war’ of pharmaceutical activism creates an image of ‘a different time’, while Brad’s confusion about long term survivors who have avoided treatment focuses on ‘difference today’. Most of the accounts we examined are structured by a complex interweaving of both narrative forms. This is significant for understanding the operations of generational discourse in these accounts, as the two narratives focus on different aspects of HIV generations. The narrative of ‘a different time’ highlights features relating to time, while ‘difference
today’ highlights features relating to inequity. This suggests that while traditional concepts of
generation relating to age and time do play a role in these lay accounts, they are also more
encompassing of the role of non-traditional generational differences than the GP accounts.

Discussion

The generational discourse identified in these interviews contributes to a characterisation of pre- and
post-HAART generations of PLHIV. A pre-HAART generation is imagined as burdened by the
limited availability, effectiveness and side effects of early treatments. Their socioeconomic lives are
seen as shaped by an inability to sustain employment, leading to entrenched disadvantage. The
surprise renewal of a long term lifecourse means this pre-HAART generation is now represented as
dealing with ‘survivorship’ issues relating to body image, community and family support, and social
status. The post-HAART generation, on the other hand, is imagined with far less clarity (particularly
by the GPs), perhaps because there are such a diversity of issues that affect PLHIV now, whether they
were diagnosed pre- or post-HAART. However, in so much as a ‘picture’ of a post-HAART
generation is being painted here, it could be best characterised by an more individualised experience
of health and illness, a greater focus on the challenges of balancing work and health priorities, and
complex new social and survivorship issues relating to sexual ethics, community and responsibility.

Some interesting issues arise, however, when considering the question of why generational discourse
might be so apparent in these interview encounters. For example, we have shown that many of the
GPs drew upon a rich generational vocabulary in their accounts of providing care for PLHIV. Yet
only one of these GPs had entered this area of medicine ‘post-HAART’. Could it be that a
‘generation’ of GPs who have worked in HIV medicine since the early years have been, in a sense,
attuned to observing changes and patterns as generational? Did the personal burden of grief they
experienced pre-HAART inspire a greater sensitivity to the evidence of historical and sociocultural
change in their daily clinical practice? It is interesting to observe that the concerns of the pre-HAART
generation take precedence in the GP accounts examined here. This could be because pre-HAART
patients more often require complex treatment strategies (due to a longer history of side effects and
treatment resistance), have more ‘difficult to shift’ socioeconomic issues, and are finding it more challenging to develop new ways to live with HIV long term. But it could also be related to the fact that many of these GPs have long and complex histories of identification with the pre-HAART generation. Or perhaps – if you accept the thesis that medical culture often uncritically reproduces a linear logic of scientific progress – it is simply that the pre-HAART generation offers the most dramatic medical success story to form the backdrop of these GPs reflections.

The question of why generational discourse was produced at all in the interviews with positive gay men must be approached differently: it was certainly not as dominant in these ‘lay’ accounts compared with the GP accounts. Drawing insight from a quite different setting, Janine Pierret (2001) has identified four ways that long-term HIV non-progressors in France reconstructed their past in research interviews around the time of the introduction of HAART. She suggests that because these men did not have a collectivist frame (using our terminology) available to explain their exceptional capacity for survival, they ‘had to fall back on … deeply individual and individualistic life-stories’ (2001: 177). Although the men we interviewed for our study were not approached as medically ‘exceptional’, many also did not speak of themselves as part of wider HIV positive ‘collective’ or generation. This seems to support the hypothesis (as summarised in the Background) of Rawstorne et al that: ‘Improvements in health may mean there are now less compelling reasons to commune on the basis of one’s HIV status’ (2005: 598). In any case, where generational discourse was evident in these interviews, it can be seen to accommodate lines of difference that are ‘traditional’ in the sense of being marked by time, but also ‘non-traditional’ in the sense of being more concerned with how inequity is shaping generations of PLHIV in Australia.

There are several limitations of our analysis which are important to acknowledge here. The first is that our analysis depends on an entirely clinical sample as both the GPs and positive gay men were recruited through general practice clinics. Second, the primary focus of both sets of interviews was depression, which may have influenced the stories shared in this context and perhaps the manner in which they were expressed. While this is not a problem per se, it is possible that generational
discourse may have had quite different modes of expression in a different context. Third, this sample was small, Australian and urban (except for the two regionally-located GPs) and so cannot in any way be claimed as representative of either the broader populations of GPs or of HIV positive gay men in Australia or elsewhere.

**Conclusion**

Rather than limit our analysis to a single definition of pre- and post-HAART ‘HIV generations’, we have tried to remain open to the many and complex ways in which generational discourse was produced in interviews with Australian GPs and their HIV positive gay male patients. The three features of generational discourse that we initially identified in the interviews with GPs had a great deal of resonance with the interviews with positive gay men, even if the generational discourse was less common in these men’s accounts of their own treatment histories, socioeconomic status, and modes of survivorship. We found that many of the examples of generational discourse in the positive gay men’s accounts wove together two narrative forms that we have described as ‘a different time’ and ‘difference today’, suggesting that concepts of time and inequity – both traditional and non-traditional aspects of generational discourse – are deeply embedded in these men’s understandings of the HIV experience. By exploring these discursive impressions of pre- and post-HAART generations we have highlighted that generational concepts play a significant role in shaping both professional and ‘lay’ understandings of changes and patterns in the Australian HIV epidemic, while also affirming the significance of temporality in representations of health and illness more broadly.
References


