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‘We just don’t know’: Ambivalence about treatment strategies in the Australian community-based HIV media

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Abstract

The community-based HIV media in Australia provides a unique arena for the negotiation of competing models of medicine between activists, clinicians, government and people living with HIV/AIDS. This paper examines how this media has interpreted developments in HIV treatment strategies since the introduction of new treatments in 1996, and identifies the discursive elements employed in journalistic constructions of the temporality and character of HIV medicine. A discourse of ambivalence recurs throughout this journalism, framing the negotiated shifts in treatment strategies as evidence of the uncertainty and unpredictability of HIV medicine. Associated with this discourse are metaphors of medical ambivalence that employ provocative imagery such as fashion, rollercoaster, obstacle course and guessing game to shore up a notion of the volatility of HIV medicine. This paper participates in ongoing engagements between the communities and clinicians affected by HIV/AIDS and, more broadly, in the production of knowledge around medicine and the media.

Keywords

HIV/AIDS; Medical treatments; Community media; Ambivalence; Metaphor
Introduction

The field of HIV medicine has become increasingly complex since highly active antiretroviral therapy (HAART) was first made available in Australia in 1996, with many different treatment strategies advocated and contested since that time. These developments were closely observed by the community-based media that are produced within the HIV sector in Australia. As a specialised and non-profit media industry, the Australian community-based HIV media — also described by Rosengarten as the ‘HIV consumer-led treatment information media’ (2004: 97) — provides a unique discursive arena for the negotiation of competing models of HIV medicine by a diversity of voices, including activists, educators, clinicians, government representatives and people living with HIV/AIDS (PLWHA). Published by non-government organisations that represent the interests of PLWHA, there is no equivalent mainstream arena for debating new developments in HIV medicine. This paper focuses on how HIV medicine is constructed as a field of change and uncertainty within this dynamic media arena. By tracking these processes, this analysis provides a novel insight into how the discourses of medicine, education, public health and community activism have intersected and changed over time, contributing to the social construction of the contemporary field of HIV medicine.

Methods and media context

In the past decade, the Australian community-based HIV media has been made up of five publications, each produced by a non-profit ‘community’ organisation aiming to provide information and support to PLWHA and those with a personal or professional interest in HIV/AIDS: Talkabout¹, Positive Living², HIV Australia, the HIV Herald and the National AIDS Bulletin³. Production funding is drawn from the resources
already available to these organisations through government grants, community partnerships, membership support and a small amount of community advertising. Therefore, this media industry cannot be captured by traditional models of media production and journalistic independence. For example, it is quite normal for content to be authored by non-‘professional’ writers, particularly PLWHA and community advocates. It is also the norm for editors and journalists to play a significant role in the development of policy and advocacy strategies within these organisations. In other words, the Australian community-based HIV media is an industry engaged in a politics of community activism, and a profession committed to a multi-sectoral and collaborative response to the HIV epidemic.

To examine how this media tracked developments in HIV medicine over time, an archive of treatments journalism was compiled, drawing upon resources available in the National Centre in HIV Social Research library collection. Each available issue published between 1996 and 2003 was searched for any item that addressed HIV treatments. These items were sometimes focused on a specific treatment (e.g., Ritonavir) or class of treatments (e.g., protease inhibitors). But in most cases, content was organised around a discussion of the many associated issues, such as clinical treatment strategies, dosing schedules, adherence, side-effects, finding the right doctor, complementary therapies, monitoring technologies, pregnancy, toxicities, treatment failure, the global development and distribution of new treatments, and so on. A total of 258 such items were identified, collated and electronically annotated with bibliographic information, keywords, and quotes. Although this archive is not intended to be exhaustive, it nonetheless provides a useful indication of the scope of the Australian community-based HIV media over this time of significant change.
Table 1: Publications included in the Treatment Histories Project media archive

<table>
<thead>
<tr>
<th>Publication</th>
<th>Publisher</th>
<th>Years of publication</th>
<th>No. of articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talkabout</td>
<td>PLWHA NSW</td>
<td>1988 – ongoing</td>
<td>99</td>
</tr>
<tr>
<td>Positive Living</td>
<td>NAPWA</td>
<td>1989 – ongoing</td>
<td>70</td>
</tr>
<tr>
<td>HIV Australia</td>
<td>AFAO</td>
<td>2002 – ongoing</td>
<td>24</td>
</tr>
</tbody>
</table>

