

HIV cure research: print and online media reporting in Australia

Jennifer Power^{1*}, Bianca Fileborn^{1,2}, Gary W Dowsett^{1,3}, Jayne Lucke^{1,4}, Graham Brown^{1,3}, Jeanne Ellard¹, Sharon R Lewin^{5,6}, Joseph D Tucker^{7,8}, Sean Slavin³, Jeremy Sugarman^{9,10} and Sophie Hill¹¹

¹ Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

² School of Social Sciences, University of NSW, Sydney, Australia

³ Centre For Social Research in Health, University of NSW, Australia, Sydney

⁴ UQ Centre for Clinical Research, The University of Queensland, Brisbane, Australia

⁵ The Peter Doherty Institute for Infection and Immunity, University of Melbourne and Royal Melbourne Hospital, Melbourne, Australia

⁶ Department of Infectious Diseases, Alfred Health and Monash University, Melbourne, Australia

⁷ UNC Project-China, University of North Carolina, Guangzhou, China

⁸ University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

⁹ Berman Institute of Bioethics, Johns Hopkins University, Baltimore, MD, USA

¹⁰ Department of Medicine, School of Medicine, Johns Hopkins University, Baltimore, MD, USA

¹¹ Centre for Health Communication and Participation, School of Psychology and Public Health, La Trobe University, Melbourne

Abstract

Objectives: While still in its early stages, recent scientific research towards a cure for HIV has generated widespread media interest. The aim of this paper was to explore the ways in which this research has been represented in Australian print and online media and discuss implications of this.

Methods: A search of databases from four selected media outlets was conducted to identify published articles that directly discussed HIV cure research. Content analysis was used to explore the discursive framing of HIV cure research and identify the presence or absence of people living with HIV in articles.

Results: In total, 95 articles were identified that had been published in print or online between 2007 and 2015. Media reports tended to focus on research breakthroughs or the future potential of HIV cure research, rather than more immediate implications of research findings. While not inaccurate, this focus often implied the field of HIV cure research was more advanced than was generally the case. There was a notable absence of commentary from people living with HIV or community advocates in media reporting.

Conclusions: Media reporting may generate unrealistic expectations of HIV cure research. This raises ethical concerns that media reporting may inadvertently contribute to therapeutic or curative misconceptions among potential participants in HIV cure-related trials. To address this, scientists, HIV advocates and people living with HIV will need to work collaboratively to engage with reporters and media outlets to provide more consistent input and guidance into reporting about research towards a cure for HIV.

Keywords: HIV cure, media reporting, HIV cure clinical trials, discourse analysis, HIV cure language, therapeutic misconception

Introduction

In recent years, there has been increasing scientific interest in research directed towards curing HIV. While this research is in relatively early stages, the prospect of a possible cure for HIV has generated widespread media attention, often in response to high-profile patient cases, most notably Timothy Brown (originally described as the Berlin patient, the only patient cured of HIV) and the Mississippi child who, following early antiretroviral treatment, had a period of prolonged HIV suppression while off treatment [1,2]. Media attention on HIV cure research raises a number of questions about the nature and influence of reporting. Does it accurately represent HIV cure research, and in what ways is cure research being represented? To what extent is media reporting likely to generate unrealistic expectations of this research? This paper addresses these gaps in knowledge through an analysis of recent media reporting on HIV cure research in Australian online and print media.

HIV in the media

Reporting on biomedical and scientific research comprises a large component of media reporting related to HIV and AIDS. Yet, this has sometimes been marked by recklessness or hyperbole [3]. For instance, writing about the US media's response to the introduction of highly active antiretroviral therapy (HAART) in the mid-1990s, Cohen [4] noted that any efforts to describe caveats or caution

in media reporting was over-ridden by accompanying exaggeration or oversimplification of complex research:

A casual browser of recent newsstands might conclude that AIDS is now all but cured. Last fall, the *New York Times Magazine* featured a cover story headline 'When AIDS Ends.'

Cohen observed that this hyperbole had potentially serious implications, ranging from a loss of public faith in medical science to setting unrealistic expectations among people living with HIV (PLHIV) at a time when the long-term impact of HAART was not yet clear [4].

The concerns observed by Cohen in relation to HAART could similarly be applied to research towards a cure for HIV. There is potential for media reporting to misrepresent the likelihood of a cure being imminently available simply by giving prominence to stories of scientific advances or successes with individual patients, most notably Timothy Brown [1,2].

Media reporting is a key conduit through which many stakeholders, including advocates, policy makers and funders, learn of the successes and constraints of current research towards an HIV cure [5]. While unrealistic representations of success or advancement may undermine trust in the research, the media are also a means through which optimism and enthusiasm for such research is generated. A lack of optimism, which may occur if there were no media reporting on HIV cure research, may undermine support and funding for future research. Hence, there is a delicate balance between optimism and caution that researchers and advocates may try to communicate through the media.

