

Women and HIV: transformative stories in magazines and the internet as a potential mechanism to address stigma, isolation and prevention of HIV transmission in Australian women

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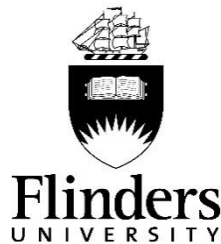
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In the

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Dedication

To Marylyn

.....and in memory of John R. and Eileen

Abstract

Introduction

The incidence of HIV in women in Australia is increasing and there is a dearth of prevention campaigns appropriate for women. The proactive and successful HIV prevention strategies to date are aimed at people known to be at high risk, including gay men, drug-users and sex workers. This list does not include women, even though all sexually active people are at risk. Women with HIV face being stigmatised as deviant, which leads to a reluctance to disclose being infected, and this is often associated with social isolation and depression. In addition, because women are not regarded as high risk they face delayed diagnosis and treatment. Public health messages regarding prevention strategies and testing do not reach women and strategies promoting condom use ignore that this may be out their control. There is a need to reach a wide audience of women to raise awareness about their risk for HIV and to encourage personal agency regarding negotiating safe sex and testing. There is agreement that narratives, using specific message features, are persuasive and promote belief in a story's conclusion. Narratives are useful for health communication, and stories using women's voices and experiences are empowering for women. This study was designed to investigate whether transformative stories of women with HIV, shared via magazines online, is a potential effective vehicle to reach women about HIV.

Method

A study using hermeneutic phenomenology and narrative enquiry, using both qualitative and quantitative methods for data collection, was set up in three stages. First, to understand how women with HIV are portrayed, a directed descriptive content analysis, of personal stories in magazines on the internet about women with HIV, was conducted. A relational data base organised the large amounts of narrative data to allow for thematic analysis and constant comparison of data. Second, to determine audience reception of the stories, interviews were conducted with eight women without a diagnosis of HIV, using two of the stories. The interview guide was developed from the results of the content analysis, as well as the relevant literature. Third, for all the stories, the message features of transformative stories, which contribute to the persuasive nature of a narrative or story, were assessed. One key feature, transportation, was measured using the same two stories for each of the interviewed participants. Transportation or absorption in the story leads to persuasion and the reader may align with the beliefs in the story

Results

The women were portrayed positively, as living well with HIV and without the stigmatisation previously described in the literature. The content analysis demonstrated a potential impact of a reduction in social isolation for women and the audience felt that such stories would reduce stigma and raise awareness. The stories supported findings from the literature, including that women get HIV from their partner, which raised concerns about trust in relationships, and are late to test for HIV. There was agreement in responses across all data sets that targeted education is required to reduce ignorance about HIV in the general public. The value of stories was agreed, as long as they were not overly positive, to reduce the likelihood of encouraging complacency. The stories scored only moderately for persuasive message features and could have been written in a way that would have had a more persuasive outcome.

Discussion and conclusion

Reducing stigma and isolation in women with HIV has the potential to have an impact on the burden of disease in women with HIV, including depression. In the face of an increase in the incidence of HIV in Australian women and the lack of appropriate prevention messages, sharing personal stories about women with HIV via online magazines, has potential to reach women about HIV, addressing stigma isolation and prevention. Using women's voices and narrative message features that are known to be effective in changing beliefs, presents a mechanism that could reach a wide audience. Research to date has not included men in prevention efforts for women, and heterosexual men need to be aware of strategies to protect themselves and their partner. Further research to investigate this approach in men's magazines could address topics of prevention, protection and the negotiation of safe sex within relationships.

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

SignedHelen R. Nikolas.....

Date18 February 2018.....

Acknowledgments

This is a joyful part of my thesis. To thank those people who have supported me on my journey. I returned to complete my thesis, so my experience has been in two sections.

Firstly my thanks go to my supervisors. Dr George Tsourtos guided my dissertation and kept me on track. I am very grateful for everything I have learned throughout this process and thankful for his attention to detail that enabled me to finish. Adjunct Associate Professor Priscilla Robinson shared her research knowledge with me and helped me understand what I was doing. She has had faith in me for many years and I both appreciate and feel honoured by that. This page might not exist if it were not for Priscilla.

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Like some of the women I spoke with, I recalled poignant memories. Like Andrew, with his smiling face and shiny auburn hair. 1988. As a young dietitian on a cancer ward in Canada I knew nothing about AIDS, indeed none of us did. He was the first person I met. I felt utterly helpless three months later: he was so ill; no hair; a visual shock. His friends were holding him and there was nothing I could do to help.

Women are going under the radar with regards to HIV, the virus that leads to AIDS. I am grateful for this learning experience and the opportunity to investigate this issue. Thank you.

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Chapter 1: Introduction

Although, the incidence of HIV overall in Australia has stabilised, the incidence of HIV in women is increasing (Cameron, 2012a). Women are generally not included in the stereotype of people considered at risk for HIV (Department of Health, 2014) and prevention messages and strategies are aimed at high risk groups such as gay men, intravenous drug users and sex workers, not women. Nor have women adopted strategies of negotiating safe sex, early testing for HIV and treatment, the successful strategies adopted by the gay community that resulted in HIV stabilising in that high risk group (Brown, G. et al., 2014). Women, and some health professionals, may not realise that women are at risk for HIV. Many women contract HIV from their partner and usually only consider testing after their partner has become ill. This can lead to a delay in being tested for HIV and subsequently starting antiretroviral therapy (ART).

As a public health issue, this raises a question. Even though the number of women diagnosed with HIV is increasing, the numbers are small relative to the overall incidence of HIV and to the numbers of people affected by other chronic diseases. The choice of where to allocating funds for prevention campaigns becomes difficult. In addition, all women who are sexually active are potentially at risk, so that any preventive health campaign needs to reach a large target population. Thus, the question remains: how can messages about HIV reach women in a cost-effective manner?

There has been a trend toward publishing the personal stories of people who are living with HIV in magazines and online websites. They have a large readership and wide reach. Stories or narratives have been used in public health and health promotion to provide health messages and increase familiarity with, and understanding of, diverse communities. In the fields of psychology and communication, narratives have been researched to identify message features that have an effect on the reader. Narratives have a persuasive effect. If the reader is engaged with the character and absorbed by the events in the story, they may develop a strong belief in the character and the beliefs presented in the story (Green & Brock, 2000). As a result, narratives or stories can affect behavioural intention and have been useful in communicating health messages (Barbour et al., 2016, Hinyard & Kreuter, 2007; Lee et al., 2016).

As a significant news item, HIV/AIDS has been the focus of newspapers since the 1980s, with extensive research by Deborah Lupton on the way people affected by HIV/AIDS were portrayed. From the 1980s to the 1990s there was a shift from an initial outright blaming to a more empathetic approach. However, there remained an underlying layer of stigma and blame, for example referring to deviant behaviour

that had led to the person contracting HIV (Lupton 1992). If stories by journalists are to be considered as a vehicle to share personal stories about women with HIV, it was crucial to understand current approaches. In stories from magazines and online news sites 2014-2017, this study looked at how women with were portrayed to determine whether the stories had been written in a way that was stigmatising toward the women. Stigma was an important theoretical perspective.

Despite contracting HIV mainly through heterosexual contact, women with HIV are generally blamed for their diagnosis, seen as deviant, assumed to be a drug user or sex worker and are judged more harshly than are men (Amaro et al., 2001, Costello, 2012, Ho & Holloway, 2016). The presence of stigma was investigated, using Goffman's (1963) theory of stigma. Fear that a person has deviant traits is labelled *othering*, thus maintaining distance such that "I am not in that group of people". Stigma in women leads to a reluctance disclose that they have the virus, known as *passing*, hiding symptoms and dissociating with the deviant group to avoid being stigmatized. In women with HIV, a reluctance to disclose their HIV status can lead to isolation and as a result, 50% of women with HIV develop depression (Morrison, 2012), a crucial public health issue in itself.

The stories were also viewed through a theoretical perspective of feminist theory. The main protection that women have against the HIV virus is the male condom, a strategy that is not under the control of women (Amaro, 2012). As a result, using condoms and negotiating safe sex are more difficult for women to achieve. Messages about HIV cannot simply espouse women to use condoms or put the responsibility on them. Neither is it appropriate to label women as a vulnerable and powerless. The rhetoric of HIV prevention, whilst ignoring women, also ignores heterosexual men and their need for protection and to protect their partner. Although it was beyond the scope of this study is important to acknowledge that the best solution will include men (Higgins et al., 2012). However, in respect to personal stories about women with HIV, telling those stories in women's voices and from women's experiences will have an impact.

The study was organised in three stages with the qualitative methodologies of hermeneutic phenomenology and narrative inquiry, using both qualitative and quantitative methods of data collection and analysis. Existing stories were gathered from the internet about women with HIV that had been published in magazines and on-line news websites, publications that many women might read.

Since personal stories of women with HIV have been published, it was valuable to investigate the existing stories with regard to the way women are portrayed as well as their content, to note if health

messages such as safe sex or testing are being shared. This would provide insight into how stories are currently being used, as well as the presentation and the suitability of magazines as a vehicle. Although written by journalists, with an expectation that some narrative properties would be included, it was also valuable to investigate the extent to which the stories were transformative, or would be expected to have a persuasive impact, an aspect that potentially could be exploited. Lupton (1992) identified that one aspect of the use of stories that is frequently missed, especially in relation to communicating health messages, is the reception of the stories; how the stories are understood by the reader. So the opportunity to assess audience reception was added.

The three stages included a directed, descriptive content analysis of stories found on the internet, using themes known from the literature as a starting point. This included gathering qualitative excerpts that illustrated language and context (Lupton 1992), narrative moments and the two theoretical perspectives. Quantitative counting and the collection of variables into a data base supported the qualitative findings. The results informed an interview guide for focused interviews with women who did not have a diagnosis of HIV, split into two age groups: one group who would have been young women when HIV was first diagnosed, the other a group for whom HIV has always existed. Additional audience reception came in the form of online reader feedback attached to the stories. Thematic analysis with constant comparison was used for Stages One and Two (content analysis and audience reception) and the results were analysed together to compare themes across the stories and from the two audience data sets. Finally, evidence based measures were applied to the stories to determine the presence of message features and potential for absorption or transportation in the reader (Green & Brock, 2000; & Barbour et al., 2016). All stories in the data set were assessed for a range of transformative message features, including story structure and perception. Two stories selected for interview discussion were also scored by the participants using a validated transportation scale.

There was agreement across the content analysis of the stories and the two audience data sets, with results presented together in one combined data analysis. Personal stories came across as a valuable tool for sharing messages about HIV. The women were portrayed in a positive light, seen as overcoming difficulties and living well with HIV. The recent stories, though discussing stigma, did not stigmatise the women and were considered by the audience to be a mechanism to raise awareness and reduce stigma. The stories were deemed to have the potential to carry messages about safe sex or testing, if that content and intent was specifically included. As described in the literature (Cameron, 2012b), betrayal of trust of women in relationships was a theme and there was support for women to act on their own

behalf and negotiate safe sex. However, the difficulty women face regarding their ability to achieve that was noted by the participants, mirroring discourse in the literature (Amaro, 2001, Cameron, 2012b). Concern was raised that stories presenting an overly positive outlook could result in complacency, especially in younger people. It was thought that if HIV is described as being managed easily with medication and if the women are doing so well, the seriousness of the virus would be ignored, regarding protection. There was agreement that ignorance about HIV still exists and that there was a need for education, predominantly to reduce stigma and promote prevention in women, in the general public. In addition, it was suggested that health practitioners understand that women are also at risk of HIV, not only those at high risk, as is the focus of current strategies. About one third of the stories were deemed to have enough persuasive message features to be considered transformative. The two stories scored as being reasonably transporting by the participants. This shows that greater attention, to the writing and message design of personal stories, is required if their purpose is to carry health messages that have an impact to women in the general public. The accuracy of the stories and the background information about HIV are also important. One significant finding showed that the presentation style or ideology of the magazine had an impact on audience reception. A presentation style that is sensational, lurid and busy may have a detrimental effect on the reception of an otherwise useful message. The results found that a story perceived as sensational and incongruent to the story subject, could override the reception of an otherwise persuasive story. This would be crucial in choosing an appropriate vehicle for the personal stories and negotiating with the publisher to ensure the most fitting presentation style.

Further research on the use of personal stories and men's magazines may offer a way to include men in finding a solution to protecting both heterosexual men and women from HIV. Determining the most effective vehicle to carry personal stories to the general public would also be valuable, for example a comparison of the effectiveness of online magazines versus directed promotion via Instagram.

There is potential for online magazines to be a vehicle to share personal stories about women with HIV to reach a large number of women to raise awareness of the risk of HIV for women and the negative impact of stigma, including isolation. The stories would need to follow message design principles, known to result in absorption and persuasion in the reader, contain accurate information and refrain from stigmatising the women. They would need to be presented in an appropriate context, using a suitable vehicle.

Chapter 2: Literature Review

Background

HIV in Australia

The human immunodeficiency virus (HIV), the virus that leads to AIDS (acquired immune deficiency syndrome), is still a public health issue with the prevention or reduction of transmission of the virus a key prevention strategy, including safer sex and behaviour change (Aggleton et al., 2012) and antiretroviral therapy (ART). In developed countries including Australia, the gay community swiftly acted to develop a culture of safe sex strategies, including the use of condoms and negotiating safe sex in relationships (Brown, G., O'Donnell, Crooks & Lake, 2014). Since the 1980s, public health campaigns and community activism have mostly targeted high risk groups such as gay men (Brown, G. et al., 2014); as a result women were not addressed specifically. Although the overall incidence has remained relatively stable for the last 10 years (Kirby Institute, 2016; Australian Federation of AIDS Organisations (AFAO) 2016), largely due to prevention efforts (Department of Health, 2014 and Land 2016), the incidence of HIV in women was reported to be rising steadily in the 1990s in the USA (Kimberley, 1995; Amaro, 1995) and is increasing in Australia¹. The number of women in Australia diagnosed with HIV rose substantially between 2001- 2010 to 9% (Cameron, 2012a). In 2012, women represented 10% of people living with HIV in Australia (Koelmeyer, McDonald & Grierson, 2012) with that proportion expected to rise further to 10.5 % in 2020. The geographical and clinical forecast of numbers of women with HIV is shown in Table 1. Despite that, the overall numbers are relatively small and women with HIV have been described as 'invisible' (Amaro et al., 2001; Koelmeyer et al., 2012). In contrast, in 2012, women represented 50% of people living with HIV globally (Costello, 2012) and in 2015, 66% of teens infected with HIV in Sub-Saharan Africa were girls and 56% of new adult infections were women (United Nations Women, 2015). To put this in context, the overall prevalence in men and women globally has been about the same since 2001 (Merson et al., 2008).

Table 1 Geographic and clinical forecasts of numbers of people living with HIV in Australia UNSW

	2010 ²	2014 ⁴	2020 ²	Increase 2010-2020
People living with HIV	20,956	27,150	28,422	36%
Women with HIV	1886	2,715	2984	58%
% of women of total new diagnoses	9	10	10.5	

According to the HIV Futures Six report (Koelmeyer et al., 2010), over one quarter (28.7%) of women in Australia in 2010 living with HIV had been born in countries other than Australia. In addition, some of the heterosexual contact, resulting in women being infected with HIV, occurred in high HIV prevalence countries (Cameron, 2012a). The remaining women, therefore, contracted the HIV virus in Australia. Women have not mobilised to address transmission of HIV, likely because they may not believe they are at risk (Helfland, 2003; Costello, 2012; Persson, 2014). It would be valuable to find a mechanism that is effective both in reaching and informing women in Australia that can be expanded overseas (Parker & Aggleton, 2003). As the numbers of women with HIV in Australia are relatively small, compared to other chronic disease initiatives that require funding, the best mechanism will require extensive reach at low cost.

Seventh National HIV Strategy 2014–2017

Overall, Australia has had a successful response to HIV. The Australian Department of Health National HIV Strategy 2014-2017 (Department of Health, 2014) suggests a focus on testing (reducing the time between infection and diagnosis), treatment and safer sex practices. However, the strategy targets high risk populations and does not specifically refer to women, except as female sex-workers, who have a very low incidence of HIV; by implication in the term 'drug users', which overall represents 3% new infections; and by referring to mother-to-child transmission, which they report as being very rare in Australia. The strategy, updated in 2014, noted that 15 % of new HIV infections were through heterosexual contact, including people from high prevalence countries (South-East Asia and Sub-Sahara Africa) and their partners. The strategy does not identify the 10% increase in new infections in women (op cit). Even though that rate appears to be higher than in female sex-workers, it is female sex-workers identified as being at high risk who are included in the strategy, rather than women overall. The approval of rapid testing now available in general practice and community settings, as well as in sexual health clinics is a good strategy. However, the message is that rapid testing is for populations at high-risk, women are not flagged for this with health professionals. The strategy does recommend the use of approaches that effectively address language, cultural and gender issues, but only in reference to women with partners from high prevalence countries.

HIV and women

Women, drug therapy and access to services

Strategies to prevent the transmission of HIV have changed since 2011 and, in addition to barrier protection, including condoms, and interpersonal strategies to reduce risk, there are now a number of effective approaches using antiretroviral therapy (ART) (Haire, 2016). These include PEP, where ART is taken post-exposure; PrEP, where people at substantial risk high risk take ART in advance to reduce the chance of acquiring HIV (WHO, 2015); and TasP, with ART used by individuals with HIV to achieve viral suppression (Haire, 2016, AFAO 2016), reducing transmission of the virus to others. PEP and TasP have been widely available in Australia for a number of years. Thanks to the introduction of highly active antiretroviral therapy (HAART), HIV-1 is now a manageable chronic disease in people who have access to medication and who sustain suppression of the virological load⁵. Combination anti-retroviral therapy (ART) is recommended for all people with HIV, and the earlier it is instituted the better the outcome (AFAO 2016; Brown, Debattista & Hooper, 2016). ART controls the virus, prevents it from multiplying and reduces the amount of the virus in the body. It therefore reduces the risk of transmitting HIV to others. However, the drug trials were conducted in groups of men, with women excluded from clinical trial research (Amaro et al., 2001). It is often the case that drug therapy works differently in men and women (Higgins, 2010) and there is little information on the treatment and side effects of ART on the female body (Koelmeyer et al., 2012). Women may be ignorant of their access to testing and treatment and they generally rely on their general practitioner, who may have limited knowledge about HIV/AIDS in the context of women (Amaro et al., 2001). Although specialized clinics exist, they were set up in areas where the gay community predominantly live and generally serve that population (Brown, G. et al., 2014) Koelmeyer and co-workers (2012) noted that the HIV community, being a support mechanism for HIV positive gay men, had not been set up for and so do not provide that same support for women. There is support now for women with HIV. Positive Women Victoria⁷ is a national organization in Australia 'advocating for women living with HIV through all stages' and Positively UK has a similar function in the UK. However, if women and health professionals do not consider HIV as an issue for women they may not access the existing supports for information on prevention, testing and treatment.

Women, early testing and timely diagnosis

In the 1990s, lack of information about the impact of HIV on women, including symptoms and progression of the disease has led to mis-diagnosis of HIV in women and delayed onset of treatment (Amaro et al., 2001). Similarly, white, professional women who do not fit the stereotype of being HIV positive may not be seen as being at risk for HIV by their General Practitioner (Amaro et al., 2001). If left untreated, HIV will attack the immune system and eventually progress to AIDS³. The earlier ART is instituted the better the outcome and current public health strategies emphasize regular testing and early diagnosis so that ART can be prescribed (AFAO 2016; Brown, Debattista & Hooper, 2016). Even though the use of ART by women has increased since the late 1990s, women are generally late to be tested, tend to seek testing only if their partner tests positive (Koelmeyer et al., 2012; Costello, 2012) and are unlikely to have testing for HIV included as a regular part of their health checks (Cameron, 2012a). In 2015, the total percentage of late HIV diagnoses was 29% (AFAO 2016). In contrast, between 2005 and 2014, 46.4% of women with HIV had been diagnosed late, that is after HIV had already had a significant impact on an individual's immune system⁴. It still appears that either women are not receiving messages about early or regular testing, or they do not relate to them. As S. Brown and co-workers (2016, p397) said 'Early detection of HIV is critical ... Testing strategies... [need to include] emphasis on decreasing actual and perceived barriers to testing'. In addition to being invisible with regard to risk for HIV (Koelmeyer et al., 2012; Amaro 2001), barriers to testing for women include, lack of awareness, stigma and issues with testing sensitivity.