Total number of items from 1996-2003 included in this analysis 258

During the collation of this archive, it became apparent that, in the words of Coupland and Williams, ‘certain discursive elements play and replay themselves’ (2002: 421), with particular evidence of the replaying of a discourse of ambivalence. Therefore, a more focused analysis was conducted to identify how ambivalence has been deployed as a journalistic technique in the Australian community-based HIV media. This approach is differentiated from quantitative public health methodologies which tend to be limited to measurements of the presence or absence of health information in the media (e.g., Moyer, Vishnum and Sonnad, 2001). It is also distinct from health communications methodologies which tend to examine how media bias distorts the accurate or effective communication of health issues (e.g, Andsager and Powers, 2001). This paper is concerned with how media texts operate in a complex discursive environment which is cooperatively constituted by authors, audiences, structural conditions and cultural context. Following Fairclough, this approach ensures that the ‘analysis of texts [is not] artificially isolated from analysis of institutional and discoursal practices within which texts are embedded’ (1995: 9). Therefore, this paper is aligned with a relatively new tradition of critical studies of health and the media in
which the discursive construction of media texts is seen to be both indicative of and implicated in cultural understandings of health and medicine (e.g., Bonner and McKay, 2000; Kitzinger, 1999; Lupton, 1992, 1999b; Petersen, 2001; Seale, 2001).

There is a growing body of research in which such critical methodologies have been applied to the question of how HIV is rendered within media environments, whether in relation to HIV prevention campaigns (Dodds, 2002; Tulloch and Lupton, 1997), the media representation of HIV-positive bodies (Dworkin and Wachs, 1998; Lupton, 1999a) or audience negotiation of safe sex messages (Gavin, 2001; Tulloch, 1992). A similarly critical lens has been applied to HIV treatments in recent years (e.g., Persson, Race and Wakeford, 2003; Rosengarten, Imrie, Flowers, Davis and Hart, 2004). Although each of these approaches has been important to the development of the current analysis, there has been very little published on non-profit, community-produced media, particularly in relation to health and medicine (see, for example: Newman, 2005). James Gillett is one of the few authors to write about community media in the HIV sector, arguing that the development of ‘community-based’ treatments media ‘was an attempt to remain accountable to the needs and concerns of those HIV-infected and affected… [and] an effort to privilege and foster the opinions, views, and expertise of those living with HIV/AIDS’ (2000: Bit 1). Most international studies of HIV and the media are focused on how the global media impacts the public and government response to HIV/AIDS (Bardham, 2001; Brodie, Hamel, Brady, Kates and Altman, 2003). And yet, in an Australian context, there is very little evidence that the mainstream media plays more than a framing role in the public representation of HIV treatments. This suggests that the Australian community-based HIV media provides a unique environment for the collaborative constitution of
community knowledge around new treatments, which lends weight to the significance of the current paper. For the remainder of this paper, each of the authors to which the media extracts are attributed should be assumed to be a treatments journalist, unless they have been otherwise described as a clinician, government spokesperson, academic researcher or otherwise.

**Temporality and uncertainty: A media chronology of new treatment strategies**

Accompanying developments in HIV medicine are debates around the best ways to use the available range of treatments. The continuous improvement of treatment strategies is intended to maximise positive clinical results (reductions in viral load and increases in CD4 counts) and minimise negative impacts (side-effects, toxicities, demanding regimens, and so on). A multitude of individual treatment strategies were identified in this media material, including non-pharmaceutical therapeutic alternatives. However, for the purpose of this analysis, the most dominant and recurring strategies were organised into a temporal model of three negotiated shifts in HIV medicine. Each of these shifts represents a distinct meta-strategy, which we have described as *early intervention*, *individualised intervention* and *episodic interventions*. The community-based HIV media has tracked these developments over time, locating each shift in an approximate chronological succession in the recent history of HAART. And yet this succession is not represented as a necessarily linear evolution in medicine. Rather, each new mode of delivering HAART is seen to move in and out of popularity at different times and in different contexts. Thus, the journalism of this period frames debates about treatment strategies in terms of a problem of choice. Rather than actively promoting any new developments, they are committed to
sustaining a position of ambivalence in the sense of remaining doubtful and concerned about the ongoing uncertainties inherent to this field of medicine.

**Early intervention**

When a greater range of treatments were first made available in 1996, and they were found to be more tolerable than the much maligned AZT, clinicians and journalists began to communicate a tentative optimism to those communities still reeling from the devastating number of AIDS deaths that had occurred over the previous decade (e.g., Rofes, 1998). Because the new treatments were so desperately needed, activist groups lobbied governments to speed up the processes of drug approval and access (Delaney, 2002; Machon, 1999a). As HAART began to be made more widely available in Australia, the local HIV media focused on the therapeutic potential of combination therapy, that is, the prescription of a combination of different classes of treatments, including the new class of protease inhibitors, simultaneously targeting different phases of HIV replication. In the *National AIDS Bulletin*, Paul Kinder reported that ‘There is increasing evidence that two or more drugs may be the most effective use of available treatments. The virus finds it more difficult to get around two drugs than one, effectively slowing its progress for longer periods’ (1996: 50). The response to this new scientific claim was also tentatively optimistic, as can be seen in Derek Hand’s article in that publication in the same year: ‘There is a growing belief that the use of several drugs in combination will eventually achieve long-term suppression of the virus’ (1996: 53). The attempt to achieve viral suppression was the motivation behind the dominant treatment strategy of that period: early intervention. This new strategy of ‘hit hard, hit early’—attributed to renowned HIV clinical researcher Professor David Ho (1995)—involved an intensive program of treatments
early in the progression of infection, in the belief that complete viral suppression would preclude further progression of HIV disease and immune system damage.

