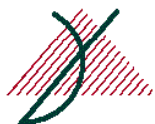


Strategic and Conceptual Issues for Community-Based, HIV/AIDS Treatments Media

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Summary

This paper was originally written as a contribution to discussions about HIV treatments media occurring between the Australian Federation of AIDS Organisations (AFAO) and the National Association of People Living with HIV and AIDS (NAPWA). The Executive of NAPWA tabled the paper at the HIV sub-committee of the Australian National Council on AIDS, Hepatitis C and Related Diseases. The paper was based on research undertaken by the HIV Treatments Education Project of the Researchers in Residence Program. The implications of this research for how community-based HIV/AIDS media are best understood are more extensive than the original motivation for the paper allowed, consequently it has been somewhat revised for wider circulation.

The purpose of this paper is to extend the conceptual frameworks used to understand HIV/AIDS media. In particular, it queries notions of these media that see them solely as distribution mechanisms for treatments information and introduces the notion of cultures of care in which the HIV media play a key role.

National, community-based, HIV treatments media (*Positive Living* and *HIV Herald*) are active, core elements in the maintenance, circulation and quality control of cultures of self-care amongst people living with HIV.

In general these media:

- link basic science, clinical research and clinical practices with experiences of living with HIV, of taking HIV treatments and of making treatments decisions;
- relay self-care practices amongst, and between, people living with HIV, service providers, clinicians and affected communities;
- assist informed, self-reflexive understandings of HIV treatments;
- create a community controlled, quasi-clinical space that enhances self-management of HIV as a chronic disease;
- broker understandings of what living with a chronic disease means from the perspectives of people living with HIV with service providers, researchers, clinicians; policy makers and funders.

In particular, *Positive Living* performs five key roles simultaneously. It:

- enables social bonding amongst the HIV positive and with the HIV negative;
- educates and informs;
- entertains;
- brokers techniques and perspectives on treating and living with HIV;
- negotiates tensions between clinical and living with HIV perspectives that are sometimes mediated variously by gender, sexual identity and differences in clinical best practice.

Some background data relevant to the discussion

Figure I: The *HIV Futures* studies and readership of HIV/AIDS media

The two *HIV Futures* studies (Ezzy *et al* 1998; Grierson *et al* 2000) show that amongst people living with HIV there are close connections between HIV media coverage of treatments information and living with HIV and the size of the readership of the national, community-based HIV media. In *Futures II*:

<i>Positive Living</i>	was read by 55.6% of respondents (62% in <i>Futures I</i>)
<i>HIV Herald</i>	was read by 38.6% of respondents (51% in <i>Futures I</i>)
<i>National AIDS Bulletin</i>	was read by 18.3% of respondents (25% in <i>Futures I</i>)

Though the two *Futures* studies involve two different samples, we can infer that over 50% of the people living with HIV in Australia read *Positive Living*.

Downward variations in readership size amongst HIV positive people should not be read as automatically diminishing the core cultural role of these publications in circulating self-care practices. Their role as primary sources on living with HIV strengthened between *Futures I* and *II*.

Connections between living with HIV and size of readership are even stronger in state based media which have high readerships amongst HIV positive people in their state:

<i>Talkabout</i> (NSW)	was read by 76.9% of respondents (81% in <i>Futures I</i>)
<i>QPP Alive</i> (Qld)	was read by 78.3% of respondents (49% in <i>Futures I</i>)
<i>Positive Life</i> (WA)	was read by 51.9% of respondents (70% in <i>Futures I</i>)

These state-based publications are not dealt with specifically in this paper, but there is an assumption that they also play highly influential roles in information feedback loops and the relaying of self-care practices amongst HIV positive people.

Some background data relevant to the discussion

Figure II: The 2000 *Positive Living* Readership Survey

Respondents to the ***Positive Living* Readership Survey** (Hurley 2000) overwhelmingly see *Positive Living* as a primary source of information (88%), as highly informative (89%) and as stimulating.

The 183 respondents were male (80%), gay (70%), HIV Positive (61%), female (20%), heterosexual women (13%) and lesbian women (5%).

***Positive Living*:**

- is overwhelmingly seen to be pitched at the right level (82%);
- has a large, non HIV positive readership (39%);
- has a readership 40% wider than the number of copies picked up;
- is easy to read for most (65%), but 30% find it “moderately demanding”;
- is usually co-read with the *HIV Herald* by HIV positive respondents (74%), except by those aged 30 or under;
- is strongly liked as a resource for its combination of humour and reliability.

Irrespective of HIV status, respondents make up a faithful, ageing readership.

They have read the publication for two years or more (67%). HIV positive respondents are even more likely to have done so (76%). Respondents generally are likely to be aged 31-49. They are more likely to be aged 50 or over (24%), than 30 or under (11%).

Respondents generally read most issues regularly and intensively to find out ‘what’s happening’.

HIV positive respondents are likely to be taking antivirals (73%) and to have done so for longer than 2 years (79%). They are more likely than non-HIV positive readers to have read *PL* for longer than two years, however HIV positive readers not currently taking antivirals are even more likely to be long term readers. They are very unlikely to be aged 30 or under, and are very likely to come from the east coast of Australia. They overwhelmingly feel part of a wider group as a result of reading *PL* (86%).

HIV positive respondents also prefer articles to be written in a personal style that is informative and accurate. They want information about antivirals located within a living with HIV framework, rather than in either a purely “factual” medical perspective or a living with HIV framework that dissipates the authority of medical knowledge and the experience of treating allopathically.

* Slight arithmetic anomalies occur due to a rounding out of percentages to whole numbers.

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1. INTRODUCTION

The notion that the news media are merely a neutral conduit for information is dying hard. (Lumby 1999)

In treatments I think we've laboured under the misapprehension that the job of public health education was best facilitated simply by the provision of clear and factual information, and that somehow this was enough to facilitate behaviour change. (Batrouney 1997)

Social networks play a particularly important role in the development of a sense of capacity with respect to health practices. They also play an important role in producing a different sense of selfhood than that associated only with doctors and treatment. (Race et al 1997)

1.1 Purpose

The purpose of this paper is to extend the frameworks used to understand HIV/AIDS media. The paper demonstrates that current understandings of HIV treatments media minimise their role in constituting and reinforcing cultures of reciprocal care. These media provide much more than the distribution of accurate, up-to-date information on HIV treatments.

The paper links three bodies of research in this discussion. The research includes data from *HIV Futures II* (Grierson et al 2000), the qualitative work of Race and others on HIV health practices (Race 2001; Race and Wakeford 2000; Race et al 1997) and my work on treatments information loops and the HIV media which confirmed and extended community sector media evaluations (Hurley et al 2000b; Hurley 2000c; Malcolm 1998). These research publications are empirically rich, but more importantly they allow for complementary analysis. This, in turn, enables the kind of discussion that occurs below.

The Introduction asks two questions and uses the discussion of them to identify a number of themes that are then followed through in the rest of this paper.

- What does current and past research on the Australian HIV media tell us?
- What conceptual frameworks are embedded in the ways we speak about the HIV media and how well do they help us conceptualise what those media do?

Australian HIV social research indicates that HIV/AIDS media generally, and *Positive Living* specifically, play a key role as sources of information on HIV treatments and living with HIV (Grierson et al 2000, 52, 54). Indeed they are part of a dense network of information feedback loops feeding treatments information to HIV positive people and relaying responses from HIV positive people to other sites (Hurley 2000a, 2000b).

What this research allows us to do is to configure the fields in which sources of information are linked to social networks that are themselves partly constituted by the media relaying of practices of self-care. The HIV media are agents in an active mobilisation of a culture of care.

What is a self-care practice?

In a health context, a self-care practice is any technique used to better a person's quality of life.

What is a 'culture of care'?

A 'culture of care' is the everyday **social** space created when self-care practices are actively socially supported and relayed amongst and by people (i) affected by the presence of a disease, and/or (ii) sharing or negotiating a community of interests.

This discussion paper mostly refers to the publications *Positive Living* and, to a lesser extent, *HIV Herald*. The perspective developed, however, is of wider application than to just those publications. It is a cultural perspective that identifies a need to name and support key elements in the relaying of self-care practices amongst people living with HIV.

What is meant by 'living with HIV'?

In this discussion 'living with HIV' is understood from a cultures of everyday life perspective that includes several different emphases according to context: clinical, quasi-clinical and non-clinical versions of living with HIV. That is, sometimes living with HIV involves no clinical reference to the virus, but has much to do with how being infected does and/or doesn't play out in personal social relations.

Understanding this cultural perspective requires that we develop clearer notions of what it means to do health promotion for people living with HIV in a media culture.

Figure III: What is a media culture?

The concept of a 'media culture' involves understanding 'society' as a social space profoundly affected by narratives of everyday life that are circulated by media. These narratives consist of both 'stories' about events, people, places and the conventions used to tell the stories. So, for example, television news tends to tell stories as 'breaking' news, 'catastrophes', 'breakthroughs' and 'human interest'. In a media culture, these stories are rapidly relayed nationally and internationally, often at saturation level, because the print and electronic media rely on a small number of news gathering and relaying companies (AAP, Reuters). Ordinarily we think of stories as 'made up' and understand this in two ways: as 'fictional or 'untrue' and as 'made' or 'constructed'. This paper is using 'stories' in the second sense to mean narratives of how we construct our lives and the role of the media in this making.

A media culture approach involves understanding experience, feelings and personal psychic life as socially narrated, even though they are individually experienced. This is because we use language to communicate and because internal experience (thoughts, feelings) has to be socially coded in language if it is not to be totally private. Media moments are primary sites for viewers/listeners/readers to rehearse everyday life as a form of story telling. We learn how to enact experiences of 'love', 'anger' and 'relationships', how to 'perform' them by seeing them performed. We practice different kinds of performances using media related stories as resources, 'props' if you like.