Stigma and isolation in Women with HIV

Authors of health promotion research papers agree that the use of fear, punishment and confronting messages in health promotion is counterproductive; people may react by distancing themselves or denying it is happening to them (Lupton, 2015; Hains-Saah et al., 2014; Brown, G. et al 2014; Slavin, Batrouney & Murphy, 2007). Stigma in relation to HIV can be difficult to define at both an individual and societal level (Mahajan et al., 2008) and 'experiences and ideas about what stigma is can vary from one person to the next' (Slavin, 2012 p27). In addition to the impact on the person, this potentially leads to delaying treatment due to a reluctance to disclose and be tested (Slavin, 2012). The community or cultural narrative has an impact on perception of HIV held by both the person with HIV and people around them. Stigma is felt as a perception of others' negative attitudes or as negative feelings people with HIV have about themselves (Slavin, 2012). Slavin (2012) suggested that campaigns to reduce stigma may have better outcomes if they focus on building resilience in people with HIV. Similarly, Ho and

Holliday (2015) found that stigmatising behaviour toward a woman with HIV may result from personal beliefs and perceptions as well as social context and cultural beliefs and suggested it would be valuable to enable HIV positive women to share their experiences and coping strategies. Sharing and publishing positive personal stories is now a strategy used by organisations that support women and people living with HIV⁷. In contrast, portraying people as the infected and diseased or feared-other has been found to lead to discrimination and stigma, with associated poorer health outcomes (Lupton, 2015; Slavin et al., 2007).

Despite contracting the virus through heterosexual contact, with 52.9% being in a regular relationship (Koelmeyer et al., 2012), women are generally considered responsible for being infected by the virus (Morrison et al., 2002). Women are often seen as the vectors of the disease (Amaro et al., 2001). They are generally blamed for their diagnosis, seen as deviant, assumed to be a drug user or sex worker (vectors of HIV) and to be judged more harshly than men (Amaro et al., 2001; Costello, 2012; Ho & Holloway, 2016). McDonald (2012 p14) describes layers of stigma where women are not only deemed to have a 'feared, contagious disease', but also are assumed to have 'deviance in their personal traits'. In a review of HIV related stigma in women, Ho and Holliday (2015) suggested that women may selectively disclose their status to avoid stigma, resulting in isolation. Experiencing isolation, women have a greater chance of developing depression, a significant outcome of stigma in women with HIV (Morrison et al., 2002) and an additional public health issue to manage. Of interest, although Morrison and co-workers (2012) found more symptoms of both depression and anxiety in women with HIV, compared to women who did not have the virus, there was no difference in the rate of anxiety disorders between the two groups.

Gender, power and vulnerability to HIV

The stigma experienced by women may also be related to societal expectations of women, for example in their biological and social role as mothers, carrying the responsibility of their own and their children's health (Koelmeyer et al., 2012, Costello, 2012). Incorrect assumptions of how women contract HIV can lead to women with HIV may experience unwanted and unwarranted disclosure from family or health care workers (Amaro et al., 2001), highlighting a need for education not only of the general public but also health care workers (Koelmeyer et al., 2012).

Women are biologically at greater risk than men of contracting HIV through unprotected sex (Amaro, 1995; Higgins et al., 2010; Costello, 2012) and are at risk of transmission of HIV from their partner or a sexual encounter (Costello, 2012). In legal cases presented for prosecution of HIV transmission to

women, their partners' behaviour included, removing condoms during sex, lying when directly asked about HIV status, forging test results and concealing medical appointments (Cameron, 2012b). Cameron (2012b, p35) further points out that 'betrayals of trust in intimate relationships, including infidelity, are frequent' and suggests that even fleeting sexual encounters require a level of trust and expectation.

Individualistic public health approaches to HIV prevention in women, i.e. assuming a person has control over their own behaviour, are simplistic and do not address the contextual factors, such as gender roles and power imbalances, that influence women's behaviour and put them at risk for HIV (Amaro,1995; Amaro et al 2001; Harvey, 2000). In addition to issues of biological susceptibility, reduced sexual autonomy and men's sexual power and privilege, prevention and public health approaches need to also include social structure, gender and HIV risk for both men and women (Higgins et al., 2010). HIV prevention research is beginning to take a contextual view of women's HIV risk and include gendered perspectives, for example looking at why HIV is continuing to increase in women (Amaro et al., 2001),

HIV/AIDS in the news and popular press

A brief history of HIV/AIDS in the media

Lupton, Chapman and Wong (1993) proposed that in addition to deliberate health education campaigns, the general public do have access to additional sources of information in the popular media. However, the role of newsmakers is to sell their product rather than educate. They may choose to take a sensational perspective, such as the use of emotive headlines or sexual content to attract attention, or slant a story based on their ideological perspective (Hayes et al., 2007). As a result, the popular press, when publishing personal stories, may not share the same goal as health educators (Lupton et al., 1993; Zuckerman, 2003) and the story may be dramatized and portrayed differently by the media than a reported personal experiences (Persson, 2014). In significant reviews of newspaper coverage, Lupton and her co-workers (1993) found that AIDS lost its newsworthiness over time, with decreased support in the community for continued efforts to fight the epidemic. They found that inaccurate reporting was misleading and counter-productive to raising awareness of the risk of HIV for women. For example, two newspaper articles in 1990, reported that the 'spread of AIDS appeared to have reach plateaued in Australia' and had not spread into the general community as expected; the second reported that 'Aids seems to have remained confined largely to homosexual men' (Lupton et al., 1993 p14). News media gave little if any reference to women and their risk, leaving women with the message that HIV was not

about them. The Grim Reaper Campaign, released for three weeks in 1987, with its 'controversial use of shock tactics', was supported by the press (Lupton, 1991 p6). However, the impact on the general public was short-lived, returning to the message that AIDS was related to deviant behaviour and not to heterosexuals (Lupton et al., 1993).

Testimonials or case histories of people who have contracted HIV have been featured from the early days of media reporting, personalised to provide human interest (Lupton, 1999a). These were usually written by journalists with an emphasis on AIDS-as-news rather than on the personal experiences of the person with HIV/AIDS. In her analysis of the representation of people with AIDS in the press from 1994 to 1996, Lupton (1999a) named three archetypes used to describe people with HIV/AIDS. These were 1) the victim, who was shunned by people who found out they were HIV positive; 2) the survivor, who put their good health down to a positive attitude and good self-care routines; and 3) the carrier who was passing on the virus to others either deliberately or through negligence. She noted that the trend toward positive reporting and optimism started after the International AIDS Conference in Vancouver in 1996, which had focused on advances in drug therapy and commented that if people are shown to be more responsible about their condition, they are more likely to be viewed favourably (Lupton, 1999a). In a significant review of 2795 news items during 7 months in 1990, Lupton and co-workers (1993) noted that over time, the rhetoric about HIV/AIDS changed from being emotive and judgmental, to one that was more neutral and sympathetic. However they noted that there remained an underlying theme, for example, implying guilt for person's previous high risk behaviour that resulted in them contracting the virus. The stories still had underlying tones of stigma (Lupton et al., 1993). The media uses a variety of techniques to convey what they see as newsworthy, some of which contribute to stigma. Metaphors, similes, euphemisms, and clichés used frequently in media articles about HIV/AIDS have been described by Clarke, McLellan and Hoffman-Goetz (2006) outlined in Table 4 (Chapter 3, Methodology). A final significant point noted by Lupton and her co-workers (1993) was the use of eye-catching, thought provoking headlines with potentially sub-textual messages; thought to be important since readers will often only read the headline.

HIV and the Australian Women's Weekly

Stories published in popular media and on the internet describe culturally common issues. In August 2015, the Australian Women's Weekly, a popular women's magazine, published an article with the personal stories of five women with HIV. This article was repeated online⁶ in 2016. These stories provided the impetus for this study. In her keynote speech at the Australian College of Health Service

Managers congress in Sydney, 2017 (29 Sept 2017), Ms Ita Buttrose AO OBE, founding editor of the magazine Cleo, and who later became Editor of the Australian Women's Weekly, described magazines as an effective way to reach women. As an editor in Australia in the 1980s she felt that:

“magazines had the potential to provide health messages to the community and that by using the way people talked, rather than bureaucratic language, that they could be an important vehicle for health messages to the nation at that time”

Ms Buttrose (personal communication 29 Sept 2017) explained that as an Editor with access to several women's publications, their magazines were used to distribute booklets on HIV which: 'enabled them to provide targeted information about HIV prevention' and that the 'total penetration of the journal market to women was enormous'. Ms Buttrose described her work in the 1980s as the Chair of the National Advisory Committee on AIDS (NACAIDS), invited by and working with the Federal Minister for Health, the Honourable Neal Blewett. NACAIDS had the role of 'increasing awareness of HIV/AIDS and changing the behaviour of those at risk'⁹. She felt her involvement with and the perspective she brought to the Grim Reaper campaign, released in April in 1987, was important. She explained that she provided a different perspective to the health promotion aspect. She felt that 'people's behaviour changed' and that 'the Grim Reaper campaign has not been equalled'.

The Grim Reaper campaign was directed at the general public. Although it was short lived, it had an impact in reducing the potential spread of HIV into the wider community. The safe sex message and the campaign appeared to have the greatest impact on people at low risk, including heterosexual women (Morlet., et al 1988). Morlet and co-workers (1988) suggested that future campaigns ought to be directed at people who are at high risk, which would not specifically include women. The campaign had its criticisms. It used shock tactics and elicited fear, with its portrait of death carrying a sickle. That resulted in people who were affected by HIV/AIDS being regarded fearfully by the community. As the objective of the campaign was to raise awareness, that outcome had not been considered¹⁰. In an analysis of campaigns, which included the Grim Reaper, Myhre and Flora (2000) observed that the campaign achieved high exposure and reach and hence a high level of awareness. However, they felt the campaign raised anxiety levels and produced a negative response in the general population, with little change in knowledge.

Changes in magazine readership in Australia since 2013

An article in the Australian Guardian¹² in 2013 heralded a change in the way that magazine distribution was measured. Although print was still considered to be the mainstay of the industry in 2013, the change acknowledged the wide variation in distribution that was possible due to the internet and the increased and widespread use of mobile devices. Since the print version of a magazine could be replicated online, the strength of print materials and their editorials that lead to a *'high level of reader engagement with display advertising'*¹² could also be successfully reproduced. The measure of distribution changed from a *'single, audited print circulation figure'*¹² to one that combined print and digital circulation figures. The article indicated that readers at that time wanted both types of production, hard copy and digital format.

By 2017, the conversation had changed to managing a multi-platform space and understanding how the audience uses the different platforms¹³. There was a corresponding change from publishers being product oriented to providing marketing opportunities for clients. Since 2013, changes have occurred in how magazines are distributed. Online distribution is measured by web-site visits in a four week period. The key mechanism to report magazine distribution, *Roy.Morgan.com*, noted that in the 12 months to September 2017 Cosmopolitan had experienced a 17.5 % reduction and Australian Women's Weekly (AWW) had experienced a 10.3% reduction in print magazine readership¹⁴. These were two of the magazines included in this study. In a report on magazine cross-platform audience, published on *Roy.Morgan.com*, identified in the same time period that Cosmopolitan experienced a decrease in print circulation and an increase in online circulation via the internet and mobile applications. The online presence had partially made up for some of the loss of print circulation. Unfortunately the % change for AWW online was not available. Available figures are shown in Table 2, indicating that the digital readership for AWW, also made up for the loss of print readership.

Table 2 Changes in print and digital distribution 12 months to Sept 2017 (in 000s)¹⁴

	Print	Print	%change	Digital	Digital	Total	Total	%change
	2016	2017	16-17	2016	2017	2016	2017	
Cosmo	307	254	-17.5	271	318	555	543	-2.2
AWW	1,648	1,479	-10.3	-	908	-	2,271	n/a

Health promotion and HIV

HIV and health promotion

Australia's health promotion strategy for HIV/AIDS was successful because of partnership and intersectoral collaboration (Brown, G. et al 2014). Some of the most successful HIV prevention programs and campaigns, addressing knowledge, attitudes and behaviours, were developed with people living with HIV (Willett, 2014). These include peer support and education, public speaking and inclusion of stories of lived experience. Involving people living with HIV in this way is considered best practice and contributes to the outcomes advocated by the Ottawa Charter (World Health Organisation (WHO), 1986) and the Jakarta Declaration on Leading Health Promotion into the 21st Century (WHO 1997): creating supportive environments for people living with HIV, strengthening community action and reorienting health services to better respond to the needs of HIV- positive people. The strategies in the HIV health promotion programs included risk reduction, such as safe sex and condom use; encouraging testing; and awareness of ART (AFAO 2016). Current campaigns (AFAO 2017) include Time to Test, advocating early and regular testing and Ending HIV: testing more, treating early and staying safe. These campaigns on the AFAO website are aimed at men. However, the strategies they suggest are equally appropriate for women.

Are HIV prevention campaigns in Australia targeted at women?

Prevention efforts have been significant in Australia, despite working with difficult and complex issues (Kippax & Kinder 2002; Brown, G. et al., 2014) and a rapid change in community behaviour in response to HIV was achieved (Brown, G. et al., 2014). The successful approach lay in engaging and working with gay communities and leveraging strengths. This gay-informed approach was developed by understanding more about gay relationships and life (Kippax & Kinder, 2002). Numerous public health campaigns were developed using strong imagery and language that spoke to gay men (Willett, 2014; Chan & Donovan, 2014). As a result, these were not appropriate for the general public, nor were they aimed at women, as the language of men, specifically gay men was used in the early campaigns. However, the consistent message was that 'all sexually active individuals should be aware of AIDS and, ideally practice safe sex' (Lupton et al., 1993, p5). Messages need to be delivered in a culturally appropriate way (Bond et al., 1997; Chandler et al., 2013). To date, with regard to HIV and prevention, the focus has been on gay men and other high risk groups (Department of Health, 2014) with messages designed using language suitable to and culturally appropriate for those high risk groups. Cameron

(2012, p35) rightly observed: 'How realistic is it to expect mainstream heterosexual Australia to uptake messages of shared responsibility for sexual health so diligently communicated to gay communities?'

HIV mass media campaigns - are women getting the message?

Since 1982, there have been numerous HIV campaigns including arts activism and public health campaigns as well as media coverage of HIV/AIDS. To reach and educate women about HIV, campaigns are required that are culturally appropriate (Bond et al., 1997, Chandler et al., 2013). Imagery, appropriate language, tone of language, content and relevance are factors that have been found to influence campaign acceptability (French et al. 2014; Bond et al. 1997). To reduce women's risk with regard to HIV, public health programs and approaches need to not only increase awareness of risk and provide information about safe sex and testing, but also to ensure that behaviour change will occur. An additional component that achieves an outcome, to ensure women take on the advice provided via mass media, is needed to halt and change the progressive increase in women contracting HIV. It has been suggested that targeted mass media campaigns could be useful to reach women, if used in conjunction with other in-depth interventions (Noar et al., 2009, French et al., 2014). In a study with young college women in the US, Chandler and co-workers (2013) suggested that magazines and the internet may be successful at effectively conveying HIV prevention messages and that formative research is required to determine the best messaging (and preferred media) to promote HIV prevention to young women.

Public health is a function of efficacy and reach and although mass media may have a small impact, it nevertheless has a large reach. Myhre and Flora (2000) analysed existing campaigns, with a mass media component, with a view to identifying aspects of a successful campaign that would result in behaviour change. One aspect of their study was to investigate the mechanism used to reach the target audience. They identified two successful campaigns which 'demonstrate that carefully planned, low-cost broadcast media campaigns can reach many people effectively and efficiently with HIV prevention messages' (Myhre & Flora, 2000 p37). Although they found varied use of theory in campaign development, they felt that effectively combining behavioural and message design theories would have resulted in more successful campaigns. Although this was not a campaign for an Australian audience, it might be expected that similar exposure and reach would be achieved using this as a vehicle. Similarly, looking at campaigns in English across several countries, Lacroix and co-workers (2014) suggested that mass media campaigns may be useful to address HIV because of their capability to reach people.

Syeda, Sanjukta and Shahnaz (2012) found mass media such as radio, TV and newsprint to be a high predictor of HIV knowledge in women in developing countries and suggested a need for education campaigns targeted for women in general and Bertrand et al. (2006) found that mass media campaigns had an impact on knowledge about HIV in developing countries. Could mass media using magazines and internet potentially provide a low-cost mechanism with an extensive reach for women in Australia? Any extension of a successful campaign to other countries would need to take into account cultural difference and gender-power imbalances.

The use of stories in public health and health promotion

Stories in public health and health promotion

LaBonte, Feathers and Hill (1999) noted renewed interest in researching narratives and telling stories as a means of understanding social life. They argue that the use of stories aligns with the 'constructivist postpositivist approach to health promotion' (LaBonte et al., 1999 p39). There is agreement that narratives play a role in behaviour change and are a productive tool in health communication and public health (Barbour et al., 2016; Hinyard and Kreuter 2007; Lee et al., 2016; Petraglia, 2007). For example, narratives used in public health have been shown to be effective for encouraging empathy toward stigmatized groups, improving knowledge and changing attitudes (Barbour et al., 2016; Rappaport, 1995). Stories have been used to share programs, projects and new approaches and have been a key mechanism for health promoters to share their knowledge; examples can be seen in the South Australian Health Promotion Storybook¹¹. Labonte and co-workers (1999) pointed to an increase in the use of stories or narratives in health promotion for researching, learning, planning and evaluation and described significant ways in which stories were used by health promoters to connect with people and communities. They explained that the 'emphasis on personal experience and voice' is empowering in health education and stressed the importance of using women's voices and their own words, in line with feminist criticism that women's voices are often ignored (LaBonte et al., 1999 p41). Finally, if stories are used, authors agree that a more systematic approach be taken, with a persuasive message design that ideally also addresses the underlying issue (Labonte et al., 1999; Barbour et al., 2016).

Stories and HIV health promotion with women

Stories using women's voices describe their lived experiences and can be used to make sense of circumstances, social role and, according to de Souza (2010), reframe or transform identity. Personal stories about women with HIV have been used as research techniques (Kimberley et al., 1995; Persson, 2014). Robillard and co-workers (2016) cited several papers that support the use of cultural narratives or role model stories in prevention focussed HIV interventions. Bond et al., (1997) found that HIV print materials developed for a broad audience were not suitable to target women. Working with a health communication specialist, they developed engaging stories about role-models, using true stories in women's voices that reached women who would not have been reached through traditional campaigns. The role model story project (Downing et al., 1999) used narratives to model desired health behaviours (Hinyard & Kreuter, 2007), developing their stories in an appropriate way to have an impact. However, the impact of the stories was not researched (Bond et al., 1999). This echoes Lupton (Lupton 1999a; Lupton 1992) who indicated that audience reception of stories used in a health context was lacking.

Transformative Stories – stories that make a difference

Stories and narratives

For this study, narrative and story may be used interchangeably. According to the Oxford dictionary²⁰ 'a *narrative*' is 'a spoken or written account of connected events; a story'. Story-telling is found in all known cultures and is the basic way humans communicate (Hinyard & Kreuter, 2007). It is used to share information and can provide a creative way to address and find solutions for what might seem difficult problems (Lane & Corrie, 2010). There is agreement that an individual's story is always understood in a social context (Clandinin, 2006; McCormack, 2000; Rappaport, 1995) and we may modify our world by interpreting action taken by others, seeing ourselves reflected in a dominant community narrative (Hinyard & Kreuter, 2007; Rappaport, 1995). Sustaining individual change may require a new community narrative to be created and shared (Hinyard & Kreuter, 2007; Downing et al., 1999; Rappaport, 1995).

Since HIV is increasing in women, there may be value in the use of personal stories to reach women and effect a change in perspective about HIV. First hand experiential stories are one of the five story-types that have been suggested as useful for health communication (Hinyard & Kreuter, 2007) and the purpose of this study is to investigate personal stories about women with HIV shared in popular media.

Rappaport (1995) questioned who has the right to tell someone's story and who legitimizes the content? If personal stories about women with HIV are shared via magazines, for health communication, control by the editor over the story content and its purpose for publication needs to be considered. Using mainstream media to share stories that may influence positive health outcomes likely would require collaboration across public health, communication and publishing sectors.