Early intervention was the main theme of the XI International Conference on AIDS held in 1996 in Vancouver, a conference sometimes described as the ‘protease moment’ (Rofes, 1998: 29) because of its focus on the therapeutic success of new treatment combinations that included protease inhibitors. After this conference, early intervention was adopted as the dominant model of HIV care in Australia, representing a turn away from the previous standard of delaying treatment for as long as possible and then prescribing only one therapy at a time. Announcing this shift in the *HIV Herald*, Martyn Goddard declared: ‘Single-drug monotherapy, and the practice of delaying the onset of treatment until a patient is on the threshold of AIDS, have been comprehensively discredited and must be abandoned’ (1996: 6). In the following extract, also from the *HIV Herald*, Colin Batrouney quoted the Australian clinician Jonathan Anderson:

‘I suppose I was convinced a long time ago that “hit hard, hit early” was the best strategy. In the past, we only had one drug (AZT) and I don’t think we could hit the virus hard enough to make it worthwhile … Now, we have a number of drugs we can use in combination that can work quite well in reducing the virus to very low levels … In approaching therapy for something like HIV I think it’s better if you’re not bound by a “party line” or slogan like “hit hard, hit early”, rather your decisions need to be guided by the evidence that combination therapy is worthwhile, then in consultation with the patient, by outlining the evidence, the patient can make an informed decision about whether to proceed with therapy or not’ (Batrouney, 1997b: 6-7).
In this quote, Dr Anderson describes early intervention as a significant development in the history of HIV medicine, in that combination therapies now made it possible to achieve positive clinical results in the early stages of infection. The introduction around this time of new technologies for testing viral load (the levels of virus detectable in the bloodstream) also made it possible for clinicians to begin to make such statements about treatment effectiveness (Batrouney, 1996a: 28). However, Dr Anderson remains wary in this extract, concluding that although the fashion of early intervention had its attractions, treatment strategies must continue to be based upon both medical evidence and patient preference. This indicates a synergy in the shared ambivalence of HIV clinicians and HIV journalists, with the media drawing on the words of a medical professional to shore up the evidence for circumspection.

The temporality of medicine was an explicit theme of the journalism from this period. In the *HIV Herald*, Jenny Hoy hypothesised that ‘HIV treatment strategies are tailored to the times we live in, and over the past six years, times have indeed changed’. In *Positive Living*, Bridget Haire maintained that ‘Today’s dogma is tomorrow’s heresy. I think you have to keep an historical perspective from our own personal histories of dealing with HIV, and from a medical perspective, work with what is attainable’ (1997b: 5). These quotes are exemplary of the discourse of ambivalence, and are perhaps related to what Rosengarten has termed the ‘cynical register’ (2004: 98) of treatments media. The use of this discourse reads as a journalistic strategy intended to locate early intervention in historical proximity to alternative paradigms. In the *HIV Herald*, Batrouney observed, ‘While it’s difficult not to get carried away by the tide of optimism generated by the Vancouver Conference, history has a sobering way of bringing one back down to earth’ (1996b: 14). One of the issues Batrouney identified
in 1996 as demonstrating the need for ambivalence was the Australian system of regulating access to new treatments. In his words: ‘This year we are looking at three protease inhibitors, two nucleoside analogues, and three new drugs for opportunistic infections, all negotiating a system which is ill-equipped to supply them in a timely manner to people who need them’ (1996: 39). Another issue identified by Batrouney, in the following year, was the problem of treatment compliance, that is, the difficulty of taking the number of pills in the specific ways required by the prescribing regimen (1997a: 8). These issues contributed at least part of the impetus for a negotiated shift in HIV medicine away from early intervention in the last few years of the twentieth century.