*Corresponding author: Jennifer Power, 215 Franklin Street, Melbourne, Victoria 3000, Australia
Email: jennifer.power@latrobe.edu.au

The language of HIV cure research

A complexity in the media presentation of HIV cure research is ambiguity in the term ‘cure’ itself. Within the scientific community, there is limited consensus on the most appropriate terminology to use in the presentation and promotion of research towards an HIV cure. Scientists previously sought to distinguish between a ‘functional cure’ (long-term viral suppression while off treatment) and a ‘sterilising cure’ (eradication of the virus within an individual). More recently, the term clinical ‘remission’ has been suggested as appropriate [6]. However, it is difficult to identify or promote a suitable alternative to the term ‘HIV cure’ given the apparent simplicity of these two words. Even in this article we have used these terms with limited critical reflection, in part because they offer a straightforward description of this body of research and its aims. For the same reasons, complex discussions on the social or scientific implications of cure terminology are not easily incorporated into media stories [2].

People living with HIV in media reporting

The presence or absence of people living with HIV (PLHIV) in media reporting on HIV has long been a focus of community advocacy. When HIV first emerged in the 1980s, there was significant media misrepresentation of people affected by HIV infection and its mostly fatal sequelae at that time, AIDS – reports that fuelled discrimination against gay men particularly [7,8]. In Australia and other Western countries, advocates recognised that the best way to change reporting was to ensure that PLHIV had a voice and presence in media accounts to demonstrate their humanity and challenge discriminatory perceptions. A major focus of advocacy since this time has been building relationships with journalists to ensure they consult PLHIV on issues relating to HIV, including scientific and clinical issues [9].

Inclusion of PLHIV in media reporting about research towards an HIV cure would be an accurate representation of the role PLHIV currently play in scientific research as advocates, advisors, participants and educators [10,11]. Beyond this, PLHIV advocacy agencies are a major force in the promotion of public and financial support for HIV research. These individuals and agencies also build community preparedness for clinical trials by endorsing research and generating interest within affected communities. Without a presence in media reporting on HIV cure research, the roles played by PLHIV and HIV advocates in this field, and their perspectives on it, are not broadly visible.

Aims of this paper

This paper reports on an analysis of recent media reporting on HIV cure research in the Australian media. The Australian context provided a useful opportunity to conduct this research given Australia was one of the first countries to implement interventional studies towards an HIV cure, which captured media attention [12]. Australian and international cure research also received considerable attention from the Australian media during the international *AIDS 2014* conference hosted in Melbourne [13,14]. Alongside this, Australian community-based PLHIV agencies have for many years actively sought to influence the way HIV-related issues are represented in the media. They have achieved this by building strong relationships with media agencies and individual reporters. The Australian Federation of AIDS Organisations, the peak non-government agency in this sector, also publishes media guidelines that are routinely updated and currently include recommendations for reporting on HIV cure research [15]. Given this, Australian journalists and editors are likely to be attuned to issues relating to the representation of PLHIV in reporting. Yet, it is not known how much this has been incorporated into reporting

on HIV cure research – hence our study. The aims of this analysis were to: (1) identify the language used to discuss advances in HIV cure research in media reports; and (2) examine the representation of PLHIV in these reports.

Methods

This project is part of a broader study on the social and ethical consequences of HIV cure research, for which ethics approval was granted by the La Trobe University College of Science, Health and Engineering Human Research Ethics committee (S15-152) and the Victorian AIDS Council (VAC/REP 15/002).

The focus of this analysis was the mainstream media as well as the lesbian, gay, bisexual, and transgender (LGBT) community media. Mainstream media were included as these are widely read and well established sources of print and online news media in Australia. LGBT community media were included as these are important sources of information about HIV for affected communities as the Australian HIV epidemic is largely concentrated among gay and bisexual men.

Four major Australian media companies were selected for inclusion in this study because they represented a cross-section of Australian mainstream and LGBT publications. The outlets were:

- **Fairfax Media**, which publishes three major Australian daily morning newspapers along with other specialised print and online news sources;
- **News Corp**, which publishes a national print newspaper along with a range of state-based publications, complemented by the news website www.news.com.au;
- **The Star Observer**, which is a national publication targeting LGBT communities, published as a monthly print magazine and online; and
- **Gay News Network (GNN)**, which is a national network of print and online LGBT publications.

Fairfax and News Corp publish newspapers in all major Australian cities and use contrasting styles of reporting and tone, with News Corp generally reflecting more conservative values than Fairfax publications [16]. The Star Observer and GNN are the major LGBT community media outlets.

As each of these companies publishes complementary online and print versions of their major news publications, we limited our searches to one online publication from each company:

- *Sydney Morning Herald* (Fairfax)
- news.com.au (which includes News Corp articles from the *Herald Sun*, *The Australian*, the *Courier Mail* and the *Daily Telegraph*)
- *The Star Observer*; and
- *Melbourne Community Voice* (MCV) (GNN).