Transformative stories

Statistical evidence is more persuasive than anecdotal evidence, but narratives have been found to be the most persuasive (Barbour et al., 2016) and it is the persuasive impact of narratives that has been shown to be useful in health communication (Barbour et al., 2016; Lee et al., 2016). In his book *Transforming Tales*, Parkinson (2009) describes the enthralling experience of listening to or reading a story, referring to the sense of absorption a reader experiences. Barbour and co-workers (2016 p816) noted that 'narratives work because they are vivid, relatable, transformative experiences'. Stories created using specific principles of message design, in context, may result in a change in beliefs and potentially in behaviour (Green & Brock, 2000; Lee et al., 2016). For this study, *transformative stories* are stories created using multiple message features that together contribute their persuasive nature. The premise being that the more features included in the story, the greater the transformative impact.

The key message features in a transformational story are 1) transportation, which refers to absorption or immersion into the story (Barbour et al., Green & Brock, 2000; Lee et al., 2016) and 2) story structure, which related to the way stories are constructed, including patterns and plot. Other important message features, such as identification, relevance and realism are thought to be mediators of transportation. For example if a reader identifies with a believable character, this will facilitate transportation and absorption into, or engagement with, the story which leads to persuasion (Hinyard & Kreuter, 2007). At that point, the reader may align with the beliefs put forward by the story and the protagonist, affecting their own beliefs and behaviours (Green & Brock 2000).

In that way, listening to and sharing stories leads to 'identification' with the characters (Parrott, 2009; Lee et al., 2016), especially if the story is deemed real, authentic and seems familiar to the reader (Lee et al., 2016; Hinyard & Kreuter, 2007). Identification facilitates transportation and absorption into the story which leads to persuasion (Hinyard & Kreuter, 2007). Green and Brock (2000) suggested that intention, imagery and feelings also play a role in the process. The immersive properties of narrative, which can make an experience seem real and believable, can result in a change in attitude or belief

through transportation, rather than through cognitive elaboration (Green & Brock, 2000). The act of focusing attention, emotional involvement and mental imagery results in a narrative-based belief change (Green & Brock, 2000). Hence, there are multiple features involved and Appendix 1 shows a summary of the message features of transformative stories, gathered from various authors.

The model story project (Downing et al., 1999) provides a good example of transformative message features. The materials included: real life stories from the target audience (relevance, identifiable, relatable), the woman's voice, emotion, a decision or struggle (turning point), language that was easily understood and reference to culturally specific norms. These factors are echoed in the culture-centric model of health promotion, by Larkey and Hecht (2010, cited in Robillard et al., 2016, p9): culturally embedded, engaging stories and characters are the factors to achieve attitude and behaviour change. The model includes: 'engagement/transportation (how ones absorbs the story) and identification with characters/story' as well as the 'inclination to 'share a good story' (Robillard et al., 2016 p3).

How are messages received: a gap in the literature?

It is important to understand how the intended audience receives health-related messages in the media. Lupton (1999b; 1992) found that this area had had little research attention. For example, on reading stories about women with HIV, do women see themselves in the story, how do women perceive their risk of contracting the HIV virus, how do they see prevention as it relates to them and how do they relate to the women in the stories? This requires analysis of the social context of the health messages, in this case stories, looking at audience reception and awareness of the issue (Lupton 1992).

Lupton and co-workers (1993) felt that the tenor of reporting could influence the public with respect to, for example, attitudes and discrimination. They suggested a number of factors that may influence the way a story and its message are received by the audience, women, including the voice (who is telling the story, or point of view), imagery, language used, content and tenor (Lupton et al., 1993). In that way, the the point of view, has influence over the reader (Winterbottom, 2008). In a small sample of participants, Mowbray (2016) also found that the way in which health messages are written has an influence on reception of the message as credible. Hence, the concept of audience reception of health messages aligns well with research on narrative persuasion and the premise of this study the *transformative* potential of stories. In looking at the potential for stories to be a vehicle to influence women about HIV, it is not only important to review how those stories are designed, but also how women as readers react to them.

Aim, Objectives and Research Questions

The objectives and research questions in this study are qualitative in nature. Hence, this is a qualitative research study using a multiple methods approach (Morse, 2003), employing both qualitative and quantitative data collection and analytical methods.

Aim

The purpose of this research is to investigate the potential for magazines and online news to be a vehicle to share transformational stories about women and HIV in a cost effective way that has scope to reach a large audience and raise awareness that women are at risk of HIV; reduce the stigma against, and sense of isolation felt by, women with HIV; and raise awareness of safe sex (prevention) and early testing and treatment for women.

Objectives

The study was designed in three stages to investigate:

- the experience of women with HIV in stories published in magazines and online news sites; including how the stories were written; the way both the women and HIV were depicted; and the knowledge of the women and others about HIV in women
- how the intended audience (women who do not have a diagnosis of HIV) receive or experience the stories; including the main messages in the stories; how the stories portrayed the women (including stigma); the effect of publication style; and the impact on the reader with regard to sharing the information; and
- the extent to which the stories are transformative, by analysing the written stories, as well as assessing story structure and transportation and engagement by the readers

Research Questions

- 1) How are both women and HIV portrayed in stories about women with HIV in magazines and on-line news?
- 2) How are the stories received; how does the audience experience the stories?
- 3) Are the stories about women and HIV in magazines and online news sites transformative?

Chapter 3: Methodology

Research paradigm

In *The New Public Health* Fran Baum includes ‘to understand how people interpret health and disease and make sense of their health perspectives’ as one of the four main applications of qualitative research to public health (Baum, 2002 p163). The research questions in this study are qualitative in nature and a predominately qualitative methodological approach enables the complexities of the issues about women with HIV to be investigated (Morse, 2003).

A qualitative study was designed, employing both qualitative and quantitative data collection and analytical methods, using a multiple methods approach (Morse, 2003). The methods chosen for this study align with MacKensie and Knipe’s (2006) suggestions for a constructionist/interpretivist paradigm as shown in Table 3. The authors describe various methods, or tools for data collection, that align with a number of research paradigms. They suggest that ‘a researcher may apply the data collection and analysis methods most appropriate for a particular research study’, being driven by the research paradigm and research questions. In addition, they suggest that the terms *qualitative* and *quantitative* refer to data collection and to the analytical methods and tools, rather than to the theoretical approach to the research. Fran Baum (1995, p464) argued for the integration of methods to conduct effective public health research. As that needs ‘*both to describe and to understand communities.....doing this effectively calls for the application of qualitative and quantitative techniques*’ combined in a study design suited to answer the research questions.

Table 3 Paradigms Methods and Tools (MacKensie and Knipe 2006)

Paradigm	Methods (primarily)	Data collection tools (examples)
Interpretivist/ Constructivist	Qualitative methods predominate although quantitative methods may also be utilised.	Interviews Observations Document reviews Visual data analysis

The theoretical framework, or research paradigm, informs the methodology, methods and research design, influencing the way the data is studied and interpreted (Crotty, 1998, MacKensie & Knipe 2006). With the research questions in mind, the overall philosophical alignment chosen for this study was

qualitative, with an interpretivist/constructivist theoretical framework to provide an understanding of stories about women and HIV from women's perspectives, both as storytellers recounting their experiences as well as women's experience as readers.

Methodological Approach

The specific qualitative methodological approaches for the study were hermeneutic phenomenology and narrative inquiry. Both of these approaches are associated with a constructionist/interpretivist paradigm and both methodologies are suited to research involving story-telling and lived experience. As such, they were suitable choices to answer the research aims and questions. Deductive reasoning, based on the literature and existing knowledge (theory driven), as well as inductive reasoning, driven by the analysis and data, were used. However, prior knowledge (deductive ideas) acted as a guide, allowing flexibility in the investigation. The women's experience, as it is portrayed through the stories themselves and the interviews of women as the audience was a focus during data collection (Mayan, 2001 p 10, Edwards, 2002 p 84) to gain insight into their experience.

A constructionist/interpretivist paradigm is appropriate for this study. Coming from Edmund Husserl's hermeneutic phenomenology i.e. interpretive understanding of human experience, a constructionist/interpretivist approach, accepts that reality is socially constructed and relies on the participant's view of the situation being studied (MacKensie & Knipe 2006), in this case the women's view. In a constructivist approach, a pattern of meanings is developed using a qualitative approach, with quantitative data to support or expand the qualitative data and deepen the description (MacKensie & Knipe 2006). This is the approach used in this multiple methods study (Morse, 2003).

Hermeneutic Phenomenology

Phenomenology, initiated by Husserl in the 1800s, is both philosophical and methodological, including a range of research approaches. It is a study of phenomena, their nature and meanings (Kafle, 2011). Heidegger rejected the prevailing idea in phenomenology that 'personal opinion can be suspended' and developed a branch of phenomenology termed *hermeneutic phenomenology* which enabled a focus on understanding the 'subjective experience of individuals and groups... to unveil the world as experienced by the subject through their life world stories' (Kafle, 2011). Kafle, (2011) explained that according to Langridge, 'our experiences can be best understood through stories we tell of that experience. To understand the life world we need to explore the stories people tell of their experiences'. This methodological approach was well suited to this study, which not only investigated the lived experience

of the women with HIV in the stories, but also the experiences of the women who read the stories, the intended audience. Hermeneutic phenomenology relies on the hermeneutic cycle of 'reading, interpreting, reflection and re-reading' to keep the research question at the forefront, explore the lived experience and describe the phenomenon through writing and reflection.

Narrative Inquiry

Narrative inquiry is an interest in lived experiences as told by the people who live them (Chase, 2011 p421) and provides a research methodology suitable to study and understand the women's experiences in this study. Sharing narratives, or telling stories, plays a fundamental role in human behaviour and the persuasive nature of narratives has been shown to be useful in public health and health promotion (Barbour et al., 2016; Hinyard & Kreuter, 2007; Petraglia, 2007). Whilst narrative inquiry is a way to study lived experience, narrative theory has an inherent assumption that humans are storytellers who interpret life as an ongoing narrative that help make sense of the world (Lee et al., 2016, Clandinin, 2006). Petraglia (2007) further explains that the constructivist stance suggests that our knowledge of the world, and who we are, is woven into our individual and collective stories. The stories in this study are both individual, they are about women with HIV, as well as existing within a social context, as the intent of the stories is to be read by many thousands of women in a magazine. As such, an individual woman's story, in her own voice (LaBonte et al., 1999) becomes part of a learning experience about HIV for a wider group of women and potential cultural narrative. We can learn from looking at ours and other peoples' lives (Clandinin, 2006).

Narrative inquiry has a personal dimension as well as social, place and historical contexts for the characters and the reader (Clandinin, 2006). The experience of each of the women in the stories in this study is located in a particular place and year, which might have an impact on how they are received socially as women with HIV. It may also affect their experience of treatment, for example some of the women became infected when the drug therapy, ART, was newly developed and some when ART was advanced. As the researcher, I am also located in a particular place and time, with the ability to view historical and contextual changes in women's experience of HIV over time through the stories and to relate that to my own experience and learning.

Theoretical perspectives

The research questions also examined three main theoretical perspectives: stigma theory, feminist theory, and narrative theory. Feminist work lends itself to a qualitative approach, in which the methods

do not represent a masculine epistemology but enable the investigation of women's voices, often in their own words (Edwards 2002 p 28; Labont et al., 1999). Investigating stigma is crucial in any study of HIV and for women in particular, where stigma manifests differently than for men, for example women are reluctant to disclose that they have HIV due to fear of stigma. This can be isolating, leading to depression (Morrison, 2012). The analysis of the women's stories, their content and their structure, required a narrative lens over both the stories and the women's experience to determine the transformative story features, including transportation theory and story theory (Barbour et al 2016, Lee et al., 2016).

Stigma theory and women with HIV

Stigma has a negative impact on the people who experience it. Goffman (1963) described stigma as an undesired difference in another, resulting in the adoption of stigma-theory to rationalize the animosity and reduce or discredit the person who possesses the stigmatising attribute (Parker & Aggleton, 2003). Negative labels and metaphors are used, including a wide range of additional imperfections. This leads to othering, where either the person of difference is labelled by their community, or they discount health messages as not being related to them (Slavin et al., 2007). Failing to live up to expectations, the person becomes isolated (Goffman, 1963). The person responds by managing the identity or managing the information or hidden traits that could expose the identity of belonging to a discredited group, described as passing (Goffman, 1963, Ucockis, 2016). Women in particular respond in this way, to maintain their identity as a good woman (Sandelowski et al., 2004), which has crossover with the feminist theoretical perspective taken in this study. For women with HIV, the concept of othering, enabling blaming (op cit) and the experience of women with HIV being isolated and invisible within the epidemic (Koelmeyer et al., 2012), which enables passing, is supported by Goffman's theory of stigma.

In their extensive review of HIV/AIDS related stigma and discrimination, Parker and Aggleton (2003) argue that Goffman's theory, that an attribute leads to a spoiled identity, has led to an individualized approach to the analysis of stigma and suggest that much of the research on stigma has focused on emotional responses and negative feeling towards individuals with HIV. They point out that stigma and discrimination are also linked to groups of people as expressions of cultural values within a framework of culture, power and difference and suggest that hegemony and Bordieu's notion of symbolic violence. (Parker & Aggleton, 2003). Again, the feminist theoretical perspective taken in this study provides crossover on this view point. Parker and Aggleton (2003) also suggest new models of localized intervention strategies, aimed at community mobilization and social change, be developed within a

multi-dimensional program, addressing issues both at an individual and broader level. As the personal stories in this study represent one woman's story at a time, being read by one person at a time, thus taking an individualistic approach, Goffman's (1963) theory of stigmatization was considered to be appropriate to investigate the women's experience of stigma through their stories. However, it is also important to take a broader community perspective when seeking solutions, as stigma is socially constructed but is experienced as an individual. Since the reach of stories in magazines is large and being read by many, there may be an impact on the community perspective (Lupton et al., 1993), potentially influencing a new community narrative, not only about stigma but also women's experience of HIV. Stories in magazines would represent one strategy and, if useful, may have the potential to be up-scaled to address the global HIV response, as suggested by Parker and Aggleton (2003). In addition, Barbour et al (2016) have suggested that messages designed using a narrative approach may be valuable to address public health issues.

Although there have been a number of authors who have developed it further, Goffman's basic theory, considering perspectives of *othering* and *passing*, provides a suitable framework to investigate women's experience of stigma in this study. In addition, the work of Clarke et al. (2006) who described techniques from the literature that media use to promote stigma, is also useful in examining women's experience of stigma in stories published in popular media. The authors cited a number of others, including Lupton (1993), in their analysis of the impact of the media. They suggested that media, in its various forms, may shape public ideas, both at an individual level and cultural level, thus maintaining established order, providing information about diseases and influencing beliefs about the attributes someone with a particular disease may exhibit (Clarke et al., 2006). Relevant to this study, they noted that the media can 'moderate perceived threats of disease and the likelihood of taking action.... reject or legitimize their beliefs about particular diseases' (Clarke et al., 2006 p 496). A summary of their findings of techniques used in media to promote stigma as they relate to Goffman's (1963) perspectives of *othering* and *passing* can be seen in Table 4:

Table 4 Stigma Techniques used in media to promote stigma (Clarke et al 2006)

*Goffman's theory of Stigma	Negative labelling	Examples used in media
*othering	Polarisation Comparisons	Black or white. Innocent or guilty. Deserving Frequent reference to higher incidence in one group Political/economic difference eg access to treatment Majority versus a deviant group
*passing	Hide factors that associate them with	Spoiled identity Women invisible

	the disease	Health message is not for them (is for labelled person)
	Victim blaming	Result of lifestyle, personal choices E.g. Gay lifestyle, IV drug users or partners of same, Sex worker Deserve illness due to behaviour
language	Euphemisms	On a journey. Making a transition Wake up call. Withered away
	Metaphors	Shocking portrayal such as the Grim Reaper advert Combat (attack, war, battle). Courage (fight, brave)

Feminist theory and the ‘vulnerability paradigm’

If HIV is increasing in women and if to date a male-centred approach has been taken as the approach to prevention, then for this study, a feminist perspective is important. Harvey (2000) suggests that an appropriate theory to understand women’s risk factors for HIV is the theory of gender and power. There are a number of viewpoints for feminist theory. For this study, the viewpoint of gender inequality, with women being located in a social situation that is unequal to men, and the viewpoint of gender oppression, where women are in a powerless position related to men and can be subordinated, fit the history of women and HIV (Amaro et al., 2001).

However, feminist theory takes an inclusive approach to promote equity regardless of gender. In understanding the inequalities faced by women in their ability to stay safe in the face of HIV, it is also important to include heterosexual men in the solution (Amaro et al., 2001, Higgins et al., 2010). Although it is a strategy that would keep women safe and is valuable to encourage, the simplistic view that women should insist that their male partners use condoms would not be sufficient. Although the gay community adopted strategies to negotiate safe sex (op cit), within a heterosexual relationship this is less of an option due to the inequality and imbalance of power in relationships between men and women (Amaro et al., 2001). It is a strategy that may be difficult for women to achieve and according to Higgins et al (2010), feminists recognized early in the AIDS epidemic that this strategy would fail. It has also been critiqued as being inappropriate for ethnic/minority women (Bowleg, 2012). It is of value to raise awareness of HIV risk for women, including safe sex, testing and treatment, in a way appropriate for women to hear, but it is necessary to consider the social and community context, including men.

Importantly, however, Cameron (2012b, p36) argues that to portray the women with HIV as ‘victim of the HIV man’ will disempower and stigmatise the women, suggesting that this will undermine ‘Australia’s public health response’. Similarly, Higgins and co-workers (2010) argued that a key view of women earlier in the epidemic has its limitations. They questioned why women were described as the

most vulnerable victim of HIV and named that approach the 'vulnerability paradigm', in that 'women are susceptible to HIV because of biological differences in susceptibility, reduced sexual autonomy and men's sexual power and privilege' (Higgins et al., 2010 p 1). They noted that the paradigm implies that men engage in deliberate risky behaviour, where women do not and that women want to protect themselves, whereas men do not; gendered views of behaviour. Similarly, sex workers and pregnant women are described as vectors of HIV transmission (Amaro et al., 2001), whilst the man's role is not considered. As women are most likely to be infected with HIV by a male partner (Cameron, 2012a), this view of a woman as the vulnerable victim not only undermines her power and personal agency, but also fails to take the needs of the heterosexual man into account in developing public health prevention policy and programs (Higgins et al., 2010). In a commentary on the theory of gender and power as it relates to the risk factors for HIV and women, Harvey (2000), suggests that current models to promote behaviour change are individualistic and ignore the power imbalances related to gender. They point out that more research is needed into men's involvement in HIV prevention behaviours and the impact of the power imbalance attributed to gender (Harvey, 2000).

Bowleg (2012) argues for intersectionality, as a theoretical framework or perspective to be used in public health. For example, a woman may also be of colour and of low income and may already face discrimination and decreased access to health care (Amaro et al., 2001). Although this approach is seen as valuable, in this study, as the focus was on relevance to women in Australia, this was not examined, nor was the incidence of HIV in Aboriginal women, although the incidence of HIV in women moving to Australia from overseas has been alluded to.

One important aspect of applying a feminist lens for this study is the use of women's stories and interviewing women, as these methods provide access to hearing women's voice and their thoughts in their own words (Edwards, 2002, pp 28).

Transformative stories: transportation theory and story theory

The two main theories that underpin the investigation of the stories in this study are transportation theory and story theory.

Transportation theory

Barbour and co-workers (2016, p816) suggested that 'transportation theory provides a useful framework for theorizing why narrative works' and that additional message features of story structure, understanding, personal relevance and not overloading, if present, will increase transportation. The

impact of stories does not occur through an intellectual process, but by the reader becoming immersed in the text and relating to the character and their experience (Barbour et al., 2016). The strength of that immersion, transportation, or absorption in the story influences the reader's beliefs, so they may align more strongly with the beliefs in the story after reading it (Green & Brock, 2000). The elements in a story leading to a belief in the story character and its conclusions are a key factor in the persuasiveness of narratives. A validated method, developed by Green & Brock (2000), was used to measure transportation, including measures of additional message features such as story structure, understanding and relevance (Barbour et al., 2016, p817)

Story theory

A narrative has an identifiable story structure, a beginning, middle and an end; and a specific plot with vivid imagery in which a relatable character faces and resolves conflict, within a plot that follows a recognised story-curve (Barbour et al., 2016; Green & Brock 2000; Hinyard & Kreuter, 2007).