**Individualised intervention**

Although combination therapy continued to produce effective clinical results, there were many unfortunate consequences of the intensive prescribing regimens of early intervention. A subsequent shift in HIV treatment strategies then seemed to justify the ambivalence expressed by HIV treatments journalists in the early years of HAART. As Kirsty Machon wrote in the *HIV Herald*:

> Most clinicians and treatments activists have now distanced themselves somewhat from the unguarded enthusiasm which greeted the arrival of combination antiviral therapy based on protease inhibitors. Recently, the pitfalls and side effects, including the spectres of drug resistance or abnormal changes to body fat, have received a lot of attention, and many doctors have been working individually with patients to find the most effective and tolerable combinations (1999b: 3).
This extract details some of the adverse outcomes of early intervention, particularly the potential for becoming resistant to treatments and the unexpected side-effects of lipoatrophy and lipodystrophy, a condition whereby—for some people—treatments began to cause a redistribution of body fat resulting in significant body shape changes (Carr, 2003; Persson, 2004). What is most evident here, however, is a strong investment in *individualising* treatment strategies. This shift is entirely incompatible with early intervention, in that it advocates waiting until the right treatment comes along, or until the patient feels ready to begin therapy. Machon argued in another article that same year that ‘there are logical, even compelling, arguments for combination antiviral therapy. But the decision to treat or not is ultimately extremely personal, and needs to be precisely that—a decision made equipped with all the facts’ (1998a: 18). Thus, this second era can be typified by a call for PLWHA to become skilled in patient- and consumer-rights, to ensure that the negative consequences of placing ‘naïve’ faith in medical expertise would not be repeated. While this discourse of patient empowerment is not unique to the HIV sector, it has a particular resonance in the context of what Crossley has described as ‘the ambiguities of life with an HIV positive diagnosis’ (1998).

While the individualising of HIV therapy is represented in this media as good for patients, it is also represented as *good science*. According to Machon:

> The latest science implies, in any case, that anti-HIV treatment must be seen increasingly as individualised. Treatments used may need to vary widely between patients to take into account factors such as lifestyle, susceptibility to (and severity of) side effects, resistance, viral load and CD4 counts. [This stresses] the importance of doctors spending time with their patients getting...
down to the nitty gritty, in order to establish the best possible treatment regimens from within this promising but still-limited crop (1998b: 38). As indicated, the two major problems driving this scientific turn to the individual were viral resistance and side-effects, both of which were attributed to the long-term use of highly active therapies. Thus, this period also witnessed the introduction of a range of new treatment strategies designed to avoid developing resistance to certain classes of drugs, and to minimise side-effects. One of these strategies was the use of protease-sparing combinations, which entail the use ‘nucleoside analogues in combination with drugs from another class … sparing these powerful drugs for possible use later in the course of HIV infection’ (Batrouney, 1998: 1). Another such strategy was switching combinations in order to avoid those classes of drugs suspected of causing side-effects such as lipodystrophy (Nicholson, 1999: 24).

The late 1990s were also typified by a great deal of journalistic reflection on the temporality of HIV medicine. In an article in Positive Living entitled ‘It’s 1999, so what next? Treatments workers gaze into the future’, Batrouney reasoned that the end of the twentieth century provided an opportunity ‘to remind ourselves where we have come in relation to treatments for HIV/AIDS, and how far we have yet to go’ (1999: 1). This and other extracts from this period argue that the promotion of individualised intervention is not only good science, but also good journalism, since HIV medicine had proven to have problematic consequences for many PLWHA. The implications of having occupied a position of sustained ambivalence since the introduction of HAART were discussed in an article by Batrouney and Haire in Positive Living, a publication dedicated to revealing the personal impact of HIV medicine:
There was significant criticism of *Positive Living* for publishing critical treatments stories after the dawning of the ‘protease era’—some community advocates argued it was the role of treatments publications to encourage treatment uptake. It was argued that treatments publications should not publish stories which might affect community confidence in treatment. But such pressures can seriously undermine the role of the press in providing important, objective information which can help people make their own treatment decisions (1998: 23).

This extract describes a debate within the HIV sector between community educators committed to engaging PLWHA with treatment options and media activists committed to exposing their possible complications. These tensions are here resolved with reference to the need to individualise treatment interventions, implying that PLWHA must be given the right to make their own decisions about HIV treatments, rather than remaining at the whim of uncertain developments in medical knowledge. Columnist and media scholar Ann Karpf has argued that medical journalists tend to ‘see themselves as mediators between the lay public and the increasingly specialised world of science, bridging two cultures’ (1988: 6). The community-based HIV media do indeed play an important role as cultural intermediaries, ‘arbitrating between the competing claims of social and scientific rationality’ (Williams and Calnan, 1996: 1618). However, this model of mediation or arbitration relies upon the principle of objective journalism, which has been much critiqued for its investment in the idea that it is possible to be completely impartial (Schudson, 2001).
Episodic interventions

In the first few years of the twenty-first century, the HIV media continued to examine a wide range of treatment strategies. However, the most contested of these can be described as episodic interventions, which represents the third negotiated shift in HIV medicine. Episodic interventions incorporates the strategy of structured treatment interruptions, which involves monitored cycles of treatment with interruptions held at pre-planned intervals or in response to worrying changes in clinical markers. It also incorporates pulsing, which is a series of short periods of episodic treatment to encourage auto-immunisation against HIV. Episodic interventions were framed in the HIV media as a potentially revolutionary development in HIV medicine. As Dean Murphy observed in the *HIV Herald*:

> Apart from providing some welcome relief to people on treatments as well as possibly preventing side effects and toxicity, it now seems possible that strategically interrupting treatment may be one way forward for longer term control of HIV, while reducing the overall pill burden in people’s lives (2000: 14).