Search strategy

In August 2015, an electronic search using the search function of each media outlet was conducted using the search terms: HIV Cure, HIV [AND] research, Timothy Brown, Berlin patient, Mississippi Baby, and HIV remission. A search was also conducted of the Factiva [17] news database, limited to Australian publications, using the same search terms. As we were interested in the moment at which HIV cure articles began to be published in the media, the search was not limited by date of publication, although it was implicitly limited by the point at which these outlets began online publication. The *Sydney Morning Herald* site lists articles published from 1994/1995 onwards. The other sites list articles published in the 2000s.

Articles were included in the sample if they were from one of the identified news sources and referred to research aimed at increasing understanding of possible pathways towards a cure for HIV, including articles that used terms other than cure, such as long-term HIV suppression or remission. Articles were excluded from the sample if they were not directly focused on HIV cure research. For example, there were a number of articles on HIV vaccine research that were excluded unless they explicitly made reference to therapeutic vaccines that may form part of HIV cure research. Other articles were excluded because they only mentioned HIV cure in passing. In the final sample, 95 articles were identified in the four media outlets as follows:

- Fairfax/*Sydney Morning Herald*: 25 articles published between 2009 and 2015.
- News Corp/news.com.au: 43 articles published between 2007 and 2015 (although only one was published in 2007, with no further reporting on HIV cure until 2010).
- *Star Observer*: 17 articles published between 2010 and 2015.
- *MCV*: 10 articles, published between 2013 and 2015.

The headlines and publication details for articles included in this analysis are listed in Table 1. Twenty-four (25%) articles were from international media sources such as Agence France-Press (AFP), the Associated Press (AP), Reuters or non-Australian newspapers such as the *Washington Post* (US) or the *Telegraph* (UK). These were included in the analysis as they formed an important part of the overall presentation of HIV cure research in the Australian media.

Analysis

We conducted a content analysis of the articles. This involved inductive thematic analysis in which dominant and recurrent themes were identified in the text [18,19]. We did not use a coding frame or identify *a priori* themes; rather, we took an open approach designed to identify core themes present in the text. All analyses were conducted manually. Following thematic analysis, researchers undertook a close textual reading of each article, paying attention to the symbolic or cultural significance of language used. The role or position of individuals quoted or profiled in the articles was recorded. We also examined each article to identify where, and in what context, PLHIV were quoted, consulted or profiled. Two researchers (BF and JP) independently analysed the text and compared findings as a process of identifying the ‘blind spots’ that each researcher brought to the texts.

Given our analytical focuses on language, it is important to remark upon our own use of language in this paper. For ease of reading, in this paper we use the term ‘HIV cure research’ as shorthand for research that would be more accurately represented by terms such as ‘research directed towards a possible HIV cure’ or ‘research towards an HIV cure’.

Results

The results presented below outline key themes that emerged from the analysis including the discursive framing of HIV cure research and the absence or presence of PLHIV in media reports.

The language of cure

Although we searched broadly for articles that referred to relevant scientific research related to HIV cure, including ones that used terms such as ‘remission’ rather than ‘cure’, there were few articles in which the term ‘cure’ did not feature prominently. The majority of articles ($n=67$, 70%) used the term ‘cure’ in the headline. This was consistent over the timespan of included articles (2007–2015), for example:

New HIV cure hope [20]; and

Have scientists finally found a cure for HIV positive children? [21].

There was some nuance in this. For instance, in some headlines the word cure appeared in quotation marks, suggestive of cure holding an uncertain status: ‘Stem cell transplant “cures” HIV: study’ [22]. In other articles, the term cure was posed as a question: ‘First man cured of HIV?’ [23]. Despite this, the term was generally positioned uncritically in article text, with limited interrogation of what a cure for HIV would or could look like. For instance, in articles relating to the Mississippi baby/child, the terms ‘remission’ and ‘cure’ were often conflated or confused in a way that suggests readers would be unlikely to understand the difference, for example:

A three-year-old girl treated for HIV shortly after birth and still without sign of infection is evidence her apparent cure wasn’t a fluke, US researchers say ... The story of the first child known to have been cured of HIV through early treatment with powerful doses of antiretroviral drugs – what researchers call ‘sustained remission’ rather than a cure – was initially announced in March [24].

Cure as inevitable and imminent

In many articles, HIV cure research was represented as the most significant advance in HIV science in 30 years and many articles referred to study findings as a major ‘breakthrough’: ‘Breakthrough boosts hope for HIV cure’ [25]. This tended to be accompanied by language that alluded to a new wave of ‘hope’ and ‘optimism’ for a cure: ‘New hope for HIV cure’ [26]. The notion that cure research was generating breakthroughs had the effect of underplaying the preliminary nature of the research. Although it was usually mentioned that research was in its early stages, this often occurred within the detail of the article, while the opening paragraphs focused on the link between research findings and cure, for example: ‘An American man is still HIV-free more than three years after receiving a stem cell transplant, suggesting the first cure has been found for the virus that causes AIDS ...’ [22]. Reporting also often presented cure as inevitable, using terms like ‘will’ lead to a cure: ‘Melbourne scientists have made a major breakthrough they believe will lead to a cure for HIV’ [27]. This tended to minimise the ‘messiness’ or more uncertain and complicated nature of most scientific research.