Stories constructed in a specific way may effect a change in perspective of the reader. A narrative has an identifiable story structure, a beginning, middle and an end; and a specific plot with vivid imagery in which a relatable character faces and resolves conflict, within a plot that follows a recognised story-curve (Barbour et al., 2016; Green & Brock 2000; Hinyard & Kreuter, 2007). The story curve leads the reader through engagement and recognition of self in the character, raises questions, reaches a climax in the story and finally moves toward resolution (Barbour et al 2015; Hinyard & Kreuter 2007; Green & Brock 2000; Lee et al., 2016). Following the principles of a story curve is a basic requirement for a story to be transformational and an example is shown in Fig 1 (below) and aspects are included in Appendix 1, which outlines features of transformative stories. Barbour and co-workers (2016 p830) acknowledged that 'Communication Professionals', people who work in the field, are skilled in crafting narratives and often achieve story structure and character development in their writing.

Thematic Analysis

Thematic Analysis as proposed by Braun and Clarke (2006), a method to identify, analyse and report data, is compatible with a constructionist view and was the approach used in this study. It allows for flexibility in the method whilst being methodologically sound. It can be used within a number of theoretical frameworks, in this case hermeneutic phenomenology and narrative inquiry, which informed the assumptions about the data and what they represent, as did my position as the researcher. It was particularly suitable for the content analysis and audience reception of the stories. The aim of the

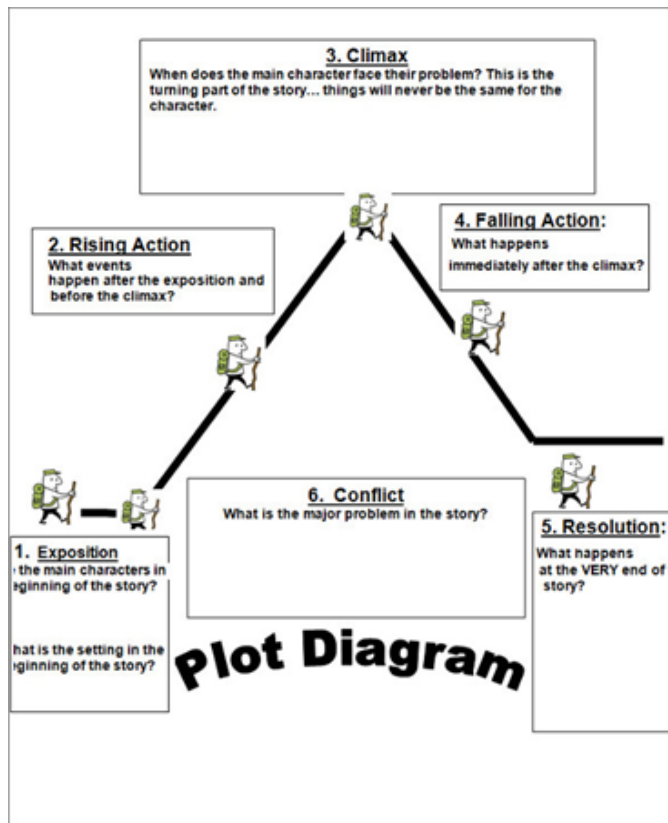


Figure 1 Plot structure and diagram template¹⁴

Fig 1 outlines a standard story curve¹⁴, including aspects of the story that would be included at each stage

thematic analysis was to achieve a rich description of the data, identifying patterns and themes, both theoretically, from the literature and inductively as new themes were noted. Themes included explicit or obvious ideas, as well as latent or underlying themes. Prevalence of a theme provided insight into the way the stories were analysed, but did not detract from its importance. In this study, the research questions guided the thematic analysis but did not restrict it. As additional themes were identified, they were included in the analysis, if they added to the broader understanding of the issues. The approaches suggested by Braun and Clarke (2006), were followed to ensure clarity and rigour to the analysis. The hermeneutic cycle facilitated familiarity with the data sets, as well as reflexivity, and continued throughout the analysis. Using a constant comparison approach, new themes were cross checked across the data sets. The analysis of both Stage One and Stage Two were presented in the Combined Data Analysis (Chapter 6).

Chapter 4: Methods

Qualitative descriptive research, which follows general principles of naturalistic enquiry to study and understand a phenomenon, brings together a variety of purposive sampling techniques, data collection and data analysis tools (Colorafi & Evans, 2016). These can include any purposive sampling technique, document review, minimally or moderately structured focus group questions, individual interviews, content analysis and descriptive statistical analysis; with theoretical frameworks to organise the research design (Colorafi & Evans, 2016) all of which have been incorporated into this study.

Research design

Table 5 Study Design

Stage	Data source	Methodology	Methods/ tools/ analysis	Research questions
Stage one	A set of 22 stories publically available in online magazines and news sites	Narrative Inquiry Hermeneutic Phenomenology	A descriptive content analysis of stories about women with HIV: variables were gathered in a quantitative data base using EpiData software; and as a deductive and inductive Qualitative Analysis	RQ1
Stage two	Focused interviews with eight female participants who do not have a diagnosis of HIV discussing two of the stories. Posts and comments online from readers about 10 stories	Narrative Inquiry Hermeneutic Phenomenology	The audience reception of stories from Stage one was investigated through focused interviews. The theme guide and interview questions were developed from both the literature review and analysis of data from stage one. Thematic analysis of online reader feedback	RQ2
Stage three	22 stories Eight participants scored two stories after reading	Transformation theory Narrative Inquiry	The stories selected from online sites were investigated: <ul style="list-style-type: none"> • Transformative story template (22 stories) • Transportation scale (of two stories by eight participants) Measures of word count and readability of 22 stories	RQ3

Study design

The study design is outlined in Table 5 (above), including the relation of the research questions to the overall methodology, the three stages of the research and the methods selected for data collection and analysis. Although the quantitative analyses and qualitative analysis were planned and are described discretely, the processes informed each other. The literature review and themes from Stage One informed the interview guide for Stage Two. The analyses of Stages One and Two were combined in a thematic analysis, with the resulting themes outlined in the Combined Data Analysis, supported by evidence from both the content analysis of the documents (the stories) and the audience reception of the stories. The transportation scores by participants of the two selected stories in Stage Two, along with some of their feedback, informed Stage Three and the investigation of transportation and transformational potential of the stories.

Project Map

A project map of the research design, components of each stage and anticipated data is shown in a flow chart format in Fig 2 (below): Research Design and Project Map. The stories in Stages Two and Three were selected from the stories in Stage one. The project mapping shows that the themes used for the interview guides in Stage Two were developed from both the literature review and the descriptive content analysis from Stage one. A number of data sets were created, allowing for triangulation of the data. This was illustrated in the Combined Data Analysis (Chapter 6).

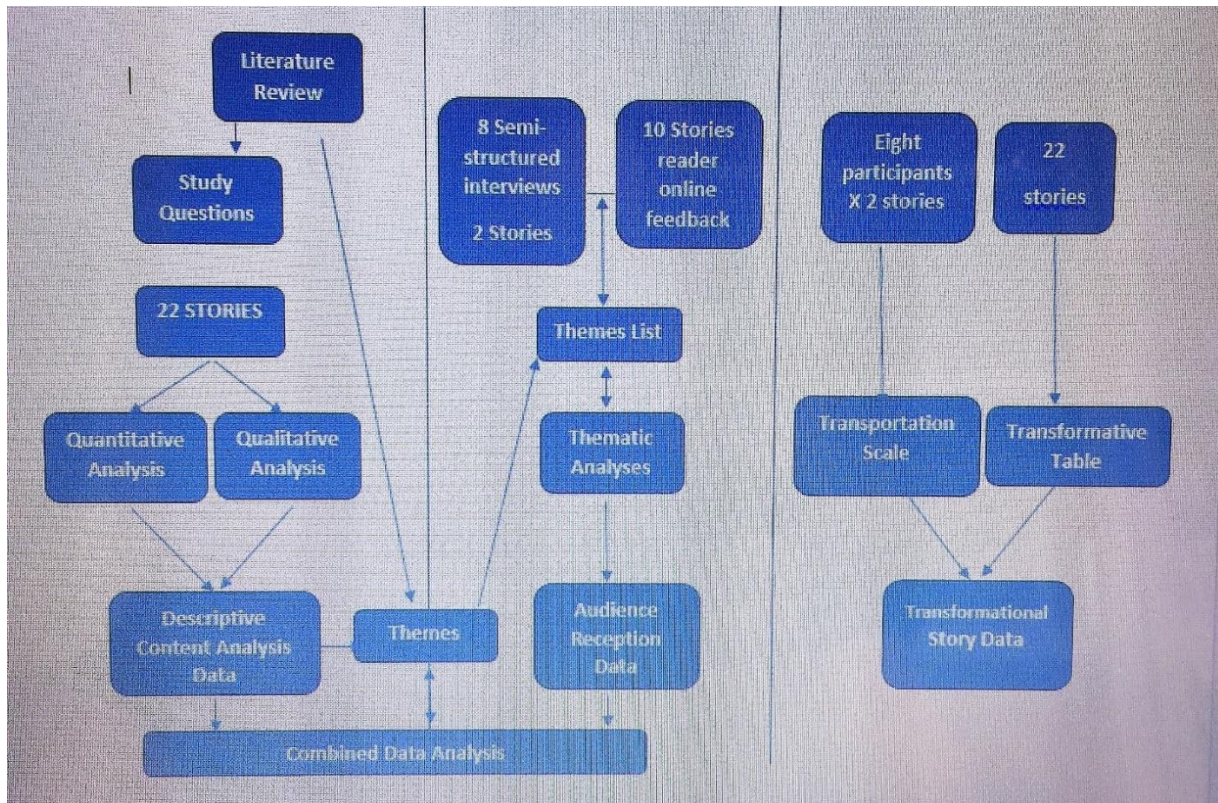


Figure 2 Research Design and Project Map

Sampling strategies and units of data for the three stages

Often the term ‘sampling strategy’ is not used in phenomenology, apart from the selection of people informants (Gentles et al., 2015). However, other theoretical perspectives form part of this study. Sampling, therefore, was planned to provide as much data as was reasonable and was conducted in a systematic way to provide answers to the research questions and strengthen the validity of the results (Curtis et al., 2000). Gentles and co-workers (2015) defined sampling as the selection of specific data sources from which data are collected to address the research objectives. For this study, sampling was predominantly purposive, whether sampling informants or documents. Careful thought went into deciding where and how to obtain data sources that would provide insight into the study questions. Purposive sampling is appropriate for the theoretical approaches in this study, as it is associated with qualitative research and provides a rich data set to allow for in-depth study (Baum, 2002 p175; Colorafi & Evans 2016).

Sampling occurred at a number of points in the study, as outlined in the Study Design (Table 6 above). It included: selection of the documents that contained content suited to the investigation i.e. stories about women with HIV; selecting which of those stories would be measured for transportation measures by the interviewed participants; and sourcing suitable informants or participants for the focused interviews.

Sampling of the Documents (The stories)

For all three stages in this study, the documents for analysis were single stories about women with HIV. The selected stories were found on the internet in magazine or online news sites. Some were published as a single published story. Some were published in a group of stories, with an overarching article. Based on the study objectives, the overall sampling strategy for obtaining stories for analysis was purposive, to investigate stories in both magazines and on-line news sites, as well as the characteristics of the population of interest, being women with HIV.

Regarding sample size, all of the suitable documents were sourced. The websites were selected following the sampling and inclusion and exclusion criteria as described in Table 6. Using the search terms “HIV, Women, stories”, 35 websites over four pages were reviewed against the inclusion criteria that the website contained stories or articles that were: publicly available; contained one or more personal stories about women with HIV; the story was written in first or third person; was text and not in video or audio format; and was relative to an Australian audience. Internet searches uncover thousands of hits over many pages. In the search for stories for this study, although many more pages were retrieved, most of the ‘hits’ that met the selection criteria were found on the first four pages of the searches. The websites found on the fourth page and beyond contained articles that were general in nature, blogs or not relative to an Australian audience e.g. Cambodia, Africa, or Black Women in the USA, where the rate of HIV in women is much higher than in Australia. Seven sites supporting People Living with HIV (PLWHIV) contained suitable stories but were not included for the purpose of this study, as those sites are not regular magazine or online news sites.

Common and popular tools readily available in Australia were used for the internet searches. The search was first conducted in Dec 2016 and repeated in April 2017 to confirm the search results and ensure that significant websites had been included. Google Chrome and Bing were thought to be the most common internet tools and Safari is the default search engine on Apple products such as I-phone or I-pad, popular and common devices. These were chosen as they were thought to represent the common

internet tools that might be used by women looking for news or magazines on the internet¹⁸. The final list of websites contained personal stories about women with HIV.

Table 6 Sampling criteria for web sites

Inclusion criteria	Exclusion criteria
publically available	News report or other article, not a personal story
purpose of website was popular media, e.g. magazine or news site	Blog, not magazine format Website to support PLWHIV
article/website contained one or more personal stories about women with HIV	Call for stories
story focus was about one or more women with HIV, written in first or third person	Focus not on women's stories
story was presented in text format (i.e. not video/audio)	Audio/video/photo/TV format
story was relative to an Australian audience	Not relative to Australian audience e.g. stories based in South Africa or about Black Women in the USA, groups having higher incidence of HIV than women in Australia (Clarke et al 2006)

Preparation of the Documents (stories)

A full copy of each article as it appeared on the internet was made, including any posts and feedback by readers that related to the whole article or the individual stories. In addition, the text-only of each story was extracted, copied and saved as a separate Word document. This not only allowed for the story itself to be analysed, but also removed the potential influence of publication ideology and presentation. The selected single stories and articles with several stories were sorted and grouped into categories based on publication type. Analyses for Stages one and two were conducted firstly on the text-only of each story, including story structure and content; and secondly on the complete article, which provided the context of the story within the publication in its original format. The full data set of 22 stories were used in Stage one. Two of those stories were selected for participant interviews in Stage two: Story Code 701 and 101 (Table 9). In Stage three, the texts of the two stories were coded for transportation effects by the participants and all 22 stories were investigated for their capacity to be transformational.

Sampling for Reader/Audience Reception

For Stage two, two sets of data were used to investigate the audience reception of the stories or documents. These were: 1) online reader feedback on the websites in response to some stories and 2) participant interviews of two of the stories: Story one⁸ (701) and Story two⁶ (101) as noted in Table 9.

For the online reader feedback, all the responses associated with the selected articles were copied and printed. The strategy was both purposive and convenient, as the comments were attached to the stories of interest and readily available and all the available comments/data were investigated. However, since the potential for readers to give feedback online can create a large data set that is unwieldy and difficult to manage, Singh, Hillmer and Wang (2011), suggested a sampling strategy where respondents comments were treated as a collection of *information units*, containing one idea. They grouped the data according to those units and then took a random sample of the comments the groups with the most information units for analysis. Although all the comments were used in this study, without further sampling, the suggestion by Singh et al. (2011) to group ideas together was used.

To select participants for the focused interviews in Stage Two, sampling was purposive, convenient and targeted (Trotter, 2012). The sampling was also stratified, to select an audience of women, able to read and write English, who do not have HIV. An additional stratification for age was adopted, to select two groups of women anticipated to have had specific but differing experience of the AIDS/HIV phenomenon. These two groups were: women aged above 45 years, who would have reached adulthood before HIV was identified as a disease; and women aged between 18-35, who would have grown up knowing that the HIV virus exists and hence have always lived with the possibility of being in contact with HIV. As the researcher, my experience of HIV/AIDS fits into the first category. Participants were approached in two ways: through social networks, which are based on likeminded people and therefore may affect generalisation (Trotter, 2012) and by individually approaching women. Regardless, participants volunteered or self-selected, and as such may have had an interest in the topic.

There are few guidelines in sample size in qualitative research (Marshall, 2013). For this study, the usual goal to 'achieve saturation' is inadequate, as the final sample size depended on the ability to recruit willing informants. Approximately ten participants has been suggested to be sufficient for interview, if participants are followed intensely (Gentles et al., 2015). The main purpose of interviewing women was to provide the perspective of audience reception, which has often been omitted from content analyses of HIV/AIDs in the media. As a result, the potential sample size of women informants was set at ten, with the intention of recruiting as many as possible within the available resources and time frame (Marshall, 2013).

As a matter of convenience and ability to reach adequate numbers of women in the time allotted, recruitment was planned through women's social networks and organisations. Initially the Victorian chapters of the Soroptimists and Sweet Adelines were approached. Key contacts for both initially gave

approval in principle, each requiring an official request to, and approval from, the local organising committees, which took time. The Soroptimists, after three months declined to participate in the study. An initial request sent out to the Victorian membership of Sweet Adelines did not result in sufficient interest and a subsequent request was sought and approved to access members across Australia, who were approached by the key contact. Several women were also recruited individually, after a conversation about the research.

Sampling for Transformation and Transportation measures

For Stage three, all 22 stories in the data set study were sampled to measure their transformative properties, using the Transformational Story Template (Fig 5). In addition, all 22 stories were scored using the Flesch-Kincaid readability measures (Table 13). As part of the focused interviews, the participants were asked to score two of the stories using the adapted Transportation Scale (Table 7). These two stories were also the focus of the interview questions, so were the appropriate choice for the participants to score regarding transportation and allowed for triangulation of the data.

Sampling the stories for the Interviews

Two stories were selected for the interviews and hence transportation scores by the participants. The choice was finalised after discussion with the second supervisor. It was felt that two stories would provide enough information to be absorbed by the participants and then be discussed in detail.

The two stories were intentionally selected from the complete set of stories. One reason was to investigate whether a difference in presentation style or publication ideology had an impact on audience reception of the story, versus reading the text-only of the story in a separate document. The Daily Mail is known for and tends to present its stories sensationally, with aspects designed to attract attention, so one of the stories from the group published in the Daily Mail⁸ was chosen. In addition, that story had a large number of images (Story one: 701). The stories presented in the Australian Women's Weekly⁶ had a simple presentation style and were more 'matter of fact', with fewer images and less surrounding detail (Story two: 101). Both of the selected stories had been published as part of a group of stories, not as single-story articles. Both articles had some background information, although the amount varied considerably. The articles also invited online feedback. Finally, one woman was diagnosed about 20 years ago, and one more recently, as another aspect to look at. The details of Story one⁸ (701) and Story two⁶ (101) are outlined in Table 9, with source noted in the footnotes.

Methods Stage one – Descriptive Content Analysis of the documents (the stories)

The descriptive content analysis was conducted on a purposive sample of stories about women with HIV, found on the internet by searching “Women, stories, HIV”. It included the collection of manifest data using EpiData software version 4.0.2.101 (Lauritsen 2003-2005) and the collection of qualitative excerpts into a template based on a relational framework.

Descriptive Content Analysis

Content analysis is a documentary method suited to print media, both written and visual (Sarantakos pp279 1998). The four traits of content analysis outlined by Karlsson and Sjovag (2016) are that the data is: published in a ‘window’ of time; all the data existed prior to the research; the text of the content is preserved and can be captured and measured; content is not affected by the researcher; and the analysis could be replicated. Content analysis can be quantitative or qualitative, both of which systematically identify ‘data segments that contain similar material’ (Morgan 1993, p114). Morgan (1993, p115) argues that in both cases the data and data segments are counted and that counting the patterns of data is also valuable in a qualitative approach:

“In quantitative content analysis, counts and tabulations of the codes summarize what is known about the data, and the analytic effort typically stops with the presentation of these numerical results. In qualitative content analysis, however, such counting leads to the crucial further step of interpreting the pattern found in the codes”

In this study, both qualitative and quantitative approaches were used, resulting in a layered, descriptive analysis. In addition to gathering excerpts to illustrate themes, as is common in qualitative analysis, the frequency and the patterns of excerpts and themes was investigated and counted across the stories, the publication types and the women whose stories were told. Counting provided insight into the interpretation of the data. By adding a qualitative approach to the more traditional quantitative analysis, the content analysis more closely met the research goals of this study, which required interpretation of the patterns in the data (Morgan 1993). Other authors agree that when both quantitative and qualitative approaches are used in a content analysis they are complimentary. A qualitative approach provides rich description of a phenomenon and can provide additional insight and an understanding of the context within which it occurs (Altheide 1987, Lupton 1992, Hains-Sahn 2014 and Colorafi & Evans 2016).