There is no assumption here that the media *determines* individual experiences. Rather, the narratives circulated by the media are resources in the negotiation of everyday life. These narratives have various amounts of social power attached to them that are situationally specific and that affect matters of access, vulnerability, equality, social capacity and resilience.

Positive Living and, *HIV Herald* are seen in the national community-based organisations (AFAO, NAPWA) as the 'treatments' publications, as distinct from *HIV Legal Link* and the *National AIDS Bulletin*. While the latter often contain treatments commentary, legal, policy and political concerns and more general issues of representation frame them. Their audiences and purposes differ, as does the extent to which people living with HIV read them.

In the two years between data collection periods for *HIV Futures* (1997) and *HIV Futures II* (1999), the HIV positive readerships of *Positive Living*, the *National AIDS Bulletin* and the *HIV Herald* appear to have declined. In mid 1998 the *National AIDS Bulletin* had a total readership of 1600 (Machon 1998). Because the readerships of the *HIV Herald* and the *NAB* are believed to include a considerable number of health and welfare service providers, and in the case of the *HIV Herald* rural providers, the possibly diminishing size of the HIV positive readerships and of total readership is somewhat mitigated by the importance of various service provision roles amongst readers. While there is a question of who should pay for this service, given a tightening in funding for national, community-based organisations, discussions of media viability also need to include calculations of the social impact of changes to these media on cultures of self care.

These calculations in turn might well provide a case for:

- (a) developing an argument to funders that a cost benefit analysis shows that the HIV media contribute to public health service economies and efficiencies;
- (b) forging a collaborative, publishing arrangement of the *HIV Herald* with other interested parties.

The primary paradigm historically in the community sector HIV media has been the dissemination of up-to date and ground breaking treatments information and its implications for living with HIV. There have been two versions of this paradigm nationally. Firstly, there is the *HIV Herald* which since 1989 has been both more clinical in its modes of address and content and is framed by the conventions of serious, popular scientific reporting and broadsheet journalism. A major proportion of its readers are health care providers, 'many in rural areas' (Machon 1998: 2). Secondly, there is *Positive Living* which, since 1996, has nationally framed scientific information and clinical practices within a living with HIV perspective and a shifting combination of the conventions of tabloid journalism and popular culture. Both versions of reporting HIV treatments information have been thoroughly imbued with the ethics of professional journalism, even as they have oriented themselves towards both separate and crossover audiences and complementary modes of representation.

Why are there different kinds of publication aimed at different audiences? Media strategies are generally discussed in two quite different ways in the community-based HIV sector, if not in health promotion generally.

The first sense involves the community sector responding to representations of HIV in the mass media (print and electronic). The concern here is as much with the formation of public and political opinion, and the effect of this opinion on people living with HIV and the organisations that work on their behalf, as it is with the accuracy of scientific and clinical reports on HIV. An active media advocacy role

involves working relations with community and mass media journalists, understanding news agendas and how to intervene in them successfully. This role is often carried out by a media officer, whose public relations and media management function is different to that of an editor, even where the same person does both jobs. It is an advocacy role which includes political agenda setting, a task that is also allocated to flagship publications such as the *National AIDS Bulletin*.

The context in which the national publications are produced is of some relevance. To a degree, these media are 'shoestring' publications. They have very small staff. Usually the editor is also the only staff journalist, and writes much of the content. Regular contributions are also made by professionals employed in other capacities than journalist, by clinicians and by key players from affected communities. The publications are housed in the organisations which produce them and there are close, daily interactions with professionals and the organisations representing the people with most at stake. There is a limited analogy between the Executive Officer of the auspicing community-based organisation as publisher and the role of a managing editor in the commercial press. Both are editorially 'hands-off', but bear a legal and/or political responsibility.

The second sense has primarily involved contexts of education, social marketing and the representation of HIV in popular culture. These contexts cross over various forms of mass and community-based print and electronic media. From the mid 1990s several strands emerged here:

- the dissemination of treatments information, including in media formats that contested the nature of social marketing by pharmaceutical companies (*Positive Living*);
- the dissemination of treatments information in print resources (booklets, fact sheets), often as part of a campaign, and increasingly within infotainment events/formats;
- the role of gay and lesbian community media in representing gayness and its relations with HIV;
- the diminution of news, in both community media and the mass media, about living with HIV after the initial flurry about triple combination antiretroviral therapy;
- the virtual disappearance of HIV narratives in Australian popular television culture;
- difficulties in sustaining wider gay community discussion of HIV, outside of the context of educational campaigns and associated events,

1.2 Key questions for community-based HIV treatments media

The pressures faced by community-based HIV treatments media in terms of the variety of demands placed on them are rarely systematically identified. These pressures have implications for future developments.

There are several key questions here:

- how do treatments media relate to cultures of living with HIV and what do HIV positive people want of those media?

- what strategic choices need be negotiated by the media to develop frameworks for thinking how HIV treatments fit into the lives of people living with HIV?
- what are the relations between these media and other systems of information dissemination, for example, those involving doctor-patient consultations, the Internet or peer based friendship networks?
- what are the relations between these and other media that do, or don't but are expected to, represent people living with HIV, and how might that representation best occur?
- what is the role of community-based treatments media in equipping people with "strategies that provoke reflection on personal values in a way that is savvy to the powerful (but not necessarily mandatory) allure of hardline medical pronouncements" (Race and Wakeford 2000)
- How can quality, accurate information continue to be best reported?

Treatments media are rarely positioned in relation to either mainstream print media or forms of social media such as the gay and lesbian community press. Rather, each is seen as a separate form of reporting, as though they (a) are not co-articulated in the circulation of treatments information, (b) do not have overlapping readerships amongst HIV positive people, and (c) do not have social and symbolic dimensions that affect how information is read.

Though this co-articulation issue is probably largely salient in the major cities, and mainly for HIV positive gay men, there are interesting unresearched questions here. For example, if it's the case that the coverage of living with HIV, as distinct from living gay, consistently 'thins' in the gay and lesbian press from 1997 on, yet HIV positive people consistently identify the gay/lesbian press as a major source of information on both treatments and living with HIV, what is going on? What are the perceptual and semiotic issues in play here? Do HIV positive people distinguish clearly and always between *Positive Living* and the press it is inserted into or are they often read as seamless.

1.3 Information loops and people with HIV

The media event (Wark 1994) that was 'Vancouver' (ie, the eleventh World AIDS Conference, 1996) saturated Australia with mainstream print and broadcast news bulletins announcing new drugs, new classes of drugs and new hopes for people with HIV. The subsequent medical effect of the 'protease moment' has been a significant fall in the death rate from AIDS and a significant downward shift in the proportion of people with HIV progressing to AIDS. This effect is well known amongst HIV populations in Australia.

The quality of, and circulation in, the commercial media, at the time and subsequently, of detailed information, on HIV natural history, viral load, combination choices, possible side effects, newly emerging drugs, resistance and compliance, are separate matters. However, these detailed matters were systematically taken up with doctors and in the HIV/AIDS media. Those media monitored for quality control and gave voice to the experiences of the people taking the treatments and those voices fed back into changing clinical practices and research agendas.

Though there is room for some discussion about the quality of information and the evenness of its dispersal initially, this discussion assumes that for the past three years we have been in an environment of information saturation on these matters.

In particular, two assumptions are undercut here: that for most people there is insufficient information, and that having the information does or ought automatically result in personal decisions that accord with medical best practice. Indeed, one might note how rapidly medical best practice shifts on these matters, how unanimity is rare amongst high HIV caseload doctors, and how unconfident low HIV caseload doctors are about their treatments advice (Batrouney 1999; Kirkman 1998).

Any media education strategies that base themselves on an information deficit model would be coming from behind and lack credibility amongst wider populations of people with HIV in Australia. The credibility discussion, however, is complicated by two highly arguable assumptions:

- that anxiety expressed about treatments is best dealt with by 'more' information, without a discussion on how already circulating information plays out in people's lives;
- that readers themselves don't have to be educated about their expectations. For example, the notion that treatments media and resources are obligated to answer complex questions about individual treatments choices and regimes, rather than the individuals using the media as resources to aid generally in making the choices.
-

The solution is not always to re-iterate basic, commonly available material nor to take on the role of the doctor in the clinical setting.

1.4 *Positive Living* and people with HIV as a treatments informed readership

Positive Living has a loyal, long-term readership. 76% of HIV positive respondents have read it for two years or more, and have been on antiviral treatments for two years or more. This readership is largely united in wanting a general perspective that locates treatments information within living with HIV perspectives. They are divided on how this is best done and how 'far' it should go. Generally, HIV positive respondents to the 2000 *Positive Living* Readership Survey required that clinical information be narrated in non-clinical genres with no loss of quality in the information. The (very impressive) capacity of *Positive Living* to do this is seen as a great strength by the readership. Differences in emphasis emerge amongst the respondents according to whether they understood living with HIV from inside or outside a modified clinical framework.

Positive Living is read by HIV positive people quite open to allopathic treatments, most of whom currently are treating allopathically, but a sizeable minority are not (27%). Treeters and non-treeters alike read it to learn about their treatments options. Understanding these options and choosing to treat allopathically or not, at any given time, are linked but separate questions, and the readership appears to systematically distinguish between them. That is, the audience is quite clear on the

difference between getting information and acting on it in ways that may or may not be consistent with currently preferred medical options.