Mitigating hyperbole

In reporting on new research, 55 articles (81%) in the mainstream press included quotations or commentary from at least one medical scientist [28–30], with some locally authored articles including interviews with local scientists to comment on international research findings. This figure was lower in the LGBT community press, with eight of the 17 (47%) including quotations from medical scientists. This was generally because articles were short and incorporated brief overviews of press statements without using quotations.

Interviews with researchers and scientists added a sense of legitimacy to articles. Many quotations from scientists also appeared to be an effort, on their behalf, to reduce potential for hyperbole or misinformation.

‘Three years is not enough... We will know that in 10 years,’ said Levy regarding the study’s assertion that a cure has been found. [22]

Table 1. Article headlines and news sources related to HIV cure in Australian media, 2007–2015

Year	Headline	Publisher	Original authorship/source
2007	Possible HIV cure found	News Corp/Perth Now	AFP
2009	Brain missing link to HIV cure	Star Observer	Star Observer
2009	HIV cure 'more promising than vaccine'	Fairfax/Sydney Morning Herald	Fairfax
2010	Berlin Patient' is still free of HIV three years after deadly stem cell transplant	News Corp/news.com.au	AFP
2010	Blood transplant cures AIDS patient of virus	News Corp/The Australian	News Corp
2010	Experts 'blown away' by HIV cure case	Fairfax/Sydney Morning Herald	AAP
2010	First man cured of HIV?	Star Observer	Star Observer
2010	New hope for HIV cure	Star Observer	Star Observer
2010	Optimism on AIDS cure before 2020	Fairfax/Sydney Morning Herald	Fairfax
2010	Stem cell transplant 'cures' HIV: study	Fairfax/Sydney Morning Herald	Fairfax
2010	Transplant may have cured man of AIDS	News Corp/news.com.au	AP
2010	Understanding HIV's infectious grip	Fairfax/Sydney Morning Herald	Fairfax
2011	Can green-glowing cats find a cure for AIDS?	Fairfax/Sydney Morning Herald	Reuters
2011	First man cured of HIV	Star Observer	Star Observer
2011	Fluro cats key to HIV cure?	Star Observer	Star Observer
2011	Gecko at risk over claims it can cure AIDS	News Corp/Daily Telegraph	AP
2011	Gene therapy raises hope for a future AIDS cure	Fairfax/Sydney Morning Herald	Fairfax
2011	High hopes of HIV cure by injection, treatment may only take month	News Corp/Herald Sun	News Corp
2011	HIV breakthrough?	Star Observer	Star Observer
2011	Hope for a cure	Star Observer	Star Observer
2011	Hope for HIV treatment as scientists boost immune system	Fairfax/Sydney Morning Herald	AAP
2011	Hoping for a HIV cure	Star Observer	Star Observer
2011	Mouse clears HIV-like virus	Fairfax/Sydney Morning Herald	AAP
2011	New HIV cure hope	Star Observer	Star Observer
2012	AIDS cure may have two main pathways	News Corp/news.com.au	AAP
2012	Aussie research part of HIV cure effort	News Corp/The Australian	AAP
2012	Being cured of HIV is 'wonderful'	News Corp/Daily Telegraph	AAP
2012	Cancer drug flushes out lurking AIDS virus	News Corp/news.com.au	AAP
2012	Cure research points way to HIV control	News Corp/Herald Sun	AAP
2012	Human trials for potential HIV stem cell cure	News Corp/news.com.au	AAP
2012	New hope in search for 'functional cure' for AIDS	Fairfax/Sydney Morning Herald	Washington Post
2012	Nobel winner says AIDS cure could come by 2050	News Corp/Herald Sun	AFP
2012	Survivors driving hope of AIDS cure	News Corp/The Australian	AFP
2012	Timothy Brown was 'cured of HIV' and is still healthy five years on	News Corp/news.com.au	AP
2012	Trials for stem-cell HIV cure	News Corp/The Australian	News Corp
2013	AIDS breakthrough: Melbourne researchers uncover HIV's genetic hiding place	News Corp/The Australian/Herald Sun	News Corp
2013	American doctors announce two patients overcome HIV	Star Observer	Star Observer
2013	Breakthrough boosts hope for HIV cure	Fairfax/Sydney Morning Herald	Fairfax
2013	Chink in the armour	Fairfax/Sydney Morning Herald	Fairfax
2013	Danish breakthrough for HIV cure expected 'within months'	Fairfax/Sydney Morning Herald	Telegraph (UK)
2013	Danish HIV breakthrough	Star Observer	Star Observer
2013	First baby cured of HIV	Star Observer	Fairfax
2013	First HIV infant cured with cocktail of drugs	Fairfax/Sydney Morning Herald	Bloomberg
2013	HIV baby cured at 30 hours	Fairfax/Sydney Morning Herald	New York Times
2013	HIV cure gets closer with drug: experts	News Corp/news.com.au	AAP
2013	HIV gets a wake-up call	Star Observer	Star Observer
2013	HIV mutation lights way to a cure for AIDS	News Corp/The Australian	News Corp
2013	HIV newborn results give scientists heart	News Corp/The Australian	AFP
2013	HIV returns in two US men after bone marrow transplants	News Corp/news.com.au	AFP