Content analysis has frequently been used to analyse texts from the media. While quantitative content analysis allows for measuring the manifest meaning of media texts, by counting messages and providing statistics about content, a qualitative approach, provides an understanding of the latent or sub textual meaning as well as insight into themes and the nature of representation of a topic in the media (Lupton 1999a, Lupton, Chapman and Wong 1993, Lupton 1992). In this study, the analysis included counting of both quantitative, manifest content, such as repeated images, themes and changes over time, as well as a qualitative interpretation of latent content, or underlying meaning (Sarantakos pp279 1998, Karlsson and Sjavaag 2015).

With this study, effort was made to ensure the processes of quantitative and qualitative data collection, including the layers used in the Descriptive Content Analysis, were systematic. There is a positivist paradigm often associated with public health, so the data was collected in a consistent fashion, using methods based on the literature, thus alleviating any criticism of subjectivity in the approach. An EpiData data base (Appendix 2 & 3) was set up to capture manifest or quantitative measures, with additional counting of phenomena or characteristics by hand. A Relational Framework (Fig 3) was adapted from McCormack's Lenses (2000) to include the theoretical perspectives of stigma, feminist and transformation theories, to collect qualitative data in a Qualitative Content Analysis Template (Fig4).

Development of the Qualitative Content Analysis Template

The qualitative data were organised into themes (Altheide, 1996, Braun & Clarke, 2006, Bowen, 2009, Kafle, 2011), including excerpts and quotations that supported qualitative analysis of the key perspectives. The qualitative analysis also used the hermeneutic cycle of reading, reflection, re-reading and interpretation (Kafle, 2011). The stories were continually referred to in order to check and recheck ideas and assumptions, ensuring rigour and promoting richness and depth of the data. A process and template were required that would enable the layers and perspectives to be collected in a systematic and clear fashion.

Initially the Relational Framework (Fig 3) was devised using 'McCormack's Lenses' as a base.

McCormack's (2000) Lenses is an existing framework which aligns with a phenomenological approach, to enable a researcher to organise and group large amounts of narrative data (Dibley, 2011). It contains four lenses with relevance to the analysis of stories in popular media about women with HIV: *language, context, moments and narrative processes*. McCormack (2000 p282) described the lenses as 'the dimensions people use to construct and reconstruct their identity and give meaning to their lives'

Additions were made to McCormack's Lenses in the areas of language (Feltham-King & Macleod, 2016; Lupton, 1992) and context (Lupton, 1992). The investigation of language and context uncovers latent meaning and provides a valuable addition to the analysis of manifest data (Shaw & Bailey, 2009; Feltham-King & Macleod, 2016). To create the Relational Framework, the data collection for the analytical lenses language, context and moments/narrative processes, as well as for the theoretical perspectives of stigma, feminist and transformation theories were incorporated (Fig3). The Qualitative Content Analysis Template (Appendix 4) was developed from the Relational Framework (Fig 3) to gather qualitative excerpts from the stories. The initial themes were deductive. As a result, the initial Relational Framework (Fig3 below) and resulting Qualitative Content Analysis Template (Appendix 4) were developed deductively from findings in the literature, with new or unexpected themes noted inductively during analysis (Altheide, 1996; Braun & Clarke, 2006; Kafle, 2011,).

This aligns with one of the three types of content analysis described by Hsieh and Shannon (2005), a Directed Content Analysis. This type of content analysis is deductive, based on an existing theoretical framework applicable to the research question. It provides an initial coding scheme with pre-determined categories and a structured approach. As the data is analysed, the qualitative excerpts are aligned with the predetermined codes, with new codes added as required. In this study, the Qualitative Content Analysis Template (Appendix 4), adapted from McCormack (2000); Lupton (1993); Winterbottom (2008), provided the initial predetermined codes against which the qualitative excerpts were coded or 'filed'.

Language

The 'tenor' theme or tone of media text has been shown to affect attitude, for example promotes discrimination (Lupton et al., 1993), so the language and subtext in a story are important features to understand. Lupton (1992) suggests that investigating language shows what might lay underneath the surface of the text, contributing to the patterns of knowledge that a reader might unknowingly take away with them. For example, the media may use a discourse of *tragedy* (sad, loss, distressing) for a child with HIV but may use a discourse of *deviance* (deserve it, guilty, sleazy, risky behaviour) for a gay man, as has been seen in early AIDS media. A discourse of *courage* (brave, fighting) may signify this was not the person's fault, as might a *victim* discourse (innocent, not in control). In addition, it is valuable to note how a phenomenon is presented (Lupton, 1992), for example does the story show that HIV/AIDS affects one particular group, or it is shown as indiscriminate with the potential to affect anyone. In this way language has an impact on the reader's reception and so the language used in sharing messages has an impact on the way the reader understands (McCormack, 2000). The author of the story is also

significant, especially for transformative impact as a reader will engage more readily with a story written in the first person.

Analytic lenses			
^Theoretical perspectives	^Feminist Theory	^Stigma Theory	^Narrative persuasion
Variable (V)			
Language <ul style="list-style-type: none"> • What is told and How (how does the woman speak about herself/ relationship/ environment) • Why (reason/purpose) • Who its being told to (target audience) Tenor (drift/Latent meaning i.e. subtext, choice of words (Lupton) e.g. Deviant, victim, brave, innocent, tragic.	Qualitative excerpts in Word file	Qualitative excerpts in Word file	Transformative Story Template Stage three
Context - How woman sees herself <ul style="list-style-type: none"> • Social context • Wider cultural context (cultural, political, historical) Personal agency - Accommodation, Challenge, Resistance Context of production <ul style="list-style-type: none"> • Headings • Location (type of publication) • Pictures/images 	Qualitative excerpts in Word file	Qualitative excerpts in Word file	Transformative Story Template Stage three
Moments (something unexpected is happening) New previously unrecognised understanding of an issue/ Personal epiphany/Leap of understanding (turning point)			Transformative Story Template Stage three
Narrative processes (imagery, emotional intensity, descriptive, argumentative, augmentation, theorisation (reflect, find meaning))			Transformative Story Template Stage three

Figure 3 Relational Framework

Language allows a person to share their experiences, emotions and situations; to communicate their experience in the world as well as how they feel. It can highlight relationships, social roles and context and as well as providing information it also conveys the meaning of a person’s story (Viney & Bousfield, 1991). People can choose what to include in their story, in other words they can decide what is told to

others, thus creating their own reality (McCormack, 2000). This has relevance for women with HIV who may choose what to disclose in their stories to avoid stigma.

Context

Lupton (1992) suggests that locating the research in a socio-political context, declaring the researchers perspective and ensuring sufficient measurable data that can be replicated, will validate assertions made in the analysis. As mentioned, there is agreement that an individual's story is always understood in a social context (Clandinin, 2006, McCormack, 2000, Rappaport, 1995). The HIV/AIDS story is also one that must be considered in a cultural context, both of the timelines of the virus and disease in Australia, for example, and the impact on society as well as location of the disease in different countries and the broader cultural differences that brings. Hence cultural and social contexts are important to note in the layers of qualitative analysis.

The context of personal agency, including acts of accommodation, challenge and resistance (McCormack 2000a), was deemed important to include in the analysis. Women may not believe themselves to be at risk for contracting the HIV virus risk (Helfland 2003, Costello 2012, Persson 2014). In addition, as noted, prevention strategies such as condom use or negotiating safe sex may not be under a woman's control (Amaro, 2001).

As this study looked at stories in the media, rather than messages created by health professionals, and as the articles or documents for review were context specific (Bowen, 2009), the context of publication, perspective of the publisher and presentation were important to note. A magazine may be interested in entertainment and as a result a sensational, human interest or drama angle might be taken (Lupton et al., 1993). Any content analysis of media documents therefore should include type of publication, purpose, reason produced, target audience, information about the author, source of information (first or second hand) and editing (Bowen, 2009, McCormack, 2000). In addition, the size, space taken and language used in headlines, images and the use of adverts is noteworthy (McCormack, 2000). A person may only read a headline and move on or a headline may attract a reader to read the story; and the language in the headline may be expressive with a sub textual meaning (Lupton et al., 1993).

Narrative persuasion

Moments and narrative persuasion were investigated predominantly in Stage three, although excerpts were also collected using the Qualitative Content Analysis Template (Appendix 4)

Data collection and analysis for Stage one

Collection of quantitative (manifest) data using the EpiData data base

An EpiData data base was set up, using EpiData software version 4.0.2.101 (Lauritsen 2003-2005). The initial DataForm represented the story characteristics/variables and article characteristics/variables, deemed relevant in the literature review. This included, for example: demographics of the subject, layout, headings, length, publication date, purpose, headline characteristics, percentage of article that included photographs, number and type of adverts (Hinyard & Kreuter, 2007). For more detail see Appendixes 2 & 3. The stories were read and re-read. The data were collected by hand for each story into a hard copy of the EpiData Dataform, using the text-only of the story. Those data were then coded into the database. The data were coded by hand initially, as some aspects that had been included, for example readability scores, required separate calculation. The complete web-pages were coded separately. New or unexpected themes that had not been noted during the literature review were noted during this process and throughout the content analysis.

The coding was checked by a co-researcher with agreement across three stories (13.6%) and partial agreement of a fourth story, with agreement after discussion. The coding of three additional stories was discussed to check that the interpretation of coding was agreed.

Review and triangulation of EpiData data collection

Findings were discussed with the second supervisor to triangulate the data, as previously discussed, and validate the method and interpretation of coding. Four of the 22 stories (18%) were randomly selected (Urbaniak & Plous, 1997) and coded separately by the second supervisor, as noted in Table 10 (Results Chapter 5) and the findings were discussed and corroborated. An additional three stories were discussed, to increase the confidence level of the data collection and to confirm the direction of the qualitative analysis. From both the discussion with the supervisor as well as reflexivity by the researcher during the initial descriptive content analysis, the EpiData dataform was adjusted. Some additions and deletions were made, which contributed to a better understanding of the experiences of the women in the stories. The changes that were made included:

- two questions, not one, were required to capture how the woman contracted HIV. Most contracted HIV from the ex-partner, but in addition, some of the women had been overseas, or due to haemophilia or drug use.

- on re-reading the stories, it was deemed important to collect: links included in the story pages to other articles and links to resources/support; and their 'appropriateness' e.g. a link to a '*new website for porn for women*' was deemed an inappropriate link.
- estimation of 'year HIV was diagnosed' was added to the Dataform, as well as 'age on diagnosis', so that historical context could be examined, for example: ART improvements, tolerance and outcomes.
- the woman's knowledge about HIV was noted, which could be cross referenced to age or year of diagnosis
- after discussion, changes were made to the collection of data about stigma, so that incidences of '*stigma experienced by the woman*' as well as '*discussion by the woman about stigma in general*' could be collected separately. This also reflected emerging qualitative themes (q.v.).

Triangulation of data is an important aspect in qualitative data collection, to strengthen confidence in the interpretation. This can be done using several research methods and comparing findings, or by coding by a co-researcher to ensure consistent interpretation and understanding. Both approaches were used in this study. As the primary researcher, the data expected to be coded into the initial Dataform, was not necessarily the data found on reading the stories. For example, the questions on 'stigma' were changed after reading and coding 22 stories. It became clear that in these 'recent' stories, the journalist did not stigmatise the women as had been expected from the literature review. Since the interpretation of stigma could be subjective, it was important to check if this was a real finding prior to making changes. Once discussed with the second reviewer and confirmed, the data form was changed and all the stories were re-read to collect the new data on stigma i.e. was the women's experience of stigma due to the diagnosis described in the story and/or was stigma discussed as a broad issue. Some changes were simpler, in that the initial 'year of publication' was not deemed to be as valuable as 'year of diagnosis', so the latter was added, again requiring all stories to be reviewed. Finally, as some of this data could be subjective, for example the 'appropriateness' or sensational aspect of a linked article, it was valuable to check where my personal limits were and that they were considered reasonable.

The final adjustment was discussed with regard to process. Each story was embedded in an overarching article, of varying sizes and content. Initially, to assess the impact of publication context, a separate Dataform had initially been developed and data collected for the overarching article. It was determined that if some of the article data was added into the story Dataform One, the process of analysis would be simplified and the variables more easily analysed against each other using the software. Only key items

about the article were kept and a decision was made to analyse the articles and their impact on the stories, if any, as part of the qualitative analysis (Appendix 10).

The text versions of all the stories were rechecked using the adjusted Dataform One and changes transferred to the EpiData database. This enabled existing data to be checked and allowed for additional items to be counted.

Collection of latent content, using the Qualitative Content Analysis framework

This process, although iterative in nature, took two main steps. Firstly, excerpts from the stories, or data extracts, were identified according to the headings in the Qualitative Content Analysis Template (Fig 4). As each story was read, the contents of the story in the form of excerpts or quotations were placed in one or more appropriate sections in the template. In essence, the stories were deconstructed as all the components of the story or excerpts were populated directly into the template.

As described previously, the deductive themes from the literature, written as the sections or headings of the template, formed the basis of the manual data coding. New ideas or headings were added as needed. The template also allowed for cross coding of theoretical perspectives, for example an excerpt located in the 'safe sex' section could also be coded as relating to feminist theory. The Qualitative Content Analysis Template itself provided a visual 'coding system'. The template contained the story code (identifying the woman's story as well as the publication) and identified the data sets by colour coding. Repeated stories could also be identified. For some of the women, their story was published in more than one publication and easily identifying repeated stories became an important factor in understanding and interpreting the data.

Once the stories and qualitative excerpts had been deconstructed into the template, the template provided a visual aspect of all the stories related to the four lenses, individual story and theoretical perspectives. The number of excerpts under each heading, or as relating to each publication or to each story, could be easily seen. The attribution of the excerpts as they related to the different women could also be seen visually. Initially each data set was analysed in a separate document, to be able to investigate commonalities or difference across publication types and the comparison of writing and presentation styles as they related to the type of publication. Then all data from the data sets of story texts was compiled together into one table. However, one additional data set was completed and kept separate, containing the analysis of all the background information from the publications.

Secondly, the grouped information from all the stories, in the Qualitative Content Analysis Template, was further analysed and combined into main themes. The themes and the excerpts collected from each story were cross referenced repeatedly with continual reference back to the original story to check accuracy. This ensured that the themes were based on evidence from the stories rather than the expectations of the primary researcher. In addition, ideas that appeared a number of times across the data set, for example 'lack of GP knowledge', were checked against the woman in the story, to ensure that repeated stories did not influence the prevalence. The populated template and initial groupings were reviewed by the supervisors, prior to finalising the main themes. The main themes, including deductive themes and new themes, are outlined in Main Themes (Appendix 5).

Methods stage two: audience/reader reception of the documents (stories)

The intent of Stage two was to investigate how stories about women with HIV might be received by the intended audience. This was achieved in two ways: 1) by analysing reader posts and comments, posted online in response to the specific articles and stories; and 2) by conducting focused interviews with a potential audience of women who do not have a diagnosis of HIV (and to whom prevention of the HIV virus transmission is a relevant public health issue).

Audience - online reader feedback

Narratives are known to reflect a stronger intention to share with others (Barbour et al 2016). Investigating how the stories were commented on and shared in the online environment was an important aspect to investigate. This reflected audience reception, but also the aspect of sharing with others something you feel is sufficiently important, which was also investigated in the focused interviews. Sharing is also a key feature of the online environment and one that can considerably increase the 'reach' of a document.

It is common for articles published online to solicit or invite feedback from the readers. There are a number of ways readers can provide that feedback. A common way is to invite readers to post a comment or provide feedback at the end of the article. Other readers can either click that they *Like* or *Dislike* what is said, or they can write their own response, which in turn can be clicked on by other readers to *Like* or *Dislike*. This can generate feedback that relates to a large number of readers. The best type of reader feedback is moderated by the publisher, a process which weeds out inappropriate or

unrelated comments. A second way is to simply *Share* the website by sending it to other readers, which can represent the article being shared with thousands of additional potential readers, increasing the reach of the both article and any attached posted comments. Finally, some feedback is invited by asking readers to 'rate' the article. In that case the rating scale is provided by the publisher, usually a Likert-type rating scale with descriptive points. These types of feedback provide the perspective of those who chose to post a response and do not necessarily represent either the opinion of all those who read the stories, nor the opinion of the general public. However, this feedback is valuable, as it is from people who had read the stories, responding in a timely fashion to record their reactions. As such, they provide some insight into how the stories are received. It also represents the large number of people who read the article and hence potential reach of the message.

All the feedback related to the stories in the data set was gathered for analysis. For the three sets of moderated posts, Daily Mail, Guardian and Herald Sun, each posted comment was placed into a template and the themes that had already been identified from the content analysis (deductive) were assigned to each comment. Where there were new ideas, these were noted, for example: writing and imagery and 'use a condom' is not a strong message for heterosexuals. The brief notations for the themes included: ignorance, misinformation, empathetic/positive, LWWHIV, Safe sex, Testing, stereotype/anyone, blame, HIV from partner, children, deliberate infection, ART, Stigma (eg fear of other), world has changed, sharing stories. This visual representation of the data allowed for cross referencing, organising and analysing the data.

Initially, the audience reception of stories was limited to interviews. However, the extent of the reader feedback available for these stories became apparent early in the study. As a result, *Online reader feedback* was added into Stage two (audience reception of the stories) as a second key source of data on reader reception.

Audience – focused interviews

Focused interviews were held with women who do not have HIV, across two age groups (op cit), to investigate their response to selected stories from the data set and to provide insight into their experience of the stories, as the potential audience. The use of focused or in-depth interviews is an appropriate data collection method in hermeneutic phenomenology. Focused interviews align on a continuum between structured interviews and conversational interviews and are similar to semi-structured interviews, which are influenced by a positivist research approach. As there was an interview

guide, the interviews were focused, yet provided flexibility to ask the questions in a way that was deemed appropriate with each participant. This fits well with the constructionist, qualitative approach, to better understand the audience reception of the stories (Rice & Ezzy, 2004 pp 52).

Due to location of the participants across Australia, interviews were conducted via Skype and were of approximately 30 minutes duration. They were audio recorded, with signed permission, and transcribed by the primary researcher and participants were offered the option to review the transcript

Development of the interview guide

An initial Interview guide (Appendix 8) was developed for the participant interviews, with the research questions and objectives in mind, and discussed with the supervisors. The questions were based on several sources: the research questions, specific aspects of interest in the study, the deductive themes and queries arising from the literature review and the themes that had been determined from Stage one, the content analysis. This is outlined in the Research Design and Project Map (Fig 2). The questions were deliberately open ended, to encourage the participant to share their views, unbiased by the researcher. However, prompts were set up for some questions, in case significant aspects were not raised by the participant. Care was taken to ensure questions were not leading and prompts were planned to gain specific feedback if needed, or another open-ended question was asked such as 'can you say why?' As an example, one question asked for the impression of the story, to answer the research question 'how do the audience receive the stories'. The question did not specifically mention stigma, as the readers true impression was wanted in answer. However, since the perspective of stigma was an aspect of the study, if the participant did not mention stigma at all, a prompt about stigma was asked, in case the participant had simply not thought about it. This was deemed important to check, as the literature review had noted that stories in the media were written in a stigmatising way, although this theme was not borne out in the content analysis of the stories. In addition to perceptions of stigma in the story, narrative persuasion of the stories is another aspect of audience reception, aligning with research question three.

In brief, the interview guide included the participant's opinion of these stories, the women in the stories and the main messages? Had they learned something; thoughts about the women in the stories and about HIV; looking at the full presentation, would they have read them, would they share, how do they read magazines? As mentioned, for example if stigma was not mentioned it was used as a prompt.

The stories were narratives, which are known to reflect a stronger intention to share with others and have been shown to have an impact on perception of the message (Barbour et al., 2016). In health promotion evaluation, a common question I have frequently used is “will you share this information/program with a friend”, to provide some simple measure of impact, the premise being that it will be shared if the content is deemed important enough. A similar question was included in the interview guide in this study to gauge whether the participant had sufficiently engaged with the story enough to share. Barbour and co-workers (2016) noted there has been little emphasis on sharing persuasive narratives in the literature. However, it was considered a key factor to investigate in this study, as the premise is to investigate the usefulness of stories as a mechanism to reach women.