Positive Living has a 40% non-HIV positive readership who see themselves as having close professional, personal and political links with HIV positive people.

On current indications, if the efficacy of combination therapies holds and the uptake rate stays about the same, then there will be about a 12% increase in people living with HIV by 2003 (NCHECR 1999). The proportion of these infected since 1995 will be about 20%. Further, about 20% of current new diagnoses are 'late', in that they are diagnosed with an opportunistic infection within 3 months of the initial HIV diagnosis. Further, because of the historical effect of early infections, reducing incidence and death rates amongst gay men, a slowly increasing proportion of people with HIV are heterosexual men and women, and younger people. The proportion of treatments experienced HIV positive people for whom treatments do not work appears to be slowly increasing.

All these factors suggest that:

- *Positive Living* will be read by increasingly diverse HIV positive populations for whom issues of gender and sexuality are played out, if not dispersed, in relations to the nature of their treatments experience, length of time diagnosed and how they frame HIV within their wider lives;
- Readers may continue to place increased emphasis on cultural rather than clinical questions;
- *Positive Living* may have a renewed choice of mobilising treatments activism around drug development and availability, and around emerging possibilities of clinical trials, including vaccine trials, however any such choice would have to be negotiated very carefully with diverse readerships.

1.5 Extending how what HIV treatments media do is thought

The primary conceptual framework used to understand the HIV/Treatments media in everyday policy practice seems to involve information transmission through social marketing. Even though sophisticated health promotion professionals understand that use of the media generally in social marketing is not just a technique for added 'reach' (NAPWA/AFAO 1997; Parnell 1996), but also involves discursive mobilisation if sustained behaviour change is to occur, this understanding also barely begins to address what it is the HIV/AIDS media do.

For example, we hardly, if ever, speak publicly about:

- the HIV/AIDS media as one of the primary ways a public, quasi-clinical space, largely controlled by the affected communities, is kept open, or
- of how these media and this clinical space are mediated and regulated by community-based organisations and the constraints of their relations with funders, medical authorities and self-regulation practices, the politics of treatments best practice and the experience of people taking the treatments, or

- of the productivity of these relations for people living with HIV, such as enabling people with HIV to speak to each other nationally and regularly, the relaying of self-care practices, keeping HIV issues in general circulation in gay communities and disseminating news, views and breakthroughs.

There is also very little public, non-specialised discussion or ongoing dialogue between journalists, doctors, researchers and readers about what it means to represent scientific and clinical information in popular media forms.

Two other relevant practices in this context of limited public discussion are:

- the ongoing, specialist dialogue that occurs as part of a process of content approval involving media producer, clinical personnel and publisher 'checking for accuracy' in specific articles, and, very rarely, censorship;
- discussion amongst professional educators, advocates and 'insiders' as to what constitutes a community response or 'take' or 'angle' on particular issues.

These dialogues and discussions occur between interested people, often independently of the media, but in contexts which often include the journalist, editor, and publisher. They also occur between journalist/editor and interested parties on both general issues and specific articles. Further, there are continuous interactions between journalist/editor and official or unofficial representative spokespeople of the organisations with the most at stake in the issues under discussion.

This small network of personnel is contextually very important in the formulation of informed opinion. The network plays a key relaying role in the circulation of narratives of authority, expertise, caution, advocacy and contestation. This relaying role is by its very nature also part of a challenging process of representation which includes, as well, how the people constituting the relay networks take into account the ongoing cultural shifts amongst HIV positive people and their relation to themselves and their communities. Taking these shifts into account poses a major challenge for the journalist/editor and the publisher in terms of how these relations are to be known and represented.

Brokering and negotiation of informed opinion in this context can also include moments of reactive formation in which the insistence of key players on HIV/AIDS media having a clear relation to the needs of people with HIV is kept separate from questions of media strategies, organisational capacity and the heterogeneous representation of HIV positivity.

1.6 Strategic considerations

Strategic and representational questions are central to any discussion of community-based HIV/AIDS treatments media in Australia. Sometimes answers to these questions are at odds with each other when they play out in relation to issues of organisational funding, media practices and the expressed needs of people living with HIV. While these questions are, and ought to be, directly linked to the needs of people living with HIV, the reporting and representation of these needs are rarely thought through in relation to either media strategies or how those strategies interface with organised educational interventions (Anderson 1999).

Strategic and representational questions are contextualised by:

- the changing nature of the lived experiences of people with HIV
- rapid changes in clinical treatments best practice
- questions of organisational funding and resource constraints
- questions of distribution and circulation
- rapidly changing media technology cultures
- past HIV media practices
- how best to communicate with HIV/AIDS service deliverers
- current understandings of health promotion and HIV education
- a health and welfare agenda of ‘mutual obligation’ that atomises the sociability of lived experience in favour of a ‘responsibilising’ moral individualism
- a lack of research into HIV treatments media, as distinct from research into (a) their role in treatments information loops, (b) the audience ‘effects’ of social marketing and (c) questions of the accuracy and nature of treatments information in the mass media.

Figure IV: Research and policy contexts

The perspectives offered in this discussion paper are consistent with the following research and policy contexts:

1. NAPWA’s insistence on “the guiding principle of positive centrality and accountability” (Canavan 2001);
2. NAPWA’s understanding of health promotion as “the proactive engagement of people living with HIV in creating a broad, life wellness construct as the lived Australian HIV reality” and the acknowledgment that this requires moving “beyond the medical response frame in encompassing a much wider understanding of health and wellness in the presence of HIV” (NAPWA 2000);
3. AFAO’s *Statement of Directions 2000-2004* acknowledging the context in which HIV occurs, AFAO’s base in the most affected communities and the centrality of positive people to AFAO’s responses (AFAO 2000)
4. Research from the Living with HIV Program, Australian Research Centre in Sex, Health and Society and the National Centre in HIV Social Research.
5. The National HIV Strategy’s goal of “minimising the personal and social impact of HIV infection” (Commonwealth Department of Health and Aged Care 2000a).
6. The Federal Government’s Chronic Disease Self–Management Program which includes the “effective collaboration between individuals, their families and health care professionals in the management of chronic conditions”, encouraging development of locally based projects to support self–management interventions” and supporting self–management initiatives (Commonwealth Department of Health and Aged Care 2000b).
7. Increasing clinical understanding of the relation between information loops, public health outcomes and the implications of the exemplary record of community HIV management in Australia for disease control generally (Morgan 2001).

2. MEDIA CULTURES

Ethnographies of group life are now directed to this world of televisual and cinematic narrativity and its place in the dreams, fantasies and interactions of everyday people. (Denzin 1997: xvi)

Much of my ensuing argument will be based on the premise that what appears on one level as the latest fad, advertising pitch and hollow spectacle is part of a slowly emerging cultural transformation in western societies, a change in sensibility for which the term 'postmodernism' is actually, at least for now, wholly adequate.

(Huysen 1984)

In a discussion of HIV/AIDS treatments *media*, it seems hardly surprising that a concept like 'media cultures' might be at its centre. Yet there are few examples of recent cultural reflection on these media in the community HIV sector. Discussion centres around (a) notions of accuracy, timeliness and information dissemination in relation to HIV treatments, (b) ways of making the information relevant, interesting and palatable by making it 'entertaining', and (c) negotiations over who is best placed to 'speak' these necessities. People with HIV are positioned as people in relation to treatments and, depending on the publication, in relation to living with HIV and the effects of the treatments.

The exceptions to this approach have largely centred on *Positive Living* and particular education campaigns directed at gay men and, more recently, a shift in educational practice amongst those 'delivering' treatments information.

2.1 The concept of Media Cultures and its relation to everyday life

The concept of 'media cultures' allows us to have these discussions quite differently. It begins by acknowledging that people narrate their lives through available social discourses (ways of understanding the world or bits of it). These discourses are themselves narrated: in personal interactions, in various kinds of media circulated texts, through organisations and politics. In other words, the 'culture' part of 'media cultures' refers to the organising role of narrative structures (stories) in everyday life, to the performance of ways of living, and to genres of experience.

'She's having a bad hair day'

Is an example of the 'culture' bit, involving as it does the narration of everyday life, the practices of everyday living. These practices are resources. 'She's having a bad hair day' is simultaneously a description of an individual, a speaking position and a recognisable figure of speech. The sentence identifies two moods, those of the speaker and the person being spoken about. The speaker is somewhat detached, and maybe excuses and dismisses the mood of the person spoken about, and how it's playing out. If spoken within the hearing of 'she', it may be heard as an invitation to enter banter that might shift the mood or it could be experienced as a deeply wounding trivialisation of personal hurt and prompt an act

of self assertion, aggression or collapse. These attitudinal resources are rich in possibility.

The concept of 'media culture' combines these notions of narration, genre and performance with an understanding that everyday life is significantly constituted by interactions with various kinds of print, broadcast and electronic media. This understanding takes for granted that these media not only set up narrative circuits, often regulating the availability of approved ways of telling stories about oneself and others, but also proliferate endless ways of striking a pose in relation to these forms of narration.

'Not happy, Jan'

What's interesting about this example, is that the advertisement in which it is spoken not only refers to an old television show ('The Brady Bunch'), but is also deeply ironic. 'Not happy' is a way of saying I'm f-ing furious'. The ad itself has struck a pose, and some audiences are delighted with this degree of savviness and a circuit of endless repetition occurs in which the statement is reiterated in all sorts of contexts for all sorts of purposes. This is a media literate culture that knows it's a media literate culture. In this example, producers and consumers unite.

So to talk of media cultures is not just to talk of the role of print and broadcast media as 'sources' of news and information, but to conceptualise a way of understanding lived experience as narratives in popular media culture.