Table 1. Continued

Year	Headline	Publisher	Original authorship/source
2013	Ideas that could change your life	Fairfax/Sydney Morning Herald	Fairfax
2013	Is this a cure for HIV? (video)	Fairfax/Sydney Morning Herald	Fairfax
2013	Monkey vaccine key to HIV cure	News Corp/The Australian	News Corp
2013	New HIV 'cure' still 'far, far away'	Star Observer	Star Observer
2013	New research boosts search for AIDS cure	News Corp/The Australian	AAP
2013	Queensland researcher David Harrich develops gene therapy which could stop HIV from turning deadly	News Corp/Courier Mail	News Corp
2013	Research shows encouraging results	Star Observer	Star Observer
2013	Researchers move step closer to finding cure	Fairfax/Sydney Morning Herald	Fairfax
2013	Scientists say baby born with HIV 'cured'	news.com.au	AP
2013	Stem cell transplant cures two US men of HIV	MCV	GNN
2013	Two men cleared of HIV infection after bone marrow transplants	News Corp/The Australian	AFP
2013	US baby in 'permanent remission' after antiviral treatment for HIV AIDS	News Corp/news.com.au	AFP
2014	AIDS 2014: cancer-fighting drug leads to HIV treatment breakthrough	Star Observer	Star Observer
2014	AIDS 2014: towards a cure	MCV	GNN
2014	AIDS cure a possibility	News Corp/Herald Sun	News Corp
2014	Anti-cancer drug wakes up HIV in hiding	News Corp/news.com.au	AAP
2014	Baby born in Los Angeles with HIV 'in remission'	News Corp/news.com.au	AP
2014	Baby girl 'cured of HIV' sees infection return ... but there's still hope	News Corp/news.com.au	AFP
2014	Cancer drug 'wakes up' HIV so immune system can kill it, trial shows	News Corp/Herald Sun	News Corp
2014	Cure for HIV 'major priority'	MCV	GNN
2014	Ending HIV: the kick and kill approach may prove a breakthrough to cure	MCV	GNN
2014	Four babies born with HIV 'cured', fuelling hopes of AIDS vaccine	News Corp/Herald Sun	News Corp
2014	French scientists find genetic mechanism by which two men were spontaneously cured of HIV	News Corp/news.com.au	AFP
2014	Fresh setback for efforts to cure HIV	News Corp/news.com.au	AAP
2014	Girl 'cured' of HIV has virus again, scientists say	Fairfax/Sydney Morning Herald	AFP
2014	HIV 'cleared' in two Australian men after bone-marrow transplants	Fairfax/Sydney Morning Herald	Fairfax
2014	HIV 'cure' girl is showing signs she still has the virus	News Corp/The Australian	AP
2014	HIV research: cancer drug breakthrough in 'kicking' disease out of hiding place	Fairfax/Sydney Morning Herald	Fairfax
2014	HIV researchers hopeful of a cure, but say long-term remission' more likely	Fairfax/Sydney Morning Herald	Fairfax
2014	How to find trustworthy information on HIV treatment in news media	MCV	GNN
2014	Long journey to cure AIDS peeks at a shortcut	News Corp/Herald Sun	News Corp
2014	Milan baby relapses into HIV	MCV	GNN
2014	Mississippi baby a stepping stone to AIDS cure (video)	Fairfax/Sydney Morning Herald	Fairfax
2014	Scientists find genetic mechanism they believe spontaneously cured two men of HIV	Fairfax/Sydney Morning Herald	AFP
2014	Two Australian men 'clear' of HIV after new treatment	Star Observer	Star Observer
2014	Two cancer patients 'cured' of AIDS after bone marrow transplants	News Corp/The Australian	News Corp
2014	Years for AIDS cure, conference told	News Corp/news.com.au	AAP
2015	WA discovery 'could lead to HIV cure'	News Corp/The Australian	News Corp
2015	Have scientists finally found a cure for HIV positive children?	Fairfax/Sydney Morning Herald	Fairfax
2015	HIV cure a possibility and hopes for an AIDS free generation by 2030	MCV	GNN
2015	HIV-positive people willing to take risks to find a cure	MCV	GNN
2015	International HIV/AIDS conference reports new modes of attack	MCV	GNN
2015	Kim Jong-Un claims North Korea has found cure for AIDS, other viral diseases	News Corp/news.com.au	AP
2015	Man who beat AIDS says he's still cured	News Corp/news.com.au	AFP
2015	Teen in remission from HIV 12 years after stopping meds	News Corp/news.com.au	AP
2015	Why curing HIV is so difficult	MCV	GNN

AFP: Agence France-Presse (international); AAP: Australian Associated Press; AP: Associated Press (international); GNN: Gay News Network.