Importantly, the treatments journalism on episodic interventions distinguished medically supervised treatment breaks (e.g., Maynard, 2000) from the *personal* decision to stop treatments, usually described as a drug holiday (Editorial, 2002a). For example, in *Talkabout*, Barrie Harrison asserted that ‘it is very important to point out that treatment interruptions are highly experimental and should only be considered under trial conditions or under close medical supervision’ (2000: 25). This article frames treatment interruptions as a risky choice to be made only in consultation with medical experts, rather than to reduce physical discomfort or facilitate social ambitions such as travelling overseas (Cumming and Norton, 2000). Thus, while
individualised intervention was concerned with the right of individuals to determine the treatment strategy most suited to their lives, episodic interventions represents a return to the medicalisation of treatment decisions.

Nonetheless, the community-based HIV media continued to represent episodic interventions as a potentially encouraging development for their readers: ‘It is about living with HIV, and not being defined by it. Breaks give PLWHAs a choice and control over their health and lives’ (Editorial, 2002b: 1). Episodic interventions were also investigated in several high-profile clinical research trials (Drummond, 2002; Machon, 2004), and so for the first time, a scientific explanation was proffered for the potential benefits of not treating HIV or, at least, of not insisting upon the kind of long-term, continuous treatment that causes serious toxicities, side-effects, viral resistance and, increasingly, ‘treatments fatigue’ (Machon, 2004: 7). Yet the discourse of ambivalence persisted in that every optimistic claim was tempered with a caveat regarding the ongoing uncertainty of HIV medicine. As Murphy argued:

These so-called interruptions may help control HIV without antiviral therapy, at least for periods of time. However, it’s important to note this is a big may, and concerns a very particular group of people: people who already have exceptionally well-suppressed virus from treatments (2000: 15).

This quote employs derisive language to represent the arena of science, constructing a critical distance between the imagined realms of HIV medicine and the HIV positive community. This distancing function is particularly apparent in an article about the role of episodic interventions in the history of HAART treatment strategies. Published in *Positive Living*, Megan Nicholson frames episodic interventions as a medical fashion to be approached with caution:
For some time now, the HIV treatment strategy du jour has been structured treatment interruption (STI). The popularity and appeal of this approach is obvious in an age of suppressed virus, boosted immune systems and nasty side effects. Effectively, STI has provided a respectable, scientific framework for what used to be called a ‘drug holiday’. However, fashion trends in HIV treatment are indeed fickle. Today’s treatment salvation is tomorrow’s failed drug or treatment strategy (Remember ‘hit hard, hit early’?) and now STI itself is on the verge of becoming HIV treatment’s latest failed endeavour … Many people clearly do not benefit from STIs. Consequently, researchers are now turning to immune-based therapies, such as interleukin-2 and therapeutic vaccines, rather than STI, to boost the immune response to HIV (2001: 4, 8).

While this quote commences with a claim to temporal significance—‘for some time now’—the overarching objective is to problematise the validity of episodic interventions. The author points to a potentially new shift in HIV medicine towards immune-based therapies. And yet the rhetorical validity of this imminent new approach is established through a parodying of the transience of outmoded treatment strategies: ‘remember hit hard hit early?’ The audience is invited to remain ambivalent so as to not get caught up in the fickle moves of scientific change. This extract also draws upon a metaphor of ‘fashion’ to convey changes in medical opinion which, as the following section indicates, is a common strategy in the community-based HIV media’s representation of medical ambivalence.

**Metaphor and ambivalence: The discursive construction of HIV medicine**

As demonstrated in this media chronology, the ‘hit early, hit hard’ approach that defined HIV medicine in the latter part of the 1990s has given way to a much more
complex and diverse field of treatment messages and strategies at both clinical and
community levels. These conventional therapeutic approaches have also been
significantly challenged by the rise of the alternative health movements (Ernst, 2000;
Race, Cristaudo, Wilkins and Prestage, 1997). Some of these changes can be
attributed to scientific progress, but the role of consumer and activist outrage over
treatment toxicity and side effects such as lipodystrophy cannot be underestimated. As
Kenneth Jones has explained of the history of medicine: ‘various forms of heterodoxy
constantly arise to challenge the course of medical orthodoxy, these being either
accommodated or opposed’ (2004: 704). The many and continuous challenges to HIV
medicine have also contributed to its representation as a science of uncertainty and,
similarly, of HIV clinicians as purveyors of professional doubt. This is particularly
evident in the use of evocative metaphors to represent ambivalence and uncertainty.
Four metaphors are identified here as exemplary of the discursive construction of
medical ambivalence.