What 'media cultures' as a concept allows us to do is to simultaneously recognise that:

- HIV/Treatments media have to be understood as 'media' before they can be understood in other ways as well;
- We can reposition how we think about HIV positive people and their experience in this media circuit. For one of the consequences of a media culture approach is an understanding that deeply personal experience is itself narrated through the available social discourses. And those discourses are generically organised.

'You don't listen to me'

Is simultaneously an assertion of a perception and possibly an assertion of a right (to be heard), an assessment of self worth (I deserve to be listened to), possibly a whinge, possibly a statement of fact. Just because it's personal doesn't mean it's not socially constructed.

Therapeutic genres of speech, especially statements of feeling, are deeply socially conventional, even when the capacity to speak this way is itself constrained by inhibition or context. Just think for example of the metaphor involved in 'own your feelings'.

2.2 Media circuits

Transnational media organisations relay images, print and sound in narrative form ('reports', 'interviews', 'stories') from one place to another electronically for use in local broadcast media. Relaying is frequently very fast ('news'), international, and is delivered to media networks that cover the entire country. For example, in the case of television, there is the national broadcaster the ABC, SBS and the commercial 'networks' 7, 9 and 10. Radio is also nationally networked. The 'Australia' is a national newspaper, however international press agencies (AAP, Reuters) 'feed' the state papers with the same 'stories'. Various political, popular and governmental responses to these stories are incorporated into the next story 'episode' and in this way a media feedback loop is created, hence the notion of a 'circuit'.

These 'stories' are narrated (constructed) and the forms of narration are ways of organising everyday events in particular genres ('natural disasters', 'catastrophes', 'human interest', and 'scientific breakthroughs') that in turn invite particular kinds of audience response. However those invitations have no guarantee they will be taken up by the reader/viewer. The audience actively negotiates an attitude toward and relationship to or within the narrative. This response may be as swift in formation as the media relaying of the story and may involve any of being intrigued, fascinated, horrified, bored, disbelieving, and outraged. These responses are incorporated into news items so that the audience is delivered a narrativised event that includes someone's 'reading' of it, expert, emotional or otherwise. Various forms of television drama, 'reality TV and infotainment shows allow viewers to position themselves in quite complicated ways, whether we're speaking of quiz shows, Oprah or an art movie.

The relaying of the text, its narrative form, its inbuilt, preferred viewing position, the responses to it and the forms of feedback allowed in 'follow-up' are circuits in media culture.

3. RETHINKING MEDIA FRAMEWORKS

Part 3 critically discusses some common assumptions about the media in health promotion. It does so by bringing together and making overt the thinking around some key concepts and contexts. The purpose is to enable an understanding that sees:

- Reading as a social rather than individualising activity;
- Health promotion in relation to lived cultures;
- Media reach and distribution in the context of cultures of care;
- Genres of journalism as narrative structures.

3.1. HIV/AIDS media and the social nature of treatments information circuits

HIV treatments media use sophisticated representational strategies to relay information about HIV treatments and living with HIV (Batrouney and Haire 1998a). They continuously monitor and develop those strategies in relation to the complexities of how their readerships relate to them.

Elsewhere I have argued that:

Positive Living performs five key roles simultaneously. It:

- **enables** social bonding amongst the HIV positive and with HIV negative
- **educates** and informs
- **entertains**
- **brokers** techniques and perspectives on treating and living with HIV
- **negotiates** tensions between clinical and living with HIV perspectives that are sometimes mediated variously by gender, sexual identity and differences in clinical best practice

These roles are best thought of as interlocking and equally important. They are 'enacted' through a combination of stylistic, informative and attitudinal characteristics that together constitute the content, authority and aura of the magazine (Hurley 2000c).

These media need to be systematically thought through as constituting an interface between people living with HIV, educational practices, service provision and media circuits. While such a discussion is in some ways necessarily conceptually demanding, it is needed to enable serious consideration of the problems posed by this interface for ongoing credibility with the readership, policy makers and funders.

For example, how do the past successes with the current readership relate to shifts in:

- (a) the demographics of the target population (a slow ageing of people living with HIV; a sizeable proportion under 30 years old; newly diagnosed; late diagnosed; a greater proportion of women and heterosexual men living with HIV)?
- (b) slow shifts in the epidemiology towards people diagnosed since 1990 or 1995?
- (c) the relations between people with HIV, community-based service providers and clinicians?
- (d) public representations of people living with HIV and HIV treatments?
- (e) the ongoing maintenance of a public, community controlled clinical space which allows for both cutting edge discussion of current treatments, the experience of taking them and what they mean for people with HIV?

Why can't HIV/AIDS treatments media be understood properly by simple notions of information circulation?

An initial answer to this question can be given after we look at what we know about how people with HIV in Australia evaluate some of the sources of their treatments information in the following table:

Table 1: Sources of Treatments Information identified in *HIV Futures 11*

	Source of Treatments Information	Most impmt source of Treatments Information	Source of Living with HIV/AIDS Information	Most impmt Source LWH/A Information
Specialist HIV Drs	94.4%	74.9%	47.7%	21%
HIV/AIDS press	65.5%	7.7%	61.2%	19%
Gay press	50.7%	0.9%	49.5%	5%
HIV positive peers	41.1%	1.5%	53.6%	19%

Source: personal communication, J. Grierson, The Living with HIV Program, Australian Research Centre in Sex, Health and Society, 21/9/00.

One way of reading this table is to say that specialist HIV doctors are the most important source of treatments information and of information on living with HIV and AIDS. However this interpretation downplays the following:

- in column 1 ('Source of treatments information') respondents clearly have multiple, overlapping sources of information, as they do in column 3;
- in column 2 (Most important source of treatments information'), though there is still a clear naming of doctors as the most important source of information (75%), respondents have been 'forced' to nominate the most important source of information. Further, 15% of respondents don't appear in the statistics given at all and 10% indicate a source other than doctors.
- In columns 3 and 4, the numerical differences between the answers on both the source and most important source of information on living with HIV/AIDS are much smaller, especially in column 4.

So let's start reading the data a bit differently by understanding the difference between 'source' and 'most important source' as a difference in (a) how authority and expertise are perceived, and (b) where the information fits in the lives of people with HIV.

On this basis we might say that people with HIV have four major sources of treatments information, but give far greater significance to their doctors as sources of treatments information. However this situation changes dramatically when the issue is information on living with HIV. Doctors are relatively no more important than the HIV media and other people with HIV.

This understanding of the data suggests to me analytic frameworks quite different to those that simply accept the numerical answers at face value and, on that basis, say only that the doctors and HIV media between them constitute the major information loop for people living with HIV. This mechanistic reading isolates each source as though it bears no socio-cultural relation to any other sources.

What if we begin instead from the following five assumptions:

- that the sources of information constitute a set of resources from which the person with HIV chooses according to purpose, need and available choice at any given moment;
- that the priority or significance given to any single source changes according to purpose and need;

- that knowledge of the existence of the sources, the processes of selection between them and the pragmatic giving of priority to any according to time, need or purpose are self-care, self-management practices;
- that the existence of a multiplicity of (re)sources and access to them, together with practices of self-care constitute a culture of care;
- that the relation between sources and their variable importance shifts over time according to usefulness and symbolic value and these shifts partly constitute the changing nature of lived HIV cultures.

These five assumptions can be justified by my own research and by a range of other research on people with HIV.

The rest of this paper elaborates this initial answer to the question of how treatments media are best understood by locating discussions of treatments information primarily in relation to a media framework, rather than to any one of treatments information dissemination, social marketing or health promotion. This perspective allows:

- a more extensive and useful understanding of my own and others' research;
- sharply focussed questions for the future direction of community-based HIV/AIDS media;
- a management strategic approach that is not only resource driven;
- the representation of cultures of care to be linked to media strategies and educational priorities.

Representing the relations between treatments information and living with HIV has been a key characteristic of Australian, community-based HIV treatments media.

When *Positive Living* became a national publication in 1995 it embodied a series of representational practices that centred a series of beliefs, attitudes and experiences characteristic of the dominant cultures of people living with HIV. Editorial practice displaced and interrogated pharmaceutical social marketing practices and was self-reflexive in the sense that it involved an understanding of HIV treatments as always 'experimental'. It understood the disjunctures between:

- basic science research,
- the best available clinical research,
- the changing nature of clinical practice,
- the role of *Positive Living* in the feedback loops as reinforcing the informing of research and clinical practice of the experiences of people living with HIV and treatments.

It did so with humour, a keen eye for design, ethical integrity. It did all this within a framework consistent with the then experience of what it meant for people to live with HIV.

Though the arrival of triple combination therapies was to complicate this task immensely, *Positive Living* has never been simply a relay of clinical information in 'accessible' language.

Megan Nicholson, freelance HIV treatments writer and researcher for Britain's National AIDS Manual (NAM) Publications (1998-present), and Executive Editor for the Australian Society of HIV Medicine, argues, for example, that community-based Australian HIV/AIDS media focus more on the lived experience of people with HIV/AIDS than some British counterparts.

In the UK, several publications and websites such as aidsmap, AIDS Treatment Update and *Positive Treatment News* focus primarily on reporting the latest medical research, and discussing the implications of such research in terms of people's treatment options. Broader health and lifestyle issues of people with HIV are covered by other publications and websites such as *Positive Nation*. The Body Positive organisation which attempted to meld treatments information with a broader health promotion /service provision framework was recently de-funded.