It was comments such as this that provided the main balance to articles, which, as mentioned previously, often overexaggerated the likelihood of an HIV cure becoming available soon.

People living with HIV

While scientists were generally afforded a high profile in media articles, there was a noticeable absence of PLHIV or HIV advocacy organisations in the mainstream (non-LGBT) media. Of the 68 articles that had been published in the mainstream press, there were four (6%) that included quotes from Timothy Brown and two (3%) that included quotes from PLHIV. One of these articles included a brief interview with an Australian clinical trial participant. In the LGBT media, it was common for articles – particularly those reporting new research findings – to include some commentary from HIV advocacy organisations (22%). In two articles, the LGBT press reported on media statements released by local HIV advocacy agencies in response to new HIV cure research. However, the majority of LGBT media articles did not include commentary from PLHIV or advocacy agencies. While all of these articles had local authorship, many appeared to have sourced content from international press releases, with limited additional research or commentary.

Discussion

Writing on the ethics of ‘talking’ about HIV cure, Rennie and colleagues pose the question, ‘Why does language *morally* matter when it comes to HIV cure?’ [2]. Ethical concerns about the discursive framing of HIV cure research relate to the role that language plays in generating unrealistic expectations of research outcomes, which may have adverse psychosocial consequences for PLHIV and other affected communities [1,2,31] and/or generate misconceptions about the therapeutic benefits of participation in a research trial [32,33]. Many media articles reviewed here implied that research was more advanced than was generally the case. This was mainly produced through subtle uses of language that misrepresented research. For instance, the preliminary nature of HIV cure research was often overshadowed by language emphasising major breakthroughs or the (much) longer-term possible outcomes of the research; namely, a cure. In addition, a large number of articles reported on cases of individuals thought to be cured of HIV, such as Timothy Brown and the Mississippi child (the ultimate outcome of that case, in which treatment for HIV eventually needed to be administered, notwithstanding). Across this breadth of media reporting, a picture emerges of a cure for HIV being imminently *possible*, a perception that could ultimately contribute to therapeutic misconception among potential trial participants [32]. Recent qualitative research has also identified low levels of understanding about HIV cure research among PLHIV and other stakeholders, including potential clinical trial participants, as an issue that warrants further attention in research and ethical consent processes [34].

Nevertheless, there was evidence in these findings that scientists and researchers have the capacity to influence media reporting on HIV cure research. The amount of media space dedicated to quotations from scientists and researchers is notable. Scientists were often given opportunities to assert the importance of restraint in predicting when or if an HIV cure is likely to become available. Given this, ensuring scientists have well-considered ‘soundbites’ to deliver media messages may be key to moderating the potential for media misrepresentation of HIV cure research.

An important finding from this study was the absence of PLHIV voices. As mentioned earlier, the Australian HIV community sector has been active in building relationships with journalists and providing reporting guidelines that encourage inclusion of PLHIV

in media reporting on HIV related issues [9,15]. Therefore, the absence of PLHIV from reporting on HIV cure research is not reflective of current levels of engagement of PLHIV and community advocates in HIV cure research [11,35]. Given much media reporting on HIV cure research is sourced from international press agencies, it may require a co-ordinated international effort by key organisations to direct media towards PLHIV advocates for commentary.

Our findings should be considered with several limitations in mind. First, while we aimed to conduct a comprehensive search for articles, it is possible that we missed some media reporting on research related to HIV cure. Second, we did not examine social media where there is extensive, and often less formal, discussion related to HIV cure. Unfortunately, the breadth and volume of information on social media would have required a separate and substantial analysis that was beyond the scope of the resources available for this project [36]. Finally, our findings could have been placed in a more comprehensive context through a comparison of HIV cure media reporting with reporting on other comparable research, such as cancer treatment research. This was, however, beyond the scope of this study.

Conclusions

We analysed Australian media reporting about HIV cure research and concluded that the presentation of research findings in the media may generate unrealistic expectations. This may be particularly problematic if potential trial participants develop misconceptions about the therapeutic benefits of participation in HIV cure research trials. Unrealistic expectations may also create disappointment or resentment among community members. These concerns are important and warrant further examination, particularly from the point of view of PLHIV.