As the interviews progressed and answers analysed, adjustments were made to the questions, or to how they were asked, for example the order in which they were asked. Simply as a practicality, all the women in the over 45 age group were interviewed first. Some ideas were raised by that group regarding their impressions or concerns about younger women and their experiences with HIV. A question was added for others in that group along the lines of ‘you can’t answer for another person, but how do you think a younger women might experience that?’ to gain insight into how a woman’s experience of HIV might have changed over the years. The question was asked of the women in the 18-35 age group. Another question was added after the first interview. There was an impression from the content analysis suggesting an overly optimistic presentation of HIV, as not a big issue and that it could be ‘fixed’ with medication. It had not included, in case it had been a personal reaction to what otherwise were positive stories. However, the first interview participant raised that same concern quite strongly and as a result it was added so it could be checked in subsequent interviews. Another example of flexibility was that questions were not asked in a regimented, identical way with each person. For example, two women in the over 45 group had significant background knowledge of HIV, one was a GP and one had worked with the San Francisco Aids Council in the 1980s. The way I phrased questions to both of them reflected respect for their potential background knowledge. Similarly, I was careful that the youngest participant fully understood what I was asking her. Finally, items that were added that included: asking about the participants’ reaction to the additional links and adverts and if they had clicked on them to look; asking the 18-35 group if ‘selfies’ was something that was attractive to a younger audience; and asking the 18-35 group if the stories would have had an impact on them as a young woman.

In interviewing, it was important to phrase questions to reflect what the participants had already said, showing they had been heard. Allowing silence also gave time for thought and to answer. Although, easy

in person, this is sometimes hard to achieve with Skype, as Skype does not provide the same opportunity to give or receive non-verbal feedback to show attentiveness.

Two stories were selected from the whole data set for the focused interviews, as previously described. The text of the stories was provided for participants to read in advance. Participants were then asked to complete the adapted Transportation Scale (Table 7) for each text copy of the story, which would provide data for Stage three. They were then asked to open a link on the internet to review the two stories in their original format in the online publication. The questions asked at the start of the interview were based on the text content of the story, or the story itself but later questions referred to the full presentation as seen online.

As described, the themes from Stage One were used as the basis of the analysis for the focused interviews. Any new themes from the interviews or online feedback (Stage Two) were noted and checked back with Stage One data. This resulted in a Combined Data analysis for Stages One and Two as noted in the Main Themes (Appendix 5). In the analysis, comparisons were made between responses made between the responses provided by the women in the two age groups as it was assumed that their experience with HIV in their lifetime was different. The two stories, transcribed interviews and potential themes were reviewed by the supervisors.

Methods stage three: Transformation and Transportation

Transformational Story Template

Since the stories in this study were written by journalists, there was an expectation that they would include elements of narrative and story structure. Nevertheless, their potential to be transformative was investigated. All the stories in the data set were compared to a Transformational Story Template, created using features of transformational stories, identified by various authors (For detail see Appendix 1: Features of Transformational Stories).

The Initial Transformational Story Template (Fig 4) was completed on the text-only version of each of the 22 stories, noting the story code and the answer to each question as: yes/no/don't know. As the researcher, I understood and was familiar with the background to this table, as described in Appendix 1.

Variable (Answer = Y/N/DK)	Story code	Yes/No D/K
<i>See : Features of Transformational Story (Appendix 1)</i>		
Does the character reflect on their situation AND reflect on more than own situation – making change to right a wrong		
Is the character believable AND relatable		
Is there an emotional connection		
Does the story engage all senses, imagery AND does story use descriptive language. Is there a 'hook' to capture attention		
Does the character struggle with a conflict AND one key struggle		
Is there tension to keep your attention AND there is rising tension culminating in a turning point		
Is there a turning point AND sufficient to result in a significant change that follows turning point.		
Is the story easy to read (Readability score)		
Is there a moral to the story		
Does the story follow story curve structure		
Is the story Transformational		

Figure 4 Initial Transformational Story Template

Confirmation and adjustment of Transformational story data

Three (15%) of the stories were co-coded by the second supervisor, using the Initial Transformational Story Template (Fig45). The results and process were discussed, with one story resulting in disagreement about its potential to be transformational. One discussion related to the 'turning point in the story, with the co-coder checking 'yes' referring to *diagnosis of HIV*. However, since that occurred in the first two lines of the story, it does not constitute a turning point, which ideally occurs after rising tension (see Fig 1, for detail of a story curve). Rising tension to a turning point results in change for the subject followed by resolution. Another discussion centred on whether the character had been 'reflective' about their situation, which entailed looking outside themselves and making change to 'right a wrong action'.

As a result, more detail from the background was included in the Transformational Story Template, to determine the most fitting answer for each feature. Following discussion and agreement, the initial Transformational Story Template was modified to enable a coder to better understand if the feature was present in the story. The additions can be seen in Fig 5 (Recoded template showing additions). All

22 stories were checked and re-coded by the primary researcher using the final version of the Transformational Story Template (Fig 6). The final results are shown in the (Appendix 6)

Story code	8-03	8-03		8-03
Variable – initial template and coding	Initial Reviewer	2 nd Reviewer	Additions to template after discussion with 2 nd Reviewer	Revised coding
Answers: yes/no				
Does the character reflect on their situation	No	Yes	+ reflect on more than own situation – making change to right a wrong	No
Is character believable	Yes	Yes	+ and relatable	Yes
Is there an emotional connection	Yes	Yes		Yes
Does the story engage all senses, imagery	No	Yes	+ use of descriptive language ‘hook’ to capture attention	Yes
Does the character struggle with a conflict	No	No	+ one key struggle	No
Is there tension to keep your attention	No	No	+ there is rising tension culminating in a turning point	no
Is there a turning point	Not sure	Yes – found 2	+ sufficient to result in significant change that follows turning point.	no
Is the story easy to read	Yes	Yes	+ readability score	yes
Was there a moral?	Not sure	Yes		yes
			Story follows a ‘story curve’	no
Is story transformative	No	No		no

Figure 5 Story 8-03 re-coded using updated Transformational Story Template

Of the 22 stories, only two scored differently using the revised template. Both had initially been scored as ‘un-sure’, with tighter criteria leading to a definitive score. There was no impact on the remaining stories. An example is shown of coding for Story 8-03 in Fig 5, where the outcome remained the same.

Variable (Answer = Y/N/DK)	Story code	Yes, No, D/K
Character reflects on their situation AND reflects on more than own situation – making change to right a wrong		
Uses the woman voice Speaks from own experience -quotes – speak ‘in their own words’ first person		
Is the character believable - seen as real life (realism)		
Identifiable and relatable – reader could see themselves reflected in story - Relevant to reader		
Is there an emotional connection- feelings about the story - Express empathy for the woman		
Story code		
Does the story engage all senses, imagery AND/OR use descriptive language.		
Is there a ‘hook’ to capture attention		

story is engaging – enthralling read to end – absorbed		
Does the character struggle with a conflict one key struggle (short story focus)		
Is there tension to keep your attention AND there is rising tension culminating in a turning point		
Is there a turning point + sufficient to result in a significant change that follows turning point.		
Emphasis on behavioural and emotional aspects of a change		
Is the story easy to read and understand (not a high level of thought)		
+ Readability score		
Is there a moral to the story		
Does the story follow story curve structure		
Is the story transformational		

Figure 6 Transformational Story Template (final version)

Flesch-Kincaid readability measures

As this study deals with written text intended for a general audience, a measurement of readability was deemed important. The Flesch Reading Ease score and the Flesch-Kincaid Grade Level Test are widely used tools that were developed for and tested on adults (Stockmeyer, 2009). They were administered on the text of the 22 stories using the Microsoft Word Readability program. Most adults in the community are considered to read at an equivalent of a US grade 7-8 level, with some having lower literacy skills (Cotunga et al., 2005). Although this tool is criticised, for not measuring above grade 12-level when the original tools measured higher, the Microsoft Word tool is adequate since the lower reading levels are the goal. The Flesch-Kincaid tools have also been noted to measure grade-level 0.9-3.2 lower than other scores (Cotunga et al., 2005), so care was taken in analysing the results. A reading grade of 7-8 is considered an appropriate level for general public, with a score of 60-70 or higher considered appropriate for the reading ease scale, with 80 and above being very easy to read (Stockmeyer, 2009). The readability results were used in conjunction with the Transformational Story Template, to provide an evidence based measure of the message feature ‘is the story easy to read’.

Adapted Transportation Scale

Transportation is a key aspect of transformative stories. An adapted transportation scale (Barbour et al., Green & Brock, 2000), was completed by the interview participants on the text of two stories prior to discussing them in their interview. This incorporated a validated score of the participants’ transportation, or engagement with the stories. This adapted scale uses a 6-point Likert scale. This was questioned as it may be unusual having an even number of choices. However, the six point scale was necessary as some of the scoring is reversed, thus requiring an even scale. In their experiments, Barbour and co-workers (2016) added 12 questions to measure story or narrative persuasion. Seven of those

Table 7 Adapted Transportation Scale

Please choose the answer that best matches your experience of reading the story	Very Much	To a large extent	About ½ the time	Some What	Very little	Not at all
Transportation Scale from Green & Brock (2000)	1 R 6	2 5	3 4	4 3	5 2	6 1
While I was reading the story, I could easily picture the events in it taking place						
While I was reading the story, activities going on in the room around me were on my mind						
I could picture myself in the scene of the events described in the story						
I was mentally involved in the story while reading it						
After finishing the story, I found it very easy to put it out of my mind						
I wanted to learn how the story ended						
The story affected me emotionally						
I found myself thinking of ways the story could have turned out differently						
I found my mind wandering while reading the story						
The events in the story are relevant to my everyday life						
The events in the story have changed my life						
While reading the story I had a vivid image of _____ (person in the story)						
Other Perceptions (Barbour et al 2016)	Strongly disagree		Neutral			Strongly agree
	1 6 R	2 5	3 4	4 3	5 2	6 1
Story structure						
The story has a clear beginning middle and end						
The story had a clear cast of characters						
Understanding						
The story made sense to me						
Personal relevance						
I could see how the issue matters to me						
The story was relevant to me						
Information overload						
It was more discussion than I wished to have (R)						
It was about the right amount of information						
R:reverse scored, 1-11:general items, 12-15:imagery items						

questions relevant for the participants in this study, were added to the adapted Transportation Scale for this study (See Table 7). These gave insight into story structure, understanding, personal relevance and information overload of the stories and their potential impact on the audience (Barbour et al., 2016).

The participants were provided with text-only copies of two selected stories (Story One 7-01 and Story Two 1-01) and were asked to read the stories and score each separately using the adapted Transportation Scale (Table 7). They were asked to choose the answer that best matched their experience of reading the story. This provided a measure of their engagement with the stories, which could be compared with any other feedback provided in the interviews.

Collection of Stage three data: audience engagement with the stories

The two stories were also the focus of discussion in the interview. Feedback about the participants' engagement with the stories was offered predominantly in answer to the first question: 'What was your opinion of the stories?' The message features relating to engagement were gathered informally, i.e. the participants were not specifically asked about their engagement with the stories, but any comments that related to the Transformational Story Template (Fig 7) were reviewed.

Ethics Approval

This study has been granted Social and Behavioural Research Ethics Committee (SBREC) approval. In accordance with the SBREC guidelines, informed consent was sought from the interviewed participants.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project 7642). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Chapter 5: Results and manifest data

Stage One

Documents (The Stories)

Following the sampling strategy and inclusion and exclusion criteria, 22 stories were selected for the study from a search of four web pages and 35 website ‘hits’, as shown in Table 8

Table 8 Sampling strategy for internet searches and websites

Search term: Women, HIV, stories	Tool	Excluded	Inclusion criteria	Source	Reason for exclusion
Four web pages of search results	Google Chrome /Safari/Bing				
Total website hits	35	6			News or other article
					Focus not women
		3			Blog
		2			Call for stories
		2			Video/photo
		3			Not relative to Australian audience
		1			Repeated
			5	Online News	
			4	Magazines	
			2	Health info	
		7		Websites that support PLWHIV	Not a magazine or online news site
		24	11		

Content analysis

The descriptive content analysis of the 22 stories and the associated on-line reader feedback, found in the online news and magazines sites, was conducted on data that did not change over time. As discussed, analysis of online data can be complicated by the potential fluid or temporal nature of the content. However, for this study, the text of the stories and any online reader feedback, was static. At some point the online feedback would have been ‘fluid’, as readers contributed their views and experiences of reading the articles. However, on examining the selected articles and stories, it was

noted that the feedback had only been invited or 'open' for finite periods and had 'closed' at the time of data collection for this study. In this way, the content analysis followed the four traits of content analysis previously outlined (Karlsson & Sjøvag, 2016). The stories were analysed as though they were print material. The main difference between these stories and stories in a hard copy of the magazine was that readers could access them more readily online and the stories were available long after their original publication date, enabling readers to access them for the first time several years after publication. The online format also allowed publishers to embellish the style and content of the article, for examples including links to other articles and websites. On examining the documents, the extent of this embellishment varied according to the publisher's style or ideology.

Although the story content remained static, aspects of the online publication that had the potential to change over time included adverts and links to other related, or unrelated, current affairs stories, often published by the same entity. As the publication style or ideology had the potential to influence the reader experience of the story, for example a sensational format, as seen with the UK's Daily Mail, or an informative format, as seen with Australia's ABC online news, steps were taken to remove this potential effect. The texts of the stories were selected out and used as the unit of analysis in all three stages. However, in Stages One and Two, the full publication was also analysed separately to allow for comparison and to assess any impact that the way the story was presented or published might have on the reader experience.

The preparation of the documents (the stories) and their use in each Stage of this study was described in Methods. The content analysis comprised: quantitative analysis of manifest content, including counting incidences of characteristics and relationships, some of which was collected and analysed using Epi Data software; and as well as qualitative approaches to analyse latent content, including context, language and narrative persuasion. Theoretical perspectives included stigma theory, feminist theory and transportation/transformation theory. The main themes from the content analysis contributed to the development of the interview guide for Stage Two.

Latent content

The latent content of the stories in Stage One is described in combination with the latent content from Stage two, the audience feedback including focused interviews and online reader feedback, in the Combined Data Analysis (Chapter 6).

Manifest content

Twenty two stories were analysed and the breakdown of the stories, their publications and subsequent data sets, is shown in Table 9. The personal narratives of 15 women were shared across 10 separate publications, with a total of 22 stories. Some articles contained several stories and some a single story. The publication type, number of stories, woman's first name and story code is detailed in Table 9. *The Guardian* and *NHS Choices* articles also included stories about men with HIV. Some stories were repeated in different publications, written by different authors. These are indicated with a * in Table 9. One young woman's story (Abby) was repeated six times, in the *Women's Weekly* set and as the five single story articles in *Cosmo*, *Mamamia*, *ABC online news* and *News.com* (2014 and 2017). The stories of two other women, Rebecca and Becky, were each repeated twice.

Table 9 Stories coding and characteristics

Publisher (Year of publication)	Story code	Type of site	Women ((age at publication)	Links to other articles	Author M/F
Australian Women's Weekly - 2015 and 2016	1-01	Magazine article	Cath (42)	Appropriate	Female
	1-02		Rebecca* (45)		
	1-03		Michelle (45)		
	1-04		Diane(45)		
	1-05		Abby* (24)		
Cosmopolitan (USA) 2014	2-01	Magazine article	Abby* (24)	Appropriate and general	Unclear
News.com 2014	3-01	Online news	Abby* (24)	Inappropriate	Female
News.com Mar 2017	3-02	Online news	Abby* (28)	Appropriate	Unclear
Mamamia.com 2014	4-01	Magazine	Abby* (24)	Appropriate	Female
ABC (Australia) Mar 2017	5-01	Online news	Abby* (28)	Appropriate	Male
Herald Sun (Austr) 2014	6-01	Online news	Sarah (27)	No links	Female
	6-02		Millie (31)		
	6-03		Kim (60)		
	6-04		Rebecca (45)*		
Daily Mail (UK)	7-01	Online news	Nici (36)	Inappropriate	Male
	7-02		Rachel (49)		
	7-03		Becky* (40)		
The Guardian (UK) 2015	8-01	Online news	Becky* (40)	No Links	Female
	8-02		Lizzie (33)		
	8-03		Jo (66)		
NHS Choices (UK) 2014	9-01	Health Info	Tina	Appropriate	Unclear
Web MD (USA)	10-01	Health Info	Anonymous	Appropriate	Male
Six data sets		22 stories	15 women Repeated stories*		

The gender of the author is also noted in Table 9 (above). The number of links to other articles varied with the publication, as did the appropriateness of the content as related to women and/or HIV. The stories were grouped into six data sets as shown by the colour/shading, which is used consistently in figures or tables that contains data from more than one publication.

The articles were published between 2014 and 2017. The women in the stories were diagnosed with HIV between 1986 and 2013. As outlined in Table 10, the ages of 14 of the women at diagnosis ranged from 19 to 59, with one woman being born with HIV and one not disclosed. Their ages at publication ranged from 24 to 66. All were true stories. Twelve were told from the first-person perspective, six were written from a third person perspective and four were written by a third person, with direct quotations from the woman taking up 50% of the story, which gave a sense of the story being told in the first person.

Table 10 The women and age and year of diagnosis

Story code	Women (age at publication)	Age on diagnosis	Year of diagnosis	Random co-coding	Voice 'person'
1-01	Cath (42)	d/k	2005	10/10	3 rd
1-02	Rebecca* (45)	25	1994		3 rd + quotes
1-03	Michelle (45)	20	1989		3 rd + quotes
1-04	Diane(45)	42	2012		3 rd + quotes
1-05	Abby* (24)	23	2013		3 rd + quotes
2-01	Abby* (24)	23	2013		3 rd
3-01	Abby* (24))	23	2013		1 st
3-02	Abby* (28)	23	2013		3 rd + quotes
4-01	Abby* (24)	23	2013		3 rd
5-01	Abby* (28)	23	2013		3 rd
6-01	Sarah (27)	21	1998		1 st
6-02	Millie (31)	28	2012		1 st
6-03	Kim (60)	40	1994		1 st
6-04	Rebecca (45)*	25	1994		1 st
7-01	Nici (36)	19	1997	10/10	1 st
7-02	Rachel (49)	39	2007	Discuss	1 st
7-03	Becky* (40)	37	2012	Discuss	1 st
8-01	Becky* (40)	37	2012	5/10	1 st
8-02	Lizzie (33)	22	2006	Discuss	1 st
8-03	Jo (66)	59	2008	10/10	1 st
9-01	Tina	20	2004		1 st
10-01	Anonymous	00 birth	1986		3 rd
	15 women Repeated stories*				

The Point of View or voice in a story has an impact. Transformation and feminist theories suggest stories told in the first person are the most engaging and the most suitable to share women's issues. Of the 22 stories, 12 (54.5%) were written in the first person and four (18.2%) were written in the third person with 50% direct quotations from the woman. Six stories (27.2%) were written in the third person. Stories written in the first person and those using direct quotes represented 73.3% (11) of the 15 stories that described the woman's experience of stigma and 66.6% (12) of the 18 stories that discussed stigma as a broad issue. The Women's Weekly series, with a stated purpose to 'de-stigmatise HIV', were mostly third person with 50% of direct quotes. A first-person Point of View would have had more of an impact. However, the use of quotes helped to provide the illusion that it was the woman's voice, as one participant noted about Story two (Cath)

Well you know I hadn't really thought about that because I actually thought they were written by the women (A04X)

Two of the stories aimed at informing young people had been written in the first person, being in Cosmo and Mamamia. The youngest participant also mentioned the impact of a first-person perspective and in discussing Nici's story, noted that if she was faced with that in future she would report it as though she had known the person

Yes, yeah especially if it's a first-hand story. They have huge impacts me..... like I was .. if I'm experiencing the same situation in the future I'll think about... 'I know someone that happened to'.... so yeah (B08Y)

EpiData

As described, characteristics of each story were coded using Epi Data software. Four (18%) of the stories were selected for review by the second supervisor with 10/10 agreement on three and 5/10 on the fourth, with agreement reached after discussion. A further three stories were discussed, as shown in Table 10 above. The results and analysis of the quantitative data in the EpiData data base were predominantly used to support the findings in the qualitative analysis and are noted in the Combined Data Analysis, where appropriate

Stage Two – audience reception

Focused Interviews

Participants

After three months, the Soroptimists declined. Sweet Adelines response was also delayed, due to changes in the committee. However, they did agree to participate and to circulate a request to their Victorian members. After only one response was received from the Victorian members, a further request to the Sweet Adelines organising committee resulted in the communication being circulated across Australia to the almost 1,500 members. This resulted in further interest, of seven over 45 and one in the 18-35 age group, of which five in the over 45 age-group were recruited successfully. The participants in the 18-35 age-group, were recruited individually. For details of the recruiting and final participants and coding see Table 11. Agreement to participate was confirmed by returning a signed consent form to the primary researcher.