**HIV medicine as fashion**
The first metaphor represents HIV medicine as a cyclic phenomenon at the whim of
trends, evolutions and hype. For example, an editorial in the HIV Herald claimed that
‘wisdoms and practices come and go like seasonal runway fashions’ (2001: 10). Most
of the articles that employed this metaphor were published in the last few years,
implying that it is a particularly useful metaphor in constructing retrospective
accounts of treatment histories. As Chris Puplick, a recent Chair of the Australian
National Council on AIDS, Hepatitis C and Related Diseases (ANCHARD), reflected:
‘Year after year, change after change, breakthrough after breakthrough, failure after
failure, hope after hope, new advice after new advice’ (2002: 11). Similarly, Machon
remarked that ‘Since the arrival of combination antiviral treatments in the mid-1990s, there has been no shortage of edicts, theories, and fashions when it comes to the question of how best to use them to fight HIV’ (2004: 7). Some journalists have identified a particular fashion in HIV medicine such as ‘the vogue for early treatment’ (Maclean and Alcorn, 1998: 15). Others interpret each new medical development as one more event in a long history of hype. As a editorial in Positive Living claimed: ‘It seems like whenever you look up these days, there’s another HIV treatments conference going on somewhere, “showcasing” the latest in therapies, new directions, and clinical research’ (1999: 6).

The fashion metaphor is also used to critique an approach to HIV medicine that is judged as impulsive, reactive and experimental. For example, the prominent Australian HIV clinician Professor David Cooper employed this metaphor in an article in Positive Living to discredit this approach:

‘As usual in HIV medicine, people come up with anecdotes that substitute for evidence-based medicine and take on a pious aura that becomes fashion for two weeks in Sydney (slightly longer in other cities), until the anecdotalists are tired of the lack of results and come up with the next fashionable hype to try on desperate patients,’ he said. ‘Depressingly they never recant their errors’ (Haire, 1998b: 21).

Others suggest that it is only possible to launch a retrospective critique of ‘fashions’ in HIV medicine, since new treatment strategies always involve a degree of risk. For example, Puplick argued that to have held back from prescribing new treatments in the early years of HAART and ‘waiting until all the evidence had accumulated before taking action would have been a deadly luxury’ (2002: 11). In the HIV Herald, Dr
David Bradford of Cairns Base Hospital is quoted as saying: ‘Doctors or patients shouldn’t feel guilty about decisions made in the past that were based on the best available evidence’ (Hoy, 1997: 4). The overarching implication of these reflections is that HIV clinicians do not always know all the answers. Indeed, Haire quotes the 1998 Chair of the US AIDS Advisory Council as admitting that ‘We are the last group of people I’d trust. Our recommended first line therapy tends to change every six months’ (1998a: 22). These extracts provide evidence of the symbiotic relationship between medicine, government and the community-based HIV media, particularly in times of significant medical urgency, and the important role of those medical and government representatives who are willing to make public claims about the uncertainties inherent to HIV medicine.

**HIV medicine as rollercoaster**

The second metaphor draws on the idea that HIV medicine is like a rollercoaster, in which the momentum of science is relentlessly propelled forward by forces outside of individual control. A lucid example is drawn from an article in the *HIV Herald* that constructs a retrospective account of HIV treatments, but which was actually published at the very beginning of the sample period:

> Over the past couple of years, at least since 1991 to the present, the community has been on a bit of a roller coaster ride in terms of treatments. For just one example all we have to do is look at AZT. Initially optimism surrounded this drug and it became the first licensed antiviral to fight HIV and AIDS, then stories began to emerge about the horrendous toxicities with its use in high doses … Then about 18 months ago, due to it being combined with
other drugs … AZT has re-emerged as one of the cornerstones of HIV
treatment (Batrouney, 1996c: 14).

This extract reenacts the experiences of PLWHA ‘riding’ through the highs (early
optimism) and lows (drug toxicities) and further highs (resurrected therapeutic value)
in the ‘lifecycle’ of a medication (Cohen, McCubbin, Collin and Perodeau, 2001). While this narrative traces the unpredictability of how HIV treatments move in and
out of favour, there is clearly a subtextual ambivalence about taking part in such a
rollercoaster ride in the first place. As Machon cautioned in the *HIV Herald*, ‘even
when big news does break, history teaches us to treat this with reserve and a healthy
dose of caution, rather than haring off in radical new directions, eyes closed to the
dangers that might lie ahead’ (2000: 7).