Annual readership surveys conducted by AIDS Treatment Update show that readers are very happy with this information-based approach to treatments information (ATU, issue 85, Jan 2000) which is possibly one of the reasons that NAM Publications has survived the recent round of funding cuts. In Australia, my experience of readership surveys of people with HIV (AFAO 1995-7) is that readers in Australia want articles and information about the experience of living with HIV and they want technical information explained in simple terms. Consequently, I think Australian HIV/AIDS media has adapted to this demand from readers and places greater emphasis on representing the experiences of people with HIV and presenting the latest research findings within the context of lived experience.

(personal communication, 14/11/00)

It is easy to minimise the complexity of the generic textual strategies involved in narrating the 'simple terms', Nicholson initially refers to. I share with her the sense that it is possible to distinguish between genre, discourse and the authority of expertise in at least three ways in these matters:

- textually, between clinical and more popular genres of writing;
- discursively, between the different effects of locating clinical and scientific information inside and outside clinical genres;
- expertly, the authority of science can be represented in ways which acknowledge that the drugs involved are experimental and treatments are experienced personally.

We might also note Nicholson's remarks on how questions of funding have been resolved in Britain. Though the relative success of *Positive Living*, for example, might suggest an 'if it's not broken, don't fix it' approach, this would seem to ignore any impact on HIV/AIDS media of strategic refocussing in organisations such as AFAO, the National Association of People Living with HIV/AIDS and the AIDS

Treatments Project of Australia, and any consequent need to reconfigure how questions of media are thought.

Current organisational, political and strategic pressures create trajectories for 'solving' the representational issues. These trajectories include developing media strategies in direct relation to organisational capacity (resources, staffing) and media strategising in a context of new media cultures and service delivery in ways that are sometimes in tension with the educational implications of how HIV positive people are and might be represented in the wider cultures from a health perspective.

3.2. Health Promotion

Health promotion increasingly offers a 'professional' tool kit to market health and information as commodities. (That is not necessarily how health professionals understand what they do.) This tool kit sits well with funders who often employ health promotion experts to evaluate community-based educators and provides a conceptual framework for understanding what they do. It was not the language first used in HIV education and was pretty well irrelevant in the dramatic successes of the first responses to the threat of HIV (Parnell 1996: 2). Parnell argued that the broader concept of 'social marketing', for all the limits he identifies, helped us address the complex imperatives of health promotion. I am increasingly doubtful about whether this is now the case, if it was before. The price paid seems to have been a loss of any understanding of what techniques constituted a 'community' response.

The social marketing kit provides the gloss of a professional language with which to speak about media 'reach', 'target' audiences and educational 'effectiveness'. That gloss is attractive as a sign of 'professionalism' and appeals in part because of its focus on how design plays out in each part of this process, however there is some question as to its usefulness (Dowsett 1995).

Lupton and Tulloch have argued in relation to social marketing and HIV health promotion that:

Attempts to engage people at risk in HIV prevention activities need to address the social and cultural dimensions of HIV risk in subcultures and the rhetoric of social marketing does not always address this. What is left under-developed in much of the social marketing literature is an awareness of the broader cultural, sociopolitical and economic issues in shaping people's health-related attitudes and behaviour. (Lupton and Tulloch 1997:1)

The context of the remarks is prevention which raises the question of how 'automatically' social marketing was assumed to be relevant in treatments information education and how print resources get positioned here as 'products' when the readers don't necessarily see themselves as consumers.

This language emerged when health promotion appropriated the advertising industry's successful relation to the mass media and the development of 'social marketing'. It comes from the 'more bang for your buck' school, and is well intended. However the social history of the appropriation of the language and

practices of social marketing and health promotion by the community sector for HIV education has now largely disappeared, leaving in its place simply the techniques, as 'innocent' means to speak and achieve our ends

My point is neither nostalgic nor reactive. Rather, I want to insist there were significant progressive dimensions to the early response that actually provide an alternative to health promotion as the dominant paradigm. Though health promotion in a public health framework is much wider than social marketing theory, there is arguably very little here that helps us understand the success of the community initiated HIV/AIDS media.

Even so, this way of thinking may be a dead end. The reality is that 'community' is itself now commodified in ways it wasn't when the initial response to HIV was generated, such that there is a greater ease with products than with 'action' oriented notions of community. That, however, on first thought, is a greater problem for prevention than for treatments education.

3.3. 'Reach': distribution, media circuits and cultures of HIV positive reciprocity

In making commodification a general metaphor for contemporary culture rather than a specifically delimited form of historical relation, they miss the extent to which non-commodity relations have been central to recent historical development, in communications and elsewhere.

(Wark 1992:151)

Questions of media strategy sometimes involve an assumption that the widest possible 'reach' ought to dominate distribution and circulation practices. Commercially this is the case given the role of circulation figures in generating advertising. However in the case of HIV/AIDS treatments media there are major nuances to be taken into account that are quite different to commercially generated understandings of 'reach'.¹

Positive Living's mass distribution strategy is as an insert in state based gay and lesbian media. It is also available in several other ways. On the surface, this mass distribution is a form of 'overkill', in the sense that the combined distribution of these newspapers is something like six times greater than the number of people living with HIV. However it is economically justified and an understanding of this strategy requires sharp distinctions between distribution, 'pick up' and readers per issue. Each issue has a readership 40% greater than the number of copies picked up (Hurley 2000a). Distribution is funded by drug companies rather than governments. The situation is less clear with the *HIV Herald* and the *National AIDS Bulletin*. However, these media together with *HIV Legal Link* and *Positive Living* are part of wider cultural circuits that link service providers, policy makers and advocates with people with HIV.

'Circulation' needs to be understood as much as an act of cultural interchange as a quantitative issue, especially as there is *prima facie* evidence of a set of

¹ This discussion occurs in greater depth in a forthcoming report from the HIV Treatments Education Project: *Education, information and media strategies. A report on the 1999 Queensland compliance campaign and its implications for HIV treatments education.*

interlocking feedback loops between positive people, the HIV/AIDS media and friends as sources of information on living with HIV. *HIV Futures II* indicated both that HIV/AIDS media were,

- a major source of treatments information after doctors
- the primary source of information on living with HIV

and that peers (19%) were almost equivalent with doctors (21%) as the single most important source, with the Internet sitting just as high as a source.

It would be a mistake to read these data as simply indicating a quantitative hierarchy of importance. Rather, they signify complex, interlocking cultural circuits in which the two main technologies are media and interpersonal interactions. There is no obvious reason to sharply separate these culturally, as distinct from seeing them as mutually interactive.

So questions of media 'reach' here have both numerical and target audience dimensions organised around both cost/benefit pressures and the political epidemiology of HIV infection categories (gay men, women, heterosexual men). The current risk is that a purely quantitative understanding of 'reach' and of what constitutes a community audience and of the relation between service providers, HIV positive people and cultural brokers will disrupt both a culture of reciprocity and a carefully developed set of journalistic practices that constitute social media practices as different to those of the mass media.²

3.4. HIV media, 'news' and journalistic practices

These social media practices are part of a media relaying system or circuit in which:

- people with HIV actively 'voice' and 'represent' themselves, though not always to the extent that they desire;
- news agendas are part constituted by notions of cultural appropriateness mediated by a 'health' agenda, wider notions of 'living' and politics

What constitutes 'news' for example, in the social media generally is a combination of competing community media practices, the history of HIV media practices, political will and political agendas. These are criss-crossed by understandings of professional journalism that are in tension with each other (Lumby 1999; Bonney and Wilson 1983).

On the one hand, there is a practical requirement that journalists overtly incorporate into their understanding of what they actually do (as distinct from what they think they do) the political elements in 'news' formation, that is, their understanding of what constitutes the currency of a 'story' and a news sense, as part of professionalism. On the other hand, there is a need to negotiate this understanding with an eye to the disparate nature of the audiences involved, and the shifting cultures of living with HIV, without an over politicising of news agendas which ignores sound media production and journalism practices in relation to audiences and credibility.

² By 'social media' I refer to those HIV/AIDS media and community publications that are not profit driven.

The result is that any notion of HIV journalism has to understand both that it is inevitably politicised and that this politicisation is itself often media savvy.

This is particularly so for health promotion media circulated amongst gay men.

3.5. HIV media, science and health promotion

However HIV social media, unlike the gay and lesbian press, are as oriented to scientific, clinical and social HIV research, as they are to reporting on, shaping and negotiating cultures of commodified and sexualised desire. This is very clear in the differences between how AFAO's two HIV education magazines *Lovers and Others* (1997) and *Wanted* (2000) negotiated popular magazine culture, lived gayness and social and scientific research. For one thing, 'Science' is far more apparent in *Wanted*.

As other researchers have argued:

One of the features of lifestyle-media is that their circulation and consumption become part of the lifestyle practices they represent: consuming gay lifestyle-media resources is, arguably, one of the practices that make up gay men's lives...If *Wanted's* textual strategy is to contextualise the dissemination of expertise and advice within an articulation of gay lifestyle experience, then its educational strategy would be to invoke the incorporation of that expertise and advice into the everyday knowledges and lifestyle capacities of those men who engage with the resource. (Bollen and Waldby, 2000: 4-5).

The social media focus on treatments and living with HIV embeds HIV media deeply in health promotion frameworks which in turn commodify 'information' as a product essential to health. There is a kind of invisible link here, a repressed link, between advertising and science that only usually becomes visible through the category of 'social marketing'. While HIV/AIDS treatments media have actively challenged the conventions that shape some aspects of advertising, pharmaceutical practice and commodity culture, they don't often see or embrace their role as one of social marketing.