Table 11 Participants: de-identified coding and details

Code	Address State	Interview conducted:	Age	Outcome	Viewed transcript
A01X	Vic	In person	58	Interview	No
A02X	Vic	Skype	63	Interview	No
A03X	Perth	Skype	45+	Interview	No
A04X	Qld	Skype	58	Interview	No
A05X	TAS	Skype	45 +	Interview	Yes
A00X	NSW	No-went o/s	71	No	-
A00Y	Perth	No –cancelled	33	No	-
A00X	NSW	No- wanted by phone and several months later	71	No	-
B06Y	Vic	Skype	18-35	Interview	Yes
B07Y	Vic	Skype	18-35	Interview	No
B08Y	Vic	In person	24	Interview	Yes
		Description	Code		
		Interested individual	B		
		Sweet Adelines organisation	A		
		Participant	01- 15		
		Age Group: 18-35	Y		
		Age group: over 45	X		

Online Reader Feedback

Being an online format, some articles provided the opportunity for readers to give feedback on what they had read. There were two aspects to these results. The outcomes of the qualitative, thematic analysis of the reader feedback are included in the Combined Data Analysis, in line with the results from the interviews and the qualitative analysis of the stories. The second aspect refers to the capability of online reader feedback to have a phenomenal reach beyond the initial published article.

Five web sites, containing 16 of the 22 stories, invited reader feedback as shown in Table 12. Two provided a Likert-scale with descriptive points, which required the reader to think about the potential impact the story may have had on them and choose a response. As seen in the table, the majority of responses were favourable and that the articles were useful. Three sets of feedback were moderated. Readers could simply click and indicate 'like' or 'dislike' to record their reaction to the stories, or they could write a 'posted comment', which could be further commented on and/or 'liked' by other readers. There were over 10,000 Likes to some comments as can be seen in Main Themes (Appendix 5). These generated additional information or opinions about HIV, as well as insight into the reader's experience of the stories. In addition, two of those provided the capability for the whole article to be 'shared'. In addition, two of the sites with moderated feedback, invited readers to 'share' with others on-line, meaning the whole article would be sent to additional potential readers, one sent to 2,400 and one sent to 3,212 others.

Table 12 Stories with Reader Feedback

Publisher	Story code	Reader feedback Posts, comments, Likes	Posts scored Article shared	Potential reach and readers
Australian Women's Weekly	1-01, 1-02, 1-03, 1-04 1-05	LOVE THS 78 MADE ME THINK 80 MADE ME SMILE 32 SURPRISING 19	No	209
Herald Sun	6-01, 6-02 6-03, 6-04	7 moderated posts	No	
Daily Mail	7-01, 7-02 7-03	36 moderated posts	like/dislikes of each post Shared with 2,400	Likes range X 2,400 shares
The Guardian (UK) 2015 –	8-01 8-02 8-03	54 moderated posts.	like/dislikes of each post Shared with 3,212	Likes range X 3,212 shares
NHS Choices (UK) 2014	9-01	VERY HELPFUL 67 HELPFUL 4 FAIRLY HELPFUL 2 NOT VERY HELPFUL 6 UNHELPFUL 10	No	89

The online reader feedback was analysed and compared, with the results from the descriptive content analysis and the thematic analysis from participant interviews. It added to the rich descriptive data as part of the combined data analysis and supported some of the main themes found in the content analysis and focused interviews. All readers do not participate in online reader feedback. However, in terms of the capacity to 'reach' people, online feedback shows the potential additional 'reach' of the stories, over and above the regular readership.

Main qualitative themes from Stages One and Two

The qualitative themes from three data sets: the qualitative content analysis of the stories, the focused interviews and the online reader feedback, were analysed separately and mapped, to show commonalities, expected themes, new/unexpected themes and gaps. The descriptive results are presented in the Combined Data Analysis (Chapter 6) and visually in Main Themes (Appendix 5).

Stage Three – are the Stories Transformative?

In the qualitative analysis, McCormack's Lenses (2000) included *moments* and *narrative persuasion*, in this study these were included in the Transformative Story Template (Fig 6) and noted as *turning points*, while *narrative persuasion* was investigated using the adapted Transportation Scale (Table 7). The results were obtained both through evidence based measures and qualitatively, with excerpts from the interviews and online feedback.

Transformative Stories

The transformative potential of each of the 22 stories is shown in Appendix 6 and Table 13 (below) along with the Flesch-Kincaid Readability scores and word count. Using the Transformational Story Template, with reading ease assessed using readability tools, eight of the 22 stories, were deemed to be transformational.

None of the single stories were found to be transformative. All four Herald Sun stories were deemed transformative, but only one of three in the Daily Mail. The three stories in the Guardian were not transformative. They were also the shortest, which might not allow for sufficient information to engage the reader. Four of the five stories in Women's Weekly were transformative, however, three scored 8-9

in the Flesch-Kincaid Grade Level, higher than the preferred grade of 7-8; in the fourth, although the story showed the features of being transformative, the Flesch Reading Ease was marginally low at 58 and the Grade Level was 11.4, which would make it difficult to understand by the average reader. Consequently in Table 13, the score for that story was changed to 'No', i.e. not transformative.

Table 13 Word count, readability scores and Transformative stories

Publisher	Type of site	Story code	Words	Flesch Reading Ease (60-70)	Flesch-Kincaid Grade level Test (7-8)	Transformative
Women's Weekly	Magazine	1-01	395	66.6	8.8	Yes
		1-02	355	66.2	8.9	No
		1-03	445	67.8	8.6	Yes
		1-04	490	(58.7) (low)	(11.4) (high)	(Yes) No
		1-05	470	67	(9.2)	Yes
Cosmopolitan	Magazine	2-01	868	71	7.6	No
News.com	News	3-01	1226	75.4	5.9	No
News.com	News	3-02	525	70.5	6.9	No
Mamamia.com	Magazine	4-01	1181	63.2	(9.2)	No
ABC (Australia)	News	5-01	758	59.1	(9.5)	No
Herald Sun	News	6-01	519	75.3	5.8	Yes
		6-02	417	75.1	6.2	Yes
		6-03	512	64.2	8.0	Yes
		6-04	536	71.8	6.6	Yes
Daily Mail (UK)	News	7-01	849	67.4	(9.4)	No
		7-02	656	68.1	7.9	Yes
		7-03	687	56.4	10.9	No
The Guardian	News	8-01	329	73.1	6.4	No
		8-02	345	75.5	5.4	No
		8-03	288	83.9	4.1	No
NHS Choices (UK)	Health Info	9-01	1092	79.1	6.3	No
Web MD (USA)	Health info	1001	865	89.6	3.4	No

Transportation Scores

The scores from the adapted Transportation Scale for Story One and Story Two by the participants are noted in Table 14. With a possible Transportation score of 12-72 and a mid line of 42, no participants scored 42, if so they would have been removed from the analysis (Green & Brock, 2000). The scores for transportation were divided into two groups, above and below the mid Line, i.e. showing their experience of higher or lower transportation effect for each story, respectively. For Story One (7-01), six participants experienced higher transportation, with two, one from each age group, experiencing less transportation. For Story Two (1-01), four participants, including all three younger participants

experienced higher transportation, while four experienced lower transportation, all of whom were in the over 45 group. Table 14 shows that all scores for both stories were around the median, ranging from 30-59, so it appears the stories neither lacked transportation effects, nor did they produce a high level of transportation. The higher the number, the higher level of transportation is experienced (Green & Brock (2000 p707), this is important as the level of transportation relates to the belief a reader has in the conclusions of the story: ‘Highly transported participants showed beliefs more consonant with story conclusions as well as more positive evaluations of story protagonists’.

Of interest the text-only of Story One (7-01) was found to be more transporting by both age groups and Story Two (1-01) was only found to be transporting for the 18-35 group. The perception by the participants of Story One, is also outlined the Combined Data Analysis (Chapter 6) and in the Discussion (Chapter 7) as the participants’ view of Story One changed when the story was read in context of the full online presentation.

For the questions in the adapted Transportation Scale that provided additional insight into the participants’ perception of the stories, with a potential score of 7- 42 and a mid line of 24.5, no participant score sat at the mid line of 24.5. As detailed in Table14, only one participant score for Story One was below the mid line, all others were above. All scores for Story Two were above the mid line. The higher the number on the perception scale, the higher the level of narrative persuasion experienced by the reader (Barbour et al., 2016). The majority of scores for both stories were in the higher range, showing that both stories were structured well with potential for narrative persuasion as received by the participants.

Table 14 Transportation scale and perception scores

Participant de- ID code	A01X		A02X		A03X		A04X		A05X		B06Y		B07Y		B08Y	
STORY	ONE	2	ONE	2	ONE	2	ONE	2	ONE	2	ONE	2	ONE	2	ONE	2
Transportation (range 12-72) Median 42	44	(41)	45	(39)	(40)	(39)	52	47	46	(37)	51	45	(30)*	47	59	53
Perceptions (range 7-42) Median 24.5	37	40	38	34	35	35	38	37	40	29	35	35	(22)	33	33	34
State	Vic		Vic		WA		Qsld		Tas		Vic		Vic		Vic	

B07Y* 2 missing data in Story one, so those answers were given minimum score of 1 each

The exception was participant B07Y, whose comments matched her lower scores for Story One:

Em..... I found it really disjointed And it just didn't flow at all and I was trying to pick up important points and I just couldn't get anything – long sentences, no full stops and even now I'd need to go back into it to see what they were trying to say (B07Y)

Audience feedback relating to engagement with the stories

From the **focused interviews**, feedback relating to engagement with the stories was noted. Two participants (A01X, B06Y) referred to the short length of one of the stories as potentially having an impact on the reader's investment in the woman, and consequently the impact of the story. For others (A02X, B07Y), issues with story structure and presence of grammatical errors, affected the credibility of the message. None of the participants found the stories difficult to read, apart from two experiences with Story One being disjointed and the storyline a little confusing, although others found it engaging

I was quite happy to read to the end of both of them. I didn't get to the stage of reading the longer one and think 'there's nothing here for me'. (A03X)

And the first story was described in the first person, so I found it more engaging..... There were lots of quotes of the girl. The second one was quite dry and just descriptive of what's occurred..... harder to get into (A05X)

In the over 45 group, the participants referred to their own personal experiences that the stories had raised for them and generally were empathetic toward the women. Their comments indicated that they felt the stories were believable and that they identified with and related to the characters' experiences:

... it was a reminder that when I was a teenager we were petrified of HIV, I think I was about 12 or 13 when we had this presentation about it and that sort of fear stayed with me (A05X)

I understand stigma because I've been stigmatised all my life and I felt empathetic towards them (A04X)

– so yeah I did relate to it some of that I guess is you know personal background and I guess having been through some of that time with people who got sick and died um you know I could picture some of this stuff andI could imagine (A01X)

An important part of investigating audience reception is to check if the reader sees themselves in the story. In transformational stories, the characters are relatable and identifiable. The participants related more strongly to the story of the woman they felt was like them in some way, or vice versa:

A gorgeous photo of her (Cath) with the horse. I'm a bit of a horsey girl so.....and I used to do a bit of riding in the high country, you know I sort of related to that quite strongly (AX01)

The first one (Nici) and I was like 'that's how I would feel in that situation'..... when she talked about, something that her parents had said "It's not AIDS, it's not HIV is it?" or something like that. I was like – 'that's something my family would say' and I totally understand like how she would have felt in that situation (B08Y)

In summary, message features that support transformation included: the participants recognised the struggles the women faced and felt they had overcome difficulties (turning point) and were pleased that they were advocating for others; they felt the stories were written in the women's own voices; and they felt the stories were believable, real life and they could relate to and identify with them. Generally, the participants preferred one story over the other, but which story was preferred was not consistent. The feedback indicated reasonable engagement with the stories, not highly transformative, in line with the results of the two measures of transportation and transformation.

Chapter 6 Results and Combined Analysis – Stages one and two

The results from the qualitative content analysis, some quantitative data, the focused interviews and online reader feedback were analysed in a combined data analysis. The results of each data set were gathered separately and the themes were mapped, looking for commonalities and differences, expected themes and new themes (Main Themes Appendix 5)

In the combined analysis of the major themes across all the data sets, below, each theme is presented in a standard fashion:

- descriptive content analysis of the full data set of 22 stories (15 women), including quantitative results where appropriate
- audience reception of the stories, comprising
 - participant interviews discussing two selected stories (Story One, Nici; Story Two, Cath)
 - online reader feedback for 10 stories

Each figure, where relevant, compare excerpts illustrate the themes from: 1) stories in the content analysis, 2) online reader feedback, 3) over 45 interview group, 4) 18-35 interview group. Additional excerpts from the interviews are identified by the participant code (B08Y) and the story code (1-01). For de-identified participant codes see Table 11. For story codes see Table 9.

The themes and mapping are also presented visually in a summary table (Main Themes Appendix 5)

Women portrayed empathetically, as brave or strong

From the **content analysis**, the women whose stories were told were described by the journalists, as strong, 'brave' and as overcoming a devastating diagnosis. The journalists portrayed the women empathetically and used positive language to describe how the women spoke to themselves to strengthen their resolve (Fig 8). They did not portray the women as victims, even though the stories described instances in which the women experienced difficulties due their diagnosis. The women all went on to help others by sharing their personal story and expressed a desire to reduce stigma and ignorance about HIV, 'bravely speaking out to de-stigmatise the disease'(1-01).

From the **online reader feedback**, the idea that the women were 'brave' and overcame difficulties was supported by 1653 people (Fig 8).

From the **interviews**, when asked to give their impressions of the women in the stories, all participants agreed that they were good, positive stories and that the women were portrayed positively. Those over 45 saw the women as sympathetic characters and everyday women who had turned their diagnosis of HIV into a positive experience. They described them as ‘brave’, ‘courageous’, ‘strong’, ‘determined’, ‘independent’ women (Fig 8) who were ‘Living well with HIV’ and ‘not letting adversity get them down’. One felt very proud of them (for being advocates) and was ‘impressed with their resilience and determination’ (A02X). The 18-35 group used words like ‘warrior’, ‘determined’ and ‘brave’ and felt that both women were facing what they had to do and ‘getting on with it’. One participant from each age group described Nici (Story One) as ‘brave’ for facing up to the people in her community who had stigmatised her, something the younger participant had felt she would not have been able to do (B08Y).

22 stories	Online Reader Feedback (5 posts)
<i>Despite the physical and emotional challenges she has faced, (she) has refused to become ‘a victim’ She has defied the odds, and proudly pushed the boundaries</i>	<i>What an informative article and wonderful people in it Brave people!!! Thanks for sharing:-) I applaud her for rebuilding her life 1653 LIKES//12 DISLIKES</i>
Interviews over 45 years	Interviews 18-35 years
<i>....also as strong independent women who didn't let adversity get them down I thought they were brave...they were strong. Strong. (Nici) was very courageous...very brave</i>	<i>They turned it into a strong experience when they could have let it get them down I thought both of them were very strong women She...challenges the way you would otherwise see them ...she's definitely an inspiration</i>

Figure 7 Women portrayed empathetically and as brave and strong

Women experienced stigma, written stories not stigmatising

From the **content analysis** of the 22 stories, any stigma directed at the women was reported as part of her story, describing the stigma she experienced after diagnosis with HIV (Fig 9). The women’s experience of stigma due to the diagnosis was discussed in 15 (68.2%) of the stories. One woman was treated by others as though she had ‘the plague’ (603). Two women were described as a ‘prostitute/slut’ (7-01, 3-01) and in 1999 one recalled that people thought she would ‘contaminate’ them (7-01). Stigma was discussed as a broad issue, in 18 (81.8%). None of the journalists wrote an empathetic piece, with patronizing, stigmatizing comments about the woman. In the two examples where the women’s lifestyle choices had contributed to the woman contracting HIV, the women’s history was reported, not in a sensational way, but to show how they had contracted HIV and that it could happen to anyone.

She'd been living out a dream, backpacking when she landed in Italy, and firmly in with the wrong crowd (1-03)

The age of the women when they were diagnosed with HIV did not appear to have a relationship to the inclusion of the woman's experience of stigma, or the discussion of stigma as a broad issue.

The women described two main types of stigma experienced after diagnosis: 1) six examples of 'misconceptions' (7-03), due to 'ignorance, a lack of education' (8-01) in the general public about HIV; and 2) seven examples describing the 'overwhelming fear' that people have of the person with HIV, including incorrect 'assumptions' about who can contract HIV, for example HIV 'only impacts gay men, sex workers or injecting drug users'(4-01). See Fig 9.

Nine (75%) of the 12 stories, of women diagnosed prior to 2012, mentioned the woman's experience of stigma. Of the 10 stories of women diagnosed after 2012 (four women), only one not report an experience of stigma. This suggests it is the inclusion in the stories that has changed rather than an absence of stigma.

Eight stories showed that the women did not label, blame or stigmatise themselves for having contracted HIV: 'there's no shame, I'm a normal woman' (8-01). Only one woman experienced blame when her partner's family blamed her: 'his family refused to believe he had AIDS – some of them even blamed me' (8-02).

From the **online reader feedback**, two posts, with 4545 *likes*, found it encouraging that the women didn't blame or see themselves as victims. However, four posts blamed the women's 'stupidity' for having 'unprotected sex', referring to that as 'risky behaviour'. It is of interest to note that there were more *dislikes* (62.2%) for those comments than *likes* (37.8%), see Fig 9.

From the **interviews**, all participants over 45 and one 18-35 stated they did not feel the women were stigmatised by the stories. They felt the women had experienced stigma and were fighting back after a shocking diagnosis, but that the stories did not stigmatise them (Fig 9). Two 18-35 participants saw Cath (diagnosed 2005) as a 'stigma warrior', but felt sorry for Nici (diagnosed 1997), who had experienced more stigma. One observed that the stories would have been different 20 years ago (Fig 9)

Content analysis 22 stories	Online Reader Feedback
<i>I remember going for a meal and being given plastic cutlery... everyone else had silver cutlery people don't want to use (parents') toilet after me and ask how hot our dishwasher is I've been asked when I was a sex worker or what drugs I used. People pre-judge how I was infected I'd heard rumours that I must've been a drug user or a prostitute</i>	<i>Don't see themselves as victims and that is encouraging Brilliant way to counter the toxic narrative in the Daily Mail that 'such people are responsible for their own infections' (Guardian) <u>LIKES 4545//DISLIKES 0</u> Four posts blame woman for having unprotected sex with an untested partner (Daily Mail) <u>LIKES 348//DISLIKES 573</u></i>
Interviews over 45 years	Interviews 18-35 years
<i>I think Nici's story does give (the idea) that it certainly was stigmatized, People were actually saying "wash your clothes separately and keep your tooth brush separately"Since then we've come a long way</i>	<i>I think the stigma today is less. I think these stories would have been portrayed very differently if they were written 20 years ago. (HIV) is still....stigmatised even by health and support workers to some extent</i>

Figure 8 Women experienced stigma, but written stories not stigmatising

Women acknowledged stigma, denied it was happening to them

From the **content analysis**, a new theme was evident. The women acknowledged that stigma exists and that they had experienced stigma on diagnosis but stated that it happened to others with HIV and not to them. Often this was related to clear statements that they were open about their status and that this was the reason they were not experiencing stigma:

Stigma happens to others but not to me.....I have never come up against negativity, which I think is partly because I'm open about my situation (8-02)

I think the reason I have avoided a lot of the discrimination a lot of people with HIV and AIDS face is because I'm really open about it. I'm really unapologetic. I'm not ashamed. It is what it is. I think the way you present it goes a long way to how people will react to you (3-01)

Twelve of the 22 stories (nine women), made a clear reference to being 'open about HIV', 'public with my status', 'informing close friends and family' or 'not wanting to hide'. Of interest Kim, diagnosed in 1994 age of 40, experienced the opposite. She was 60 when the story was published in 2014:

I was open until I realised the stigma around HIV and the overwhelming fear of people (6-03)

Like all the women in these stories who have shared their experiences to inform others about HIV, Becky, diagnosed in 2012 age 35, used the trait of 'being open' as a way of educating and changing public opinion. She was 40 when the story was published:

I knew very soon after being diagnosed that I wanted to as open and honest about my HIV as possible. While I knew it wasn't a huge deal, I also knew how other people's misconceptions needed to be changed and I hated the idea of having to hide anything.....I told all my close friends and family, who were upset and shocked (7-03)

This theme was not addressed in the **interviews** or **online reader feedback**

Some women reluctant to disclose their HIV status

Although 12 stories from the **content analysis** described the women as being open about their HIV status and all the women had shared their stories in the media, five of the 15 women expressed a fear of disclosure. Of those, three reported that disclosure was a difficult aspect to face and stated they had specifically delayed telling family members to protect them from the shock, noting that they were still selective about who they tell:

Disclosure...is still one of the most challenging aspects of being HIV positive. I chose who I tell very carefully.... It's important to speak out about the virus....but [speaking out] is also a double edged sword (1-02)

My sons don't know I have HIV.....I will just tell them when the time seems right (9-01)

Although Jo, diagnosed in 2008 aged 59, was initially open about her HIV status, she later became selective about what she shared

*I didn't tell my daughter until I'd **come to terms** with it myself. She was 18 at the time, and I was in shock....I hate the word "disclosure". I don't feel I have to "disclose" if I don't want to.....I don't talk about how I was infected.....I'm more interested in being open about life with HIV than how I got it (8-03)*

Abby, diagnosed age 23 in 2013, who was open about her HIV status, explained she was initially reluctant to disclose, until she was inspired by the stories of other women with HIV. Abby's story has been shared in six of the 22 stories across different publications.