While there is little doubt that, as Puplick observed in *HIV Australia*, ‘no area of HIV
public policy has seen so many radical shifts and swings as the issue of treatment’
(2002: 11), the metaphor of rollercoaster propagates a general distrust in HIV
medicine. The following extract illustrates this by employing the rollercoaster
metaphor in a snapshot depiction of the extreme opposites experienced during the
recent history of HIV medicine:

At some stage we’ve had just about everything: Hit it hard with everything
you’ve got—wait until it’s absolutely necessary; Never miss a single dose—
contemplate drug holidays/interruptions; Promote compliance—compliance is
a negative, coercive word; Promote concordance—concordance is too much of
a fancy word; Promote adherence—can’t we think of a better word; At last we
can be optimistic—AIDS optimism is increasingly dangerous; More people
are on treatment—treatment failure is increasing (Puplick, 2002: 11).
Other images associated with this metaphor evoke the momentum associated with uncontrollable forces of change. One example is the use of a cowboy metaphor from the *HIV Herald*: ‘It seems the hot-headed days of plunging in on the backs of gung-ho cowboys of science are over’ (Editorial, 2001: 11). This image is organised around an implied distrust of reckless science. As sociologists Joffe and Weitz have written: ‘In all areas of medicine, practitioners have some trepidation of the “cowboys” among them … those who are oriented toward practicing medicine “recklessly”, or who at least depart in significant ways from the protocols of most of their peers’ (2003: 2360). However, this metaphor also taps into the wider sense of urgency around HIV that was mobilised by community activism and consumer demand in the early years of the HIV epidemic (Delaney, 2002; Machon, 1999a).

**HIV medicine as obstacle course**

The third metaphor represents HIV medicine as a complicated obstacle course involving challenges and barriers to medical progress interspersed with occasional moments of great achievement. The metaphor of the obstacle course was most common in early HIV treatments journalism, representing the many medical challenges faced at that time. Examples of this from the *National AIDS Bulletin* include (emphases added): ‘1996 will be seen as a benchmark year after a long period of clinical uncertainty around issues of HIV medicine’ (Batrouney, 1996a: 28); and ‘one of the biggest stumbling blocks to the success of drug therapy is compliance’ (Batrouney, 1997a: 8). This metaphor envisions HIV medicine as a complex landscape requiring strategic orientation and long-term planning to navigate through the many impediments to best practice medicine. However it is also common in debates about whether the assumed goals of HIV medicine were actually achievable.
As Peter Canavan suggested in the *National AIDS Bulletin*, ‘it remains unclear whether the “golden chalice” of viral eradication is within reach’ (1998: 24). In another article from the same publication, Tony Keenan mused, ‘the changes do not signal a euphoric end to the epidemic, but rather a time to rethink, regroup and answer some basic questions - where to from here?’ (1997: 20).

The metaphor of obstacle course is embedded in a wider narrative of medical progress. HIV clinicians are constructed as strategic, tenacious and enterprising professionals who, in the words of Batrouney from *Positive Living*, have ‘throughout the course of the last ten years’ been ‘constantly faced with situations that are not covered by the guidelines’ (2001: 5). Batrouney implies that since the historical development of the HIV epidemic was slow and steady, so must the response be embodied in controlled, incremental advances, progressing slowly but surely towards the end-goal of successful treatment, and perhaps even cure. This is a positive representation that acknowledges the many difficulties that have faced HIV clinicians since the introduction of HAART. It indicates the sense of mutual challenge that is built into much of the community-based HIV media, which concedes that, as Race has argued, ‘the researchers, prescribers, manufacturers and consumers of the new drugs [have been] on a steep learning curve together, not separately’ (1997: 25).

**HIV medicine as guessing game**

The final metaphor evident in this media material is that of guessing game. This is by far the most common of these four metaphors and it could even be claimed to have become a defining characteristic of HIV medicine, perhaps in distinction from some other fields of medicine in which it may be less acceptable to acknowledge
uncertainty. This metaphor focuses on the strategic guesswork involved in making clinical decisions. As an editorial in the *HIV Herald* divulged, ‘there can be no textbook answer to any of this. This is a game of second-guessing and logic’ (2001: 10).