Importantly, however, we found that scientists can, and do, play a role in moderating media hyperbole though carefully considered commentary. This point underscores the responsibility of scientists to understand how the media operate and to adopt strategies that effectively communicate both significant findings and limitations of research. Facilitating the inclusion of the views of PLHIV in media reporting may also help to present a more nuanced picture of the social impact of HIV cure science. PLHIV have the capacity to provide insight into the potential personal and social benefits of a cure for HIV – encouraging interest and enthusiasm for cure science – while also offering critical commentary on the emotional or psychological impact of generating false hopes for a cure, thus moderating potential exaggeration in media reporting. Involvement of PLHIV is also an important part of attending to the ‘Greater Involvement of People with HIV/AIDS’ principles [37]. Achieving such involvement, however, will require deliberate action on behalf of the scientific community (both locally and internationally) as well as PLHIV and advocacy agencies to present a public image of HIV cure research as a collaborative endeavour. The media also has an important part to play in responsible reporting of new research findings and the possible implications for PLHIV. Partnerships between scientists, PLHIV and media representatives would productively generate training and guidelines in responsible reporting on HIV cure science.

Acknowledgements

This work was supported by a seeding grant from the La Trobe University, Building Healthy Communities Research Focus Area. This project was supported by the Australian Federation of AIDS Organisations (AFAO) and the National Association of People with HIV Australia (NAPWA). SL is supported by the National Institutes of Health Delaney AIDS Research Enterprise (DARE) to find a cure

(U19 AI096109), the American Foundation for AIDS Research, and the National Health and Medical Research Council (NHMRC) of Australia. JT is supported by the National Institutes of Health (1R01AI08366-01). SL is an NHMRC practitioner fellow.

Competing interests

The authors have no competing interests to declare.

Authors' contributions

JP, GD, JL, GB, SL, JT conceived and designed the broader study of which this analysis is part. BF, JP, GD, JL and GB designed the media analysis strategy. BF and JP conducted the media analysis. JP, BF, GD, JL, JE, JT, JS and SH participated in discussions regarding preliminary findings and directions for the secondary analysis. JP and BF drafted the manuscript. All authors critically reviewed and revised the article for key intellectual content.