Yet at some point this is precisely what they have in common with certain kinds of HIV prevention education campaigns. To reposition the content of a remark by Tulloch and Lupton slightly in this context: "Public health advertisements are designed for a specifically pedagogic and reforming function" (Tulloch and Lupton 1997: 30). If we replace 'public health advertisements' with 'HIV treatments media' we have the basis of a (legitimately contentious) discussion about where these media fit on such a view. Tulloch and Lupton fail, however, to understand how 'community' is implicated in this discussion, thus over simplifying how easily community-based health promotion can be seen as an arm of government.

The challenge is also not to let a public relations agenda of being seen by key political stakeholders to be 'doing something' totally dominate the media agenda, as distinct from doing so as an occasional tactical necessity. This is as true for meeting perceptions of community need as it is for placating the proliferating agencies of accountability: ANCAHRD, federal government, federal and state

health departments, departmental and government media units, ministerial advisers, scientific advisers, and social researchers.

Further, the changing nature of the lived experiences of people with HIV, including the shift away from an activist culture, has disrupted assumptions about audiences and continues to actively challenge what might constitute culturally appropriate modes of address. Especially as there is no research evidence that:

- a previously dominant formation of HIV treatments activists or current advocates for people living with HIV are capable of sustaining politicised notions of the 'PLWHA', even if that was what was wanted;
- people with HIV are now best served by keeping that link to a past moment, if it does not address emerging media necessities;

The challenge is not to allow a narrowing of the grounds of discussion, precisely at the moment where it needs broadening.

4. STRATEGIC IMPLICATIONS

From here on, discussion of HIV/AIDS treatments information is located primarily in relation to a media framework, rather than to any of treatments information dissemination, health promotion or current and past community practice. The advantage of this approach is that it highlights contrasting media practices, locating those practices in relation to educational perspectives and produces sharply focussed questions for the future direction of community-based HIV/AIDS treatments media.

4.1 Health Promotion and the media

Health promotion theory and practice has a particularly underdeveloped understanding of the roles and cultural significance of media generally. It tends to see the media only as vehicles for the dissemination of either social marketing campaigns or, with reference to people with HIV, new developments in treatments. In this view of social marketing, the media are seen **at best** as a method of program delivery. More often, they are seen as simply a conduit for advertisements of two kinds: safe sex information and notification of events and activities.

Consequently, it is the content of the campaign advertisement that is seen as the primary determinant of meaning (a message is transmitted) rather than either the medium itself or a combination of both being involved interactively in the creation of public discourses between already linked networks. The reader is conceived as an individualised, passive recipient of a message and the media are transmitters rather than key players in the cultural narration of treatments and living with HIV.

There is little understanding of recent media theory and analysis generally, or of how it might be applied to health communication and promotion.

For example, in *Building on Success 1. A review of gay and other homosexually active men's HIV education in Australia* (Commonwealth Department of Health and Family Services 1998), there is no understanding that,

- 'society' is significantly constituted by media culture;
- a framework for health promotion (pp. 21-25) is not possible without understanding media circulation of information, images and the narration of 'life';
- the media are not simply a 'method' of educational delivery through advertising (pp. 38, 45), or, for that matter, editorial ('placed' articles).

As a result the report's understanding of the educational best practice it reports is severely flawed, even though the discussion paper that preceded the review had some substantive references to the research on print media (National Centre for Health Promotion 1998).

Gay education identified the problems with these mechanistic notions of the media-as-conduit in the mid 1990s (Parnell 1996), and has systematically attempted to change its practice. This has arguably been more successful generally in prevention education, however AFAO's GES Project campaigns on relationships, living with HIV and on post-AIDS (Getting Things in Focus) began new educational practices linking HIV positive and non-positive gay men socially and culturally through sophisticated uses of the print media. This understanding fed into the implementation of the Positive Information and Education Project, but, because of assumptions it made about local capacity, in practice the social marketing involved fell back on message based activities (Hurley 2000d).

Within a context of social marketing and HIV prevention (print media campaigns), there has been some useful research and discussion identifying both the successes and limits of how print media have been used, especially amongst gay men (National Centre for Health Promotion 1998: 19, 23, 36, 40).

4.2 Representation, HIV Treatments media and popular cultures

Advertising is significant...a source of social information embedded in commodities that mediate interpersonal relations and personal identity...The result is a culture where image plays a more important role than linguistic discourse, for while verbal imagery is discursive, visual imagery is non-discursive, emotional, associative, iconic and fictive. (Harms 2000)

Research and discussion of media representations of HIV/AIDS appear to have changed considerably since the introduction of protease inhibitors in clinical trials in 1995. Whereas the first fifteen years of the epidemic, amongst gay men in particular, produced an enormous literature on both the media representation and cultural signification of HIV/AIDS and people living with HIV and AIDS, there has been comparatively little work on the media representation of living with HIV post protease, in either mainstream or social media. Ironically, for all the associated problems, drug company advertisements are as likely, if not more likely, to image having a life as a positive person than are the social media.³

³ This is a controversial remark that might seem to run counter to much community commentary on drug company advertisements. See, for example, Batrouney and Haire

In terms of general audiences, these advertisements, however, are found only in imported print and Internet media, rather than widely available local media. Even so, the importance of the imported magazine *Poz* should not be underestimated, at least in Sydney because key culture brokers read it. Commonsense notions of 'local' are consequently undone, as are any straightforward notions of accuracy and false promises. Rather what we see are the circulation of fantasised scenarios by drug companies—fantasies that are not best only understood as 'false advertising' (Emmett 1992; Petersen 1994)—and sets of reading relations with those scenarios. These reading relations are almost totally non-researched.

It can also be argued that representation of people living with HIV has almost disappeared in popular culture after a long period where Australian television series and soap operas, for example, engaged extensively with questions of HIV infection, discrimination, gayness, AIDS and death and dying (Wilding 1998). There has been almost nothing regular since 1997 on living with HIV post protease. Though there have been exceptions in high rating, imported series such as *ER*, and, I'm told, *East Enders*, living with HIV has been almost totally replaced with either clinical reports on treatments or living with HIV has been reduced to living with treatments and/or HIV morbidity.

Race puts it this way in relation to the personal experience of treatments and the privatisation of social relations into the clinic:

Rather than becoming *invisible*, HIV now becomes visible in different ways, through different techniques, and in different concentrations and intensities. For many gay men with HIV, it becomes visible as a private responsibility, as a 'chronic manageable illness', as something about which it would be shameful to make too much fuss about. (Race 2001: 22)

These visibilising technologies are not initially primarily or only questions of accuracy of information. Rather they are matters of sites, circuits and technologies. Though news media are seen as both important sources of medications information generally and as problematic in their reporting and claims for it (Moynihan 2000), there is also the issue of their cultural impact, how they are read and what is wanted of them. What is the relation between feeling part of a wider group when you read *Positive Living* and the privatisation of responsibility to which Race refers? Is relief from a perceived burden being played out here?

Indeed, to the extent that HIV treatments information media are a form of social marketing of health options they can partly be seen as advertising a product that consists of both social technologies and symbols: ways to engage with wellness. The modes of address they use invite their readers to enter particular narratives of

(1998a, b) and Wilke, M., (2001) Commercial Closet: AIDS Ads Upset Gays and Conservatives Alike, March 18, 2001 at <http://www.gfn.com/archives/story.phtml?sid=8903>. Most recently, Race has presented the strongest, critical discussion of these images discursively, especially using the work of *Sydney Star Observer* columnist Brad Johnston (Race 2000b). My difficulty with purely discursive analysis here is that it fails to account for the visual power of the advertisements, their luminosity and potential to engender fascination. To the extent that fascination 'works', we need an account that is able to take it on board without assuming the viewer/reader is unable to simultaneously decode what is happening.

health, problem solving, information utilising and personal identity. In other words the HIV/AIDS media are involved in the subjectivities business. Subjectivity refers to how people represent themselves to themselves (Bartos 1999) and others and to how these representations are relayed interpersonally, politically, socially and through media narratives

The diversity of these media narratives, their potential for education and the need for calling them to account have been lost sight of. This diversity has relevance for explanations of why popular representations of living post-protease are almost non-existent. Jillian Sandell argued in 1995, in relation to the then wave of “viral thrillers” (right before protease, I note), that ‘it is simply easier to consume narratives which pose totalising solutions than to address the complicated and difficult problems associated with the incidence and spread of TB and AIDS in the United States’ (Sandell 1995). She went on, “these narratives teach us, in other words, to have faith in the possibility of quick and easy solutions to the threat of deadly diseases. This faith relies, however, on a disavowal of the social context within which diseases occur”. She also points out that “the popularisation of viral entertainment might be useful because it promotes a sense of awareness about the relations between politics, economics the environment, and healthcare.”

While I would systematically query Sandell’s assumption that the reader is passive in this process, and not capable of critical engagement with the narratives, it’s true those narratives reinforce a common social discourse: the hope for, and implicit promise of, quick and easy solutions. The question of hope, however, is wider than this, especially amongst treatments experienced populations who know they are not treating themselves with ‘cures’, and tends to get omitted from both kinds of narrative and discursive analysis referred to above.

Armistead Maupin’s most recent novel is one of a few subsequent attempts to engage with these questions in popular fiction for a gay audience (Maupin 2000). Maupin explores how these issues play out in a long term sero-discordant relationship in ways such that, ironically, the HIV positive partner becomes freer to ‘have a life’ than does the HIV negative partner.

4.3 Infotainment, media savviness and HIV media

Notions of ‘infotainment’ are a way of addressing issues of cultural relevance amongst people with HIV, especially gay men. Most educational materials are ‘packaged’ in a way that displaces any overt didactic intent into formats that ‘speak’ an awareness of the lived cultures of the audience. This is one of the senses involved in being context specific. The consequence is respect for the audience and its ways of living, accompanied by a refusal of total cultural relativity: the materials take an ‘angle’ on the culture and practices under discussion and inflect the angle pedagogically.