In the *National AIDS Bulletin*, Batrouney observed that ‘The advances in HIV medicine in 1996 saw some conclusions being drawn—tentatively—for some of these questions, both from clinical research and from educated guesswork’ (1996a: 28). The metaphor of guessing game is also used to describe the uncertainties around HIV:

> There are no absolutes in HIV medicine. A small minority of individuals can live with the virus for over ten years and show no signs of immune dysfunction, others need antiretroviral intervention early in the course of their infection … And of course the debates around when to treat, what to treat with and what to do in the face of therapeutic failure rage on, with clinical research holding the key to answering these many questions, but the answers to those questions being still some time off - if there ever can be ‘an answer’ at all…

(Batrouney, 2000: 4)

In the same article in *Positive Living*, Batrouney quotes an HIV clinician as saying, ‘You can’t normalise the immune response in chronic infection. Does this matter? Well, we just don’t know’ (2000: 12). The sheer perseverance of this metaphor suggests that uncertainty has become a typical feature of HIV medicine. In the *HIV Herald*, Batrouney made use of this image of the professionally doubting doctor:

> Using viral load as the measure of therapeutic efficacy, clinicians are often forced to use educated guesswork in their choice and sequencing of combination therapy. In many respects, viral load has been the catalyst for a number of questions which are yet to be answered. Questions like when to
commence therapy, what to start with, what to swap to and what to do about the problem of resistance (1997b: 6).

Similarly, in *Positive Living*, Haire acknowledged that ‘deciding whether to treat [HIV infection] is a judgement call’ (1997a: 5), reinforcing the idea that medicine involves as much instinct as expertise. Dr Jonathan Anderson is quoted by Batrouney in the *HIV Herald* as claiming that ‘Clinicians work at the coalface, and on a day-to-day basis, we’re faced with people sitting opposite us saying, “what should I do?” … often in the clinic you have to rely on your instincts’ (1997b: 7). This model of the uncertain clinician may be neither new nor unique to HIV medicine, however the mere existence of these media publications suggests that the Australian community response to HIV has played a particularly important role in dismantling the ““top-down” model of treatment initiation and practice’ (Race, 1997: 25), and in creating the necessary conditions for an ongoing consumer challenge to the fiction of medical certainty.

**Conclusions**

The Australian community-based HIV media operates as a discursive arena for the negotiation of productive tensions between PLWHA, clinicians, community and government. This is a unique environment in that it has been formed by a politics of activism and produced by journalists who participate in the mobilisation of that activism. This paper has focused on the discourse of ambivalence employed in this media to represent the negotiated shifts that have occurred in HIV medicine since the introduction of HAART. In this context, ambivalence encompasses notions of uncertainty, doubt, detachment, and scepticism, as can be seen in the metaphors of medical ambivalence employed to envision the indeterminacy of HIV medicine. By
sustaining doubt about the historical legitimacy and current reliability of new treatment strategies, the community-based HIV media perpetuate a model of HIV medicine as consistently volatile and unpredictable. This suggests that there may be something about HIV as a medical problem which lends itself to the deployment of a discourse of ambivalence. Indeed, ambivalence may be the most appropriate response to a disease with so few definite outcomes. This has particular implications in the context of the community-based media because of the close ties that exist between medical professionals, government representatives and affected communities in this arena. Although it is beyond the scope of this paper, it is important to consider how the discourse of ambivalence might impact those PLWHA who must constantly negotiate new developments in HIV medicine. How do PLWHA respond to the ambivalent tone of the community-based media which attempts to inform, empower and caution, all at the same time? This is an important question that could be usefully explored in future research around HIV and the media.
Notes

1 *Talkabout* has been published since 1988 by People Living with HIV/AIDS NSW, and around 3,000 copies of the magazine-format publication are now distributed six times a year to subscribers and to relevant organisations both in Sydney and around NSW. Although dedicating a considerable portion of content to HIV treatments, the more general aim of *Talkabout* is to share information and stories about life with HIV/AIDS.

2 *Positive Living* began as a community magazine in Victoria in 1989, and has since developed into a bi-monthly newsprint publication distributed six times each year as an insert in gay and lesbian newspapers in Sydney, Melbourne, Brisbane, Adelaide and Perth, and mailed directly to individuals and interested organisations, with a total estimated circulation of 86,590. *Positive Living* is produced by the National Association of People Living with HIV/AIDS (NAPWA), which is the peak organisation representing PLWHA in Australia, so while the primary focus is HIV treatment, it is also aimed at facilitating a greater sense of connection for HIV-positive people.

3 *HIV Australia* is published by the Australian Federation of AIDS Organisations (AFAO), and around 4,500 copies are distributed to their member organisations and individual subscribers six times a year. This magazine-format publication was launched in 2002 as a replacement for the two other publications that make up this community media: the *National AIDS Bulletin* and the *HIV Herald*, which had been published since 1987 and 1991 respectively. *HIV Australia* aims to synthesise the objectives of these two publications by replacing the *HIV Herald* as a clearinghouse for news and information about HIV/AIDS treatments, and the *National AIDS Bulletin* as a journal of HIV/AIDS policy, news and debate.

4 For example, only 46 of the 95 results from a search for on ‘HIV’ or ‘AIDS’ and ‘Treatment’ in the Australian mainstream print media database *Mediascan* were actually related to HIV treatments, and of these, none was addressed to an HIV positive audience.
References