References

- Dubé K, Henderson GE, Margolis DM. Framing expectations in early HIV cure research. *Trends Microbiol* 2004; **22**: 547–549.
- Rennie S, Siedner M, Tucker JD, Moodley K. The ethics of talking about 'HIV cure'. *BMC Med Ethics* 2015; **16**: 1–8.
- Swain KA. Approaching the Quarter-Century Mark: AIDS Coverage and Research Decline as Infection Spreads. *Crit Studies Media Commun* 2005; **22**: 258–262.
- Cohen J. The media's love affair with AIDS research: hope vs. hype. *Science* 1997; **275**: 298–299.
- Grossman CI, Ross AL, Auerbach JD *et al*. Towards multidisciplinary HIV-cure research: integrating social science with biomedical research. *Trends Microbiol* 2016; **24**: 5–11.
- Tucker JD, Volberding PA, Margolis DM *et al*. Words matter: Discussing research towards an HIV cure in research and clinical contexts. *J Acquir Immune Defic Syndr* 2014; **67**: e110–111.
- Seidman S. *AIDS and the Discursive Construction of Homosexuality*. Cambridge: Cambridge University Press; 1998.
- Lupton D. Moral threats and dangerous desires: AIDS in the news media. In: Lupton D, ed. *Risk and Sociocultural Theory: New Directions and Perspectives*. Cambridge, Cambridge University Press, 1994.
- Power J. *Movement, Knowledge, Emotion: Gay Activism and HIV/AIDS in Australia*. ANU E Press; 2011.
- Harrington M. Community involvement in HIV and tuberculosis research. *J Acquir Immune Defic Syndr* 2009; **52**: S63–S66.
- Lo Y-R, Chu C, Ananworanich J *et al*. Stakeholder engagement in HIV cure research: lessons learned from other HIV Interventions and the way forward. *AIDS Patient Care STDs* 2015; **29**: 389–399.
- news.com.au. HIV cure gets closer with drug: experts. newscomau 4 March, 2013. Available at: www.news.com.au/national/breaking-news/hiv-cure-gets-closer-with-drug-experts/story-e6frfku9-1226589803350 (accessed September 2017).
- Medew J. HIV 'cleared' in two Australian men after bone-marrow transplants. Sydney Morning Herald July 19, 2014. Available at: www.smh.com.au/national/hiv-cleared-in-two-australian-men-after-bonemarrow-transplants-20140718-zuizm.html-ixzz48sfNRF3F (accessed September 2017).
- McLennan L. Years for AIDS cure, conference told. newscomau 21 July 2014. Available at: www.news.com.au/national/breaking-news/years-for-aids-cure-conference-told/news-story/08f7c8d72bb73eda3dcbf04ca9661e1b (accessed September 2017).
- Australian Federation of AIDS Organisations. *The HIV Media Guide* Sydney Australian Federation of AIDS Organisations, 2015. Available at: www.hivmediaguide.org.au/ (accessed September 2017).
- Homes D. News Corp: it's not a conspiracy ... it's just business. The Conversation 5th September 2013. Available at: theconversation.com/news-corp-its-not-a-conspiracy-its-just-business-17867 (accessed September 2017).
- Factiva Dow Jones. Proquest. 2016. Available at: www.proquest.com/ (accessed September 2017).
- Lupton D. Archetypes of infection: people with HIV/AIDS in the Australian press in the mid 1990s. *Social Health Illness* 1999; **21**: 37–53.
- Lupton D. Discourse analysis: a new methodology for understanding the ideologies of health and illness. *Austral J Public Health* 1992; **16**: 145–150.
- Star Observer. New hope for HIV cure. Star Observer 6 October 2011. Available at: www.starobserver.com.au/news/local-news/new-south-wales-news/new-hope-for-hiv-cure/31534 (accessed).
- Medew J. Have scientists finally found a cure for HIV positive children? Sydney Morning Herald. 21 July, 2015. Available at: www.smh.com.au/victoria/have-scientists-finally-found-a-cure-for-hiv-positive-children-20150720-gigal3.html (accessed September 2017).
- Sheriden K. Stem cell transplant 'cures' HIV: study. Sydney Morning Herald. 16 December 2010. Available at: www.smh.com.au/breaking-news-world/stem-cell-transplant-cures-hiv-study-20101216-18yft.html (accessed September 2017).
- Potts A. First man cured of HIV? Star Observer. 2010. Available at: www.starobserver.com.au/news/local-news/new-south-wales-news/first-man-cured-of-hiv/40138 (accessed September 2017).
- news.com.au. US baby in 'permanent remission' after antiviral treatment for HIV AIDS. 24 October, 2013. Available at: www.news.com.au/world/us-baby-in-permanent-remission-after-antiviral-treatment-for-hiv-aids/news-story/1a211bcda5f7fe6dd828473a0b057664 (accessed September 2017).
- Medew J. Breakthrough boosts hope for HIV cure. Sydney Morning Herald. 3 July 2013. Available at: www.smh.com.au/world/breakthrough-boosts-hope-for-hiv-cure-20130703-2pbr0.html (accessed September 2017).
- Noonan A. New HIV cure hope? Star Observer. 9 February, 2011. Available at: www.starobserver.com.au/news/new-hiv-cure-hope/44063 (accessed September 2017).
- Betts M. High hopes of HIV cure by injection, treatment may only take month. Herald Sun. 3 February 2011. Available at: www.heraldsun.com.au/news/victoria/high-hopes-of-hiv-cure-by-injection-treatment-may-only-take-month/story-e6frf7kx-1225999810530 (accessed September 2017).
- Botelho A. New hope in search for 'functional cure' for AIDS. Sydney Morning Herald. 28 July 2012. Available at: www.smh.com.au/world/new-hope-in-search-for-functional-cure-for-aids-20120727-22zmi.html-ixzz49RwSnDGI (accessed September 2017).
- Medew J. HIV researchers hopeful of a cure, but say 'long-term remission' more likely. Sydney Morning Herald. 21 July 2014. Available at: www.theage.com.au/victoria/hiv-researchers-hopeful-of-a-cure-but-say-long-term-remission-more-likely-20140721-zvac0.html-ixzz43E7Hfb6x (accessed September 2017).
- Medew J. Have scientists finally found a cure for HIV positive children? Sydney Morning Herald. 21 July, 2015. Available at: www.smh.com.au/victoria/have-scientists-finally-found-a-cure-for-hiv-positive-children-20150720-gigal3.html (accessed September 2017).
- Peay HL, Henderson GE. What motivates participation in HIV cure trials? A call for real-time assessment to improve informed consent. *J Virus Erad* 2015; **1**: 51–53.
- Staunton C. Informed consent for HIV cure research in South Africa: issues to consider. *BMC Medical Ethics* 2015; **16**: 3.
- Sugarman J, Paasche-Orlow M. Confirming Comprehension of Informed Consent as a Protection of Human Subjects. *Journal of General Internal Medicine* 2006; **21**: 898–899.
- Dubé K, Taylor J, Sylla L *et al*. 'Well, it's the risk of the unknown ... right?': A qualitative study of perceived risks and benefits of HIV cure research in the United States. *PLoS One* 2017; **12**: e0170112.
- Deeks SG, Autran B, Berkhout B *et al*. Towards an HIV cure: a global scientific strategy. *Nature Rev Immunol* 2012; **12**: 607–614.
- Muessig K, Whipple W, Grewe M *et al*. HIV cure goes viral. An analysis of HIV cure #Hashtags. IAS Towards a Cure Symposium July 2015. Vancouver, Canada.
- UNAIDS. *Policy Brief: Greater involvement of people living with HIV (GIPA)*. Geneva: UNAIDS; 2007. Available at: www.unaids.org/en/resources/documents/2007/20070410_jc1299-policybrief-gipa_en.pdf (accessed September 2017).