In the case of HIV/AIDS print media, these inflections also require an engagement with the genres of science writing. Mostly this is done by crossing popular science genres with a range of practices from print magazine cultures. The production values involved are generated by interactions between editors, educators and designers all of whom are highly informed by magazine cultures, both contemporary and modern. This results in often highly self-reflexive productions

that flag their understanding of the kinds of cultural literacies involved and highly sophisticated forms of health promotion (Bollen and Waldby 2000).

Popular science journalism is a field in its own right and there is a major research literature on it as a form of writing. The range of writing that occurs in this field is large, and there is no general rubric that allows us to specify the conventions appropriate to specific magazines and journals. Much of the critical discussion shows little sense of the ways magazines create their own readerships by how they position themselves in the market, or of the multiple strategies at work to do this, or the richness of the writing strategies involved.

Channel 9's Director of Program Development recognises that 'infotainment and reality television shows sit on a spectrum that includes news and current affairs: "You have to construct an information-based story, and whether it's news or infotainment, you're using the same skills. And both genres are big on consumer-oriented stories... '90's viewers don't like being patronised or lectured ... They want information, they want a touch of passion, they want programs to speak to them in their language and they want entertainment." (Lumby 1999: 51)

People living with HIV and AIDS in Australia are media savvy consumers of treatments information. However, whereas television 'infotainment' signals 'the start of a new phase in our day', in part a 'switching off' after work, in the context of treatments information, print 'infotainment' signals the producer's desire that the consumer 'switch on'. It's not, in that sense, about entertainment, even though there may be a desire for it to be entertaining. These have been complicated matters in HIV treatments education:

For some PLWHA, a shift needs to occur before they come to terms with combination therapy. Rather than perceiving treatment in terms of 'treating HIV' (which alludes to a deficient, unwell self) a more positive representation describes the practice as 'maintaining health'. (Race *et al* 1997)

Infotainment and advertorial have had to create media practices that fitted health maintenance agendas, rather than imposed treatments and compliance agendas. It was this concern about health maintenance, as distinct from 'treatments' that motivated the 1999 QuAC Compliance Campaign. However the health maintenance position as applied to people antipathetic to treatments is hard to enact in a general campaign and context where there is saturation of treatments information amongst people with HIV:

Educational strategies based on information scarcity do not work in environments of information saturation compounded by experiences of treatments morbidity and a desire for social interaction and inclusion (Hurley *et al* 2000e).

4.4 Visual style, rhetorical strategies and inclusiveness

The Malcolm Report indicated "a high degree of satisfaction" amongst readers of *Positive Living* surveyed for the evaluation, with "a greater degree of dissatisfaction" apparent amongst readers in the *consultation* (Malcolm 1998: 7). As a result of this report, *Positive Living* made a number of changes in layout

consistent with the criticisms expressed. Of interest here is that the layout and graphics “received the most comment from readers and those consulted”.

The issues raised in the Malcolm Report on these matters indicate a readership response highly literate in magazine print cultures. So, for example, the critical suggestions made show a sophisticated understanding of many of the components of layout: column width, text/graphics ratio, relation of graphics to text, font types and sizes, and the nature of headlines, front pages and indexes. This suggests a readership possibly demonstrating what they do know about and are skilled in as readers, if not producers, as distinct from some of the content.

This knowledge was confirmed by my subsequent survey (Hurley 2000a).

The issue of content and writing is complicated given the material that needs to be explained and the contexts in which this explanation needs to occur. Not surprisingly, there are some clear differences amongst the readership of *Positive Living* here:

The majority of readers (96%) who responded to the survey found the language used was simple and easy to understand. A number of people during consultations however still expressed concern about the complicated nature of the material presented and the assumption of a level of technical knowledge required to interpret this information. (Malcolm 1998: 7)

The problem with reporting things this way is that those who experience difficulties are given the same weight as the 96% of readers who expressed ease. This leads almost inevitably to a ‘deficit’ solution that involves adopting a lowest common denominator, readability strategy.

Given the sophistication of considerable sections of the readership a deficit solution would have been a serious error almost guaranteed to lessen readership. What occurred instead was a simple acknowledgment that the readership is segmented, that the large bulk of it appears to like what *Positive Living* does, that some specific changes are useful, but that the bigger issue is how to encourage the reader experiencing difficulties to persevere. Some of this has been addressed directly. A relevant analogy seems to me to be with a television serial in which each episode stands in its own right, even though there are ongoing characters and plot elements from episode to episode. As a viewer one gains in understanding of the ongoing elements the more episodes one watches. One then puts the plot together. This is one way to think about the progressive understanding of medical and scientific information and conceptualisation and is, implicitly at least, what has occurred in *Positive Living*.

What needs to be clearly acknowledged with this analogy is that firstly greater understanding doesn’t automatically bring with it progressively less effort. Rather, the hope is that the pay-off for effort increases and/or that the process of making the effort is itself given value. Secondly, the issues and challenges posed by both the HIV virus and developments in treatments continuously change. There is a constant level of demand involved in being ‘up to date’ that is in a sense separate from any decision about what being sufficiently up-to-date might mean for an individual reader.

4.4.1 Visual style

The visual and linguistic style of *Positive Living* is 'knowing' and self-conscious. That is, it declares its willingness to use tabloid conventions while parodying them. The upshot is that a reader who recognises this is able to situate himself or herself 'inside' a particular speaking position, while a reader who doesn't know this is invited to become part of the game. It's not at all an 'exclusive' strategy and is central to the entertainment value of *PL*, so highly prized by the readership.

On the surface the images act to decentre the 'seriousness' of the articles, and a very small minority of readers react sharply and negatively to this. However I suggest that the images be read as another voice in the text, a voice from popular culture, that gives *Positive Living* consumer credibility, at least amongst urban sub cultures. It's a democratic voice that parallels the 'expert' opinion found in the written text.

The images act more in relation to the headlines than to the articles by foregrounding the 'strangeness' of the conventions in play. They establish a particular kind of campy humour and the consequence is that the first page acts to set up a mode of address that invites the reader to recognise what is going on and to join in.

4.4.2 Exclusion/inclusion

While it could be argued that this 'excludes' those who don't recognise what's going on, I suggest that, when taken in conjunction with the contents' headlines in the right hand column, an ease of access to the speaking position is established. Readers can then choose whether to be engaged by this mode of address, reject or resist it. Note that nothing follows in terms of whether the articles are read. In this sense the style is democratic and 'knows' a PLWHA culture that is simultaneously irreverent, and takes treatments knowledge seriously.

It's not only the readership that is media savvy. These front-page images signify a 'savvy' product that positions itself using the visual aspects of magazine and television culture. This sets up a productive tension with much of the written content, but should not be read simply as 'cover'. Without these tabloid features, the readability of *PL* would change significantly.

The ultimate significance of treatments information for PLWHA makes it difficult for *Positive Living* to 'push' the boundaries of its generic composition further, without risking severely segmented audience responses. While one can argue that 'serious' content is sometimes/often best presented non-seriously, and that *Positive Living* in this sense makes the best of both worlds, it would also seem that it cannot push the boundaries here without threatening its status as a source of credible, treatments information. Testing this proposition would itself be difficult if it involved experimenting radically with *Positive Living's* generic composition. However, it may be possible to formally innovate through greater use of 'infotainment' features such as cross words, vox pops of some substance (a regular write in on a pre-announced issue by issue theme) or homeboy/homegirl type contributions. Features such as these, however, may well have time/resource implications at odds with *Positive Living's* funding, unless there is a commitment to 'commission' material.

The front page is a representation of a particular PLWHA speaking position. *Positive Living* as a whole speaks from inside that position and inducts others into it by reproducing it. There may be some question of its continuing stylistic details and usefulness, given the shifting relations of people with HIV to older established PLWHA cultures, but if nothing else it is historically and culturally informative. It plays an important educative role in allowing for, reinforcing and reproducing a speaking position broader and more mobile than that allowed by an insistence on lowest common denominator plain English or on officially sanctioned medical genres of clinical information.

I would also argue that though campy this mode of address is not by any means equivalent to gay. It has long been a characteristic of Hollywood movies and became a characteristic of current affairs television journalism in the late 1980s (Lumby 1999: 47). In this sense the 'campiness' is available to any audience open to it, irrespective of gender and sexuality. This doesn't mean any individual reader is comfortable with that, and given that HIV is still more or less overtly seen as a 'gay disease' this may pose problems for some PLWHA ill at ease with being associated in any slide from camp to gay. One could argue that in this way *Positive Living* also carries out an anti-discrimination function within HIV positive populations, but perhaps does so at the risk of further alienating the group that is already hardest to reach, heterosexual positive men.

Lumby argues, with some relevance for this discussion of camp, that:

There is some basis for making a broad distinction between upmarket and downmarket media formats, but it's not a division which can tell us in advance how politically or socially valuable a given story is, or how effectively the program or article communicates with its audience. (Lumby 1999: 17)

The problem with Lumby's analysis is that it gives all the ground to a particular understanding of 'information'. It's an understanding that contains several working assumptions; perhaps the most central of which is that all readers read the same piece of information the same way. However there are many ways of understanding, processing and interacting with information narratives, as there are of presenting them. The issue isn't one of how the 'hard' information is checked out, ie the degree of its reliability or accuracy, but rather the fragility of its status as 'information' is itself understated more often than might be expected.

What *Positive Living* points to is the tightness of the boundary between what are considered 'respectable' ways of reporting on scientific and medical information and issues of readability and entertainment. What *Positive Living* demonstrates is that this boundary can be pushed, but that 'expertise' becomes more uncomfortable the more the boundary shifts. At this point, issues of credibility have to be continuously negotiated between two audiences. On the one hand, those 'experts' and people with HIV who are at home with, and prefer, more conventional representations of 'hard science' and, on the other hand, those experts and people with HIV who are more at ease with, and prefer, 'infotainment'.

Cutting across this divide are (a) issues of gender, regional and racial representation and (b) issues of disease management centering on differences between catastrophic and normalising narratives of HIV treatments.

4.5 HIV Living, treatments media and treatments complexity

The stress of an HIV diagnosis has long been researched (Nott 1999). While there is increasing research into ‘the Lazarus Syndrome’, it is largely framed by uncertainty and the different stresses of renegotiating different forms of living (Brashers 1999). This research rarely foregrounds narratives of joy or pleasure vacating the field for drug companies, commentators on lived cultures of gayness (Rofes 1998; Honnor 2000) and/or the relation of an HIV diagnosis to family life and the pathologisers of unhappiness. These processes of research are complicated both by the over-riding awareness that current treatments regimes have unpredictable futures, and the complications of medical best practice in this context (Barr 1998; d’Arminio Monteforte 1998; Smith 2000; van der Horst 2000;). One of many ironies here is that medical best practice is not necessarily what doctors do, and nor is this necessarily a problem (Thompson 2001).

One could argue here that in a more complex treatments environment, in which triple combination therapies were initially announced as a ‘cure’, no totalisation is possible and the multiplicity of stories is consequently harder to represent neatly in a singular HIV positive voice. This is no loss, but it is a challenge. The increasing absence of popular representations is one thing, however there is also the matter of the kinds of narratives found in HIV treatments media and the ways in which uncertainty in the face of unknown treatments efficacy play out there. One of the ways it manifests is in the demand from some readers that media directly reflect each and everyone’s personal experience with prescriptive accuracy.

Treatments media, for example, have to negotiate clinical, quasi-clinical and non-clinical versions of living with HIV. Each of these includes treatments information, but doesn’t automatically ask to be force-read as assuming a narrative of symptomatic disease progression or side effects. HIV positive readers, of course, move in and out of illness, fearing illness, not fearing illness, and not relating much to their diagnoses at all. Their subjectivities are highly mobile, both individually and socially. This leaves little room for fixed modes of address that assume asymptomatic or symptomatic as two fixed poles of experience, framed by an outdated (and always contested) notion that the HIV positive are somehow permanent spectators of their own future morbidity. It was this contestation of HIV as a ‘death sentence’, after all, that produced the notion of ‘living’ with HIV long before the arrival of triple combinations and protease.

The mobility of these subjectivities, and their relation to the moment of diagnosis, in combination with quite different ways of engaging with treatments and treatments information, may explain why, for example, the average age of readers of *Positive Living* is rising and the low number of younger, if not newly diagnosed, HIV positive survey respondents.

In addition, the symptomatic also want non-pathologised narratives. The **first key problem** this raises is of negotiating the common ground between a treatments publication that is seen to speak with scientific reliability and a publication in which

HIV positive people speak for themselves about their lives and experiences of treating. A **second key problem** is doing so in ways that allows several different subjectivities to circulate simultaneously.

Publications such as *Positive Living* are not only faced with conflicting demands from different sectors of those living with HIV but they also have to negotiate conflicting medical best practice, approval processes and the politics of these.

4.6 Gender, media and the notion of a general HIV positive audience

If we fall back on the crudest of essentialist notions of female/male then the women get positioned as neglected nurturers and the men get positioned as selfish grabbers. This singularity of construction produces univocal voices forever in combat. The task is to identify differences as they emerge in practice (eg lack of research on effects of treatments on women, power relations in service provision) and then to analyse them in ways respectful of multiplicity.

My research on *Positive Living* indicated that people with HIV held quite different positions on questions of gender, representation and the needs of different populations.

Some saw treatments as being *partially* population specific:

- “it puts HIV into a wider context ... allows for the magazine to include articles that may pertain to other issues such as HIV/Hep C co-infection”;
- “even so it should be ok to write for just one constituency occasionally where relevant, it shouldn’t be an either or situation”;
- “selfish interest but more specific articles not a turn off”;

Others had a particular understanding of HIV treatments as being largely or totally sexed body neutral:

- “because we all need up to date knowledge to assist us in understanding our virus – this knowledge is not gender or sexuality specific”;
- “the virus is the same”;
- “basic treatments are the same, treatments do not differentiate, people do”;
- “HIV affects all people in a variety of ways and doesn’t necessarily relate to a particular group”;
- “how a person got HIV is history. Treatments is our future. Being straight or gay or needle users refers only really to how we got it”.

The commonality of infection was spoken from a position of unity in difference:

- “I reckon we all learn from reading about each other – the more styles/writers and information content the better” (bisexual male);
- “Coalitions do not blend all ingredients so that the individual ingredients are unrecognisable, rather they celebrate and acknowledge difference. Whilst there are some similarities it is still important to address the specific needs of the different groups. I still read the articles aimed at women or indigenous people, I don’t dismiss them as being irrelevant just because I am gay”;
- “treatments info should be gender/sexuality unbiased where possible. But there should be articles specific to each HIV group as well”;

- “Because gender and sexuality matter in this epidemic, as does practice. I don’t have the same experience of HIV as a straight woman-her needs should not be subsumed under mine” (gay man).

Malcolm’s earlier evaluation is very useful for these discussions. For example,

There were a number of people who found the publication did not reflect their specific needs and wanted a greater focus on certain areas. Consultation highlighted the need for more information on gay men while others wanted the paper to reflect the broad range of needs of people with HIV/AIDS. Of those who responded to the survey [116], 49% wanted more information on gay men, 35% wanted more information on Indigenous issues, 20% on women, and 12% on transgender issues. There was also considerable support for maintaining the same level of information in all these areas.

Almost 94% of respondents to the survey agreed that the magazine was useful in helping them to think about treatments. (Malcolm 1998: 6)

It is common in the HIV sector, as elsewhere, for issues of representation firstly to be polarised, such that general speaking positions are often read politically as ‘white, male, middle class gay’. Secondly, they are pitched against the specific representation of sub cultures (IDU, sex workers) or other HIV affected populations constructed around sex/gender, race, ethnicity and sexual identity. It might be noted that resistant readings are themselves not necessarily ‘representative’ of the speaking position being asserted, but they do have powerful political authority and moral purchase. These latter factors require careful consideration politically and morally and in terms of equity and ownership of community sector publications.

Even more important is a political context in which successive National AIDS Strategies have prioritised specific populations on the basis of advocacy by, or with the support of, community-based HIV/AIDS organisations. Strategic alliances with other parts of the health sector are sometimes at stake, as are fragile coalitions between these populations and subcultures. Goodwill, fairness and justice are seen as having to be constantly demonstrated and publications such as *Positive Living* are implicitly and explicitly required to share the political responsibilities involved.

While these issues complicate discussions of ‘representation’ and ‘representativeness’, there has been no major controversy about them involving *Positive Living*. They do, however, have a definite bearing on how *Positive Living* might meet its brief.

My own survey of the readers of *Positive Living* forced me to step back and think about how strongly an early, politicised PLWHA culture based around inclusion and anti-discrimination is evident-how relevant is it as a form of treatments activism post-protease?-and to ask whether, if cultures of ‘embattlement’ have shifted beyond the HIV media, how much this matters.

For example, gay male respondents were as likely to say be inclusive and respectful of gender and sexual identities as they were to say ‘give us our due’.

And 'give us our due' was never said dismissively, though sometimes it had an exclusivist edge. They were also as likely as not to acknowledge sexed body differences in how treatments and epidemic effects played out. **This combination of generosity and specific interest amongst gay respondents was also symptomatic of female and heterosexual responses.**

Confusion about how to deal with changes in the experience of people with HIV was seen in the assumption that because the virus is common to all groups therefore treatments effects were common. So an initial position of solidarity based on a common virus and social hostility is transposed into an assumption that therefore the experience of treatments is, or ought to be, scientifically and experientially the same, and that treatments information can be related and relayed in the same ways to everyone. This was further complicated by assumptions that social experiences of HIV, particularly when formulated as discrimination, create an identity of experience.

The practical problem is one of how to acknowledge commonality and difference. The price of a PLWHA identity politics often appears to be the effacement of difference, both medical and social. The way out seems to be unity in difference. It's a position that works to the extent that each population is given material specific to it within a more general framework.

But there appear to be three major stresses flowing here, Firstly, effectively an implicit demand by some non-gay people with HIV for equal space for sexed body differences. Secondly, the effacement of gay specific writing which is denied because, abstractly it looks as though the fall back position is gay, and currently dominant, and, verbal discussion of treatments effects is often gay specific in ways that don't appear in the writing. Thirdly, a limited social capacity to accept, and political tolerance for, methods of mediating these tensions that don't consistently foreground gender and sexual identity.

Positive Living has in fact negotiated these currents very well. Major ways of improving this negotiation would be:

- the inclusion of more positive voices, with a consistent practice of making sure these voices come from each of the populations involved;
- resource allocations that make this possible;
- re-working the speaking position/house style of *Positive Living* in ways that include a variety of gay and other sensibilities, but maintain the premium on humour and style. 'Camp' and 50s retro were not gay defined, whatever their origins, and worked extraordinarily well for several years, but their moment has probably passed:
- experiment stylistically and carefully with what might work across varieties of desire relating to hope, to living and to differential relations to treatments and their effects.

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