Connecting with other people and being really inspired by what they're able to do with their lives has been key to me getting to the point where I'm comfortable discussing my status (4-01)

This theme was not addressed in the **interviews** or **online reader feedback**

Isolation after diagnosis alleviated by support networks

From the **content analysis**, isolation after diagnosis was a key issue, exacerbated by a reluctance to disclose, for one third of the women. Only Rebecca reported depression after she was diagnosed, describing the isolation she experienced due to other people's misconceptions:

I thought I was going to die.....I slept for weeks afterwards and didn't leave the house.....Sometimes I have a black dog day where my fears come out of the box (6-04)

An additional ten stories, made reference to death or dying, as a fear the women experienced after diagnosis. Three referenced shock and one was 'suicidal' (901). Five (33.3%) of the women expressed ongoing feelings of isolation. Those who did not experienced a good level of support from family and close friends (seven) or sought assistance from established organisations (six). Three women cited contact with other people with HIV and hearing their experiences and stories as being very helpful:

Going to the support group was one of the best things I did..... I wasn't a victim, I realised most importantly that I wasn't alone, other women were dealing with this too (1-05)

I was really lucky that I had lots of family support. They were able to cushion me through that initial period of shock (3-01)

Even so, four of the women, who did not experience ongoing isolation and who stated they had good family support, described an initial experience of isolation and difficulty. They explained that being open

with friends and family over time, and allowing them to be supportive, reduced the sense of isolation they had felt at first.

.....today I am much more open and I no longer feel isolated...have disclosed my HIV status to friends, who have been accepting and wanted to know how best to support me (9-01)

This means that a total of nine women (60%), experienced isolation immediately after diagnosis. Women are not expected to get HIV and there was also a strong reference to women experiencing themselves as being in a minority

I was a woman with HIV I was a minority within a minority, it was so isolating (1-03)

Women with AIDS are almost invisible in this country (1-04)

This theme was not addressed in the **interviews** or **online reader feedback**

A Women feels responsible for the health of her children

From the **content analysis**, six of the 15 women were pregnant or breast feeding when they were diagnosed with HIV. They felt fearful for their children and blamed themselves for potentially passing on the HIV virus even though they weren't aware their partners had HIV (q.v.). Their relief when the children tested negative for HIV was clear.

When the doctors traced back how long I had it, it coincided with breast feeding (son) I was terrified I may have passed it on to him. It was the longest weekend of my life waiting for tests results to come in, but thankfully he's all clear.

I was one of the first women to have them and to have a baby knowing her HIV status..... My son was HIV negative and when he was born I started thinking about living.

None of the stories described unwarranted disclosure about the women's HIV status by healthcare workers, with regards to having children, which was unexpected given that some of the women had children after diagnosis.

From the **interviews** this theme was not addressed, although one 18-35 participant, a healthcare worker, noted that stigmatization by health care workers can still occur (Fig 9 above).

This theme was not raised in the **online reader feedback**

Women want children despite HIV

From the **content** analysis, some women had children after diagnosis and others had the desire to have children, despite the diagnosis of HIV. Two women, who each with a child born with HIV, went on have other children who did not have HIV.

My daughter was born HIV positive and died just before her fourth birthday. My (new) husband doesn't have HIV but my HIV status was never a barrier. We are happy and we have our beautiful son, my handsome little man, who doesn't have the virus (6-02)

Nici(7-01) described (the inaccurate) misinformation she was given by healthcare workers on diagnosis, that she would not be able to have children. She voiced the desire to have children and sense of loss many women feel. Abby, not a mother, often aimed her stories at young women. She described the role of ART in enabling women to have a new partner and also to have children (Fig 10).

From the **online reader feedback**, one comment supported women with HIV having children (Fig 10).

From the **interviews**, three participants, supported the notion that after HIV you can find a partner, have a baby and lead a full life. However, this was a surprise to the youngest participant (Fig 10)

Content analysis 22 stories	Online Reader Feedback (1 post)
<i>my viral rate is undetectable.....I'm very unlikely to transmit [the virus].....HIV positive women don't have to give up their dream of having children....with treatment, you can have a baby and the risk of passing on the virus is minuscule</i>	<i>Why should she be starved of the chance to have children when she didn't ask for this to be inflicted</i> 36 LIKES//3 DISLIKES
Interviews over 45 years	Interviews 18-35 years
<i>the devastation for her was that she would not be able to have children or a partner um which I just um got angry about that someone would have been told that (A01X)</i>	<i>I wanted the story to go more into how she'll have children. Because that's like really interesting to me because I thought that you wouldn't be able..... I knew that you'd be able to have a partner because you can have safe sex and stuff, but not have kids because, unless it's not naturally.....(B08Y)</i>

Figure 9 Women want children despite HIV

Women with HIV are described using gendered language

From the **content analysis**, the women were described more often than the men, using their age and gender, including their social context role and role as a mother.

....45 year old Melbourne mother of three (ages 3-17 years).....She is married and has a teenage son and three-year-old daughter (1-02)

Rachel, 49 when the story was published, was described in a sensational manner and identified in her current role as a grandmother, which perhaps was not her situation when diagnosed at age 35 in 2005.

Granny Rachel Dilley, 49, had unprotected sex with man she met online (7-02)

Rachel's story was written by a male author in the Daily Mail. She was described in a way that suggested she should know better. It is likely she was behaving no differently than anyone else at the time

Rachel Dilley, a 49-year-old charity worker from Harpenden in Hertfordshire, was diagnosed HIV-positive ten years ago. The mum of three – and grandmother of four – had unprotected sex with a man she met through internet dating....."I met a builder called Simon who had two children from a previous marriage. He was charismatic and attractive and very soon we started a physical relationship. It never once crossed my mind to ask him his sexual history....(7-02)

The article from the Guardian, written by a female author, contained three stories about women and three stories about men with HIV. The stories about men with HIV did not contain descriptive, gendered language and did not describe them as 'fathers' or 'brothers'. The lead-in for the stories read:

Living with HIV – 6 life affirming stories. Reality of living with the virus has changed dramatically. Stories from a male survivor of 1980's epidemic to a recently diagnosed mother in her 60s

Jo was 59 when she was diagnosed in 2008 and 66 when the story was published. She describes the difficulty people have in coming to terms with meeting an older woman with HIV, both her age and gender becoming stumbling blocks for people

I'm just wrong for HIV: female, 60s, middle class. Some people can't deal with it. I've become a kind of pin-up for ageing with HIV (8-03)

There was no clear evidence to link gender of the author and gendered depiction of the women. Of the four publications that included gendered depictions of the women, three were written by a female. It would be difficult to determine if the gendered approach by the male author in the Daily Mail was due to gender or the publication's ideology.

Of the 22 stories, 14 were written by a female (64%) and five (23%) by a male, with three unclear. The frequency of the women's experience of stigma, or the discussion of stigma as a broad issue being mentioned in the same story, was compared with gender of the author. Fig 4 shows that male authors referred to the stigma that had been experienced by the women more often than they discussed stigma as a broad issue. Female authors, in this analysis, were more likely to discuss stigma as a broad issue.

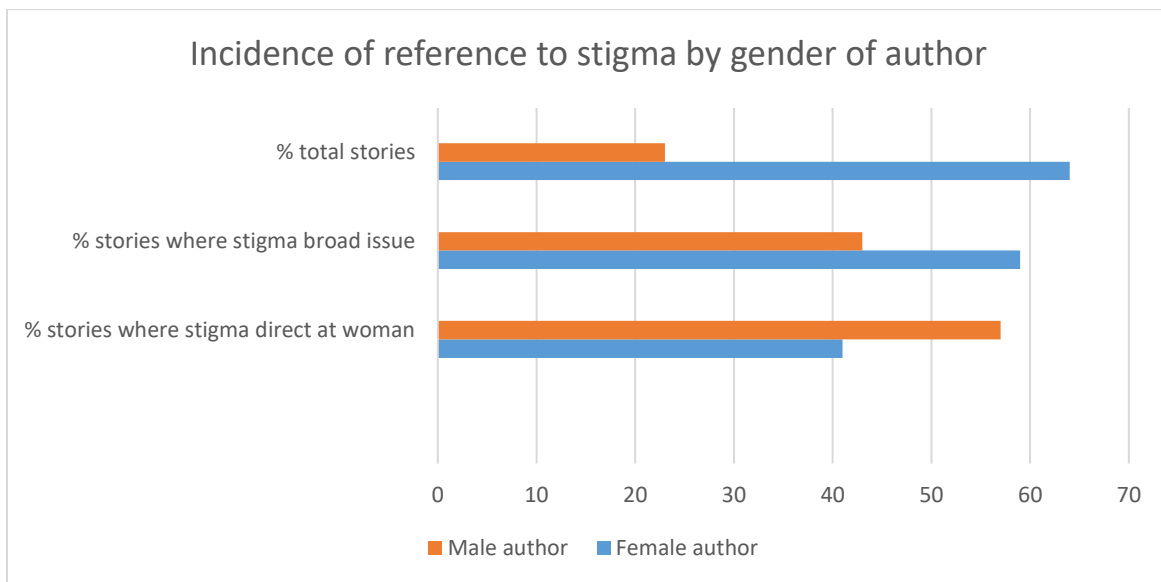


Figure 10 Incidence of reference to stigma by gender of author

This theme was not addressed in the **online reader feedback** or **interviews**

Women contract HIV from long-term partner.

From the **content analysis**, 11 (73.3%) of the 15 women contracted HIV from their current partner, 10 of whom were in a long-term relationship. This was supported by the literature review. Table 15 outlines how the women contracted HIV. Abby, whose story has been published six times, was the only woman in a short term relationship with her partner at the time she contracted HIV.

Table 15 How the women contracted HIV

# Women	Relationship	# stories	Partner knew/lied
1	Short term partner	6	1
8 women	Long term partner	9	4
1	Long term partner with haemophilia	1	Unclear
1	Lived O/S with long term partner	1	1
4	Casual sex O/Seas, Drug use, Born with HIV, Chose not to disclose	5	-
15		22	6

None of the women were still in a relationship with the partner with HIV. The age on diagnosis of the women who contracted HIV from their long-term partner ranged from 19-42 years old and the year of diagnosis ranged from 1994 to 2013. Neither variable proved significant. As expected, the women were tested after their partner became ill.

I'd actually picked up the virus from an ex-boyfriend who I'd been seeing for two years.... he'd collapsed with pneumonia.....He was rushed to hospital and he called me two days later to tell me had AIDS. I couldn't understand how my boyfriend could have AIDS as he'd told me he was a virgin when he met me (7-01)

I'd had a test when I found out my partner was HIV positive (8-01)

From the **online reader feedback** comments referred mainly to the betrayal of trust (q.v.)

From the **interviews**, two participants over 45 and one 18-35 noted that the women had contracted HIV from their partner.

Betrayal of trust in long-term relationships

From the **content analysis**, almost half of the women in a relationship believed they were deliberately infected by their partner (see Table 16). Six women in 13 (59%) of the stories reported being lied to and deceived and thought they had been deliberately infected (see Fig 12 for detail). Only one man admitted to the reason for his HIV. The women appeared unaware of their partner's potential risky behaviour. On reviewing the woman's background, age and year of diagnosis there appeared to be no pattern. Two

women, one lived in Fiji with her husband prior to migrating to Australia and one woman’s partner had haemophilia, had a potentially increased risk of getting HIV from their partner.

From the **online reader feedback**, some comments were empathetic to the women (Fig 12). Another post relayed the story of a man who deliberately infected women he met on line, commenting that people dating on line tell lies, yet other people trust whatever they are told. Interestingly, two posts with 1281 likes, suggested people should not rely on their partner to keep them safe (Fig12).

From the **interviews**, two participants in each group, addressed the issue of the women contracting HIV from their partner and that they were deceived (Fig 12). The youngest participant accepted that this behaviour happens and that ‘people lie about these things all the time’ (B08Y). She noted that if someone tells you they’re a virgin ‘it makes you wonder about them’. However, two participants over 45 were more surprised about women being deliberately deceived. One felt ‘sad and outraged that people would take risks with other people’s lives’ (A10X). The other, who was in a long term relationship, considered herself lucky that this had not happened to her. She focused on the issue, raising it in five separate points during the interview (see fig 12). She felt that long term relationships operate on trust and she questioned what you do if you can’t trust your partner, in that you can get tested, but then you still have to trust them after that to do the right thing (A05X)

Content analysis 22 stories	Online Reader Feedback
<p><i>(She) contracted the virus from her ex-husband....when their son...was conceived.over 50% of HIV infections globally are women and most of them are in a monogamous relationship, so they think. I knew I was negative when we married and I trusted my husband My then husband....knowingly infected me</i></p>	<p><i>...thought they were happily married ...but the reality was their husband was living a double life!! ...made mistake of unprotected sex even in a long term relationship</i> <i>46 LIKES//32 DSILIKES</i> <i>...the number of people infected who relied on their partner to keep them safe is still shocking.</i> <i>1281 LIKES//7 DISLIKES</i></p>
Interviews over 45 years	Interviews 18-35 years
<p><i>The scary part was where both women believed they had a safe, sexually healthy and responsible partner and they both felt comfortable to have unprotected sex...that trust was betrayed, you know, that was very scary.....an everyday person could be infected with if their partner was not doing the right thing and even though you.....believe that you were safe with them (A05X)</i></p>	<p><i>so....yeah and I felt really sorry for her because like her boyfriend that gave it to her lied and....yeah that really sucks and I totally empathise to that situation – people lie about things like that all the time....it could happen so easily. I guess I was surprised a little bit by Nici’s experience. She had no idea about, you know, her ex-partner in terms of his other pursuits and actually both of them really</i></p>

Figure 11 Betrayal of trust in long-term relationships

Women negotiated safe sex, after diagnosis

From the **content analysis**, seven of the women were in a new long term relationship. The women's acts of personal agency included leaving their partner and seeking testing (two). Those in long-term relationships had not suggested condoms and safe sex was not mentioned in relation to early partners. Two stories referred to women being accommodating with a partner and not insisting on, or challenging the use of, condoms. However, after their diagnosis, several women described being open about their HIV status and negotiating safe sex with new partners (Fig 13).

From the **online reader feedback**, two posts, whilst showing empathy for the women's situation and applauding the new partners for their acceptance, stated they would be 'too scared to do that and risk being infected myself'; the posts were equally *liked* by a small number. Fig 13 outlines two opposing reactions to a woman negotiating in her new relationship by asking her new partner to be tested. One was supportive and one felt it was sad/not romantic. However, overall respondents supported a woman taking a proactive approach. One underlined the different attitude to condoms, and hence negotiated sex, taken by the gay-community versus heterosexuals

I think the stick a condom on it safe sex message does not (I think) seem to carry the same weight among heterosexuals 1213 LIKES//0 DISLIKES

From the **interviews**, none of the participants noted that the women negotiated safe sex in their new relationships. Only two, one from each group, raised the issue of personal agency in negotiating safe sex in general. They spoke about contexts that do not support that approach for women (Fig 13). One, who had worked with young women, was concerned that alcohol and low self-worth had an impact, leading to decisions young women may regret. One in the 18-35 group, was concerned about the pressure on young women, with the advent of online dating sites and felt that people 'don't think it will happen to them' (B07Y). She explained 'people's behaviours are changing with the dating sites and not only men' and understands, from her male friends, that women are being more 'sexually assertive'. She also shared that her Mum, who has recently begun dating, told her that older men are 'out there' with regard to their sexual behaviours. On questioning, she did not know if women were similarly more assertive with regard to negotiating safe sex.

Content analysis 22 stories	Online Reader Feedback
<p><i>I'm really public with my status.....If you're close enough to me to be getting to the point where we're dating then you already know [that I have HIV].</i></p> <p><i>The way I approach it is to get to know potential partners as friends first so they get to know me as a person. I have never had sex without telling them first but that is a huge pressure. It is hard and it never gets any easier</i></p>	<p><i>I found it sad when my son met a new girlfriend, and she (they both) insisted that he had a check-up for HIV before they started intercourse. Not very romantic when you fall in love</i></p> <p>56 LIKES//0 DISLIKES</p> <p><i>I find it romantic that they care enough about each other's health to think about it and open enough with each other to be able to discuss it!</i></p> <p>910 LIKES//0 DISLIKES</p>
Interviews over 45 years	Interviews 18-35 years
<p><i>It's not about someone's judgment about a choice to sleep with somebody.....but I really worry...with this (young women)...so much of that revolves around alcohol and I then worry about the decisions people make and how they worry about that the next day and it's not about – you slut you shouldn't be sleeping around – is more was it something you really wanted to do and the next day you think “oh S*** I should not have done that”</i></p>	<p><i>When I see these increasing rates of STDs – I think, you know, ‘it's Tinda’, amongst young people ... there's a lot of pressure and people think it won't happen to them.....I think that people's behaviours have changed a little bit with those types of applications...both women and men.</i></p>

Figure 12 After diagnosis, the women negotiated safe sex

You can live well with HIV

From the **content analysis**, regardless of the purpose of the publication, such as ‘de-stigmatising HIV’ or ‘HIV is not a death sentence’, a striking common theme across all the publications and stories, was that today a woman with HIV can live a ‘long and fulfilling life’(1-04) often referred to as ‘Living Well with HIV’ (LWWHIV). The main contributions to the women’s reported good health were 1) advances in medications and antiviral therapy and 2) active self-care (Fig 14). Fourteen (63.6%) of the stories referenced treatment and medication as the reason the women were managing HIV and were symptomless. Seven stories (31.8%) referenced the women taking care of themselves, with changes toward a healthy lifestyle contributing to their good health status.

From the **online reader feedback** responses (Fig 14) showed an overwhelming understanding that people with HIV, not only live after diagnosis, but can have a healthy life after HIV. This theme garnered 5,316 supportive responses. A smaller number referenced advances in treatment as the reason people with HIV are living longer.

From the **interviews**, participants from both groups noted that HIV ‘isn’t a death sentence anymore’ (A01X) or ‘not a death warrant’ (A02X). Some comments that referred to a long a healthy life after diagnosis also related to the ability to have children. Several participants noted that it was ‘good to see photos of the women looking healthy’

Content analysis 22 stories	Online Reader Feedback
<p><i>I've maintained my health, I look after myself and do everything I can to manage the virus</i></p> <p><i>Because of the medication, and the fact that I look after myself, my health is really good</i></p> <p><i>She is not just surviving, but thriving</i></p>	<p><i>I think this article is refreshing for shattering this myth that people with HIV lead hideous lives, blighted with crippling illness and debilitating social stigma. 2829 LIKES//0 DISLIKES</i></p> <p><i>it is showing people that you can still have a life with HIV 1056 LIKES //0 DISLIKES</i></p> <p><i>Live longer due to treatment.....Now it is no longer a death sentence. 1479 LIKES//22 DISLIKES</i></p>
Interviews over 45 years	Interviews 18-35 years
<p><i>I felt they were good at doing that and showing that having HIV now doesn't mean a death sentence um and that you can have a good life. In the late 70s you got AIDS you diedand that's not the case anymore... you know there are people that have been Living with HIV for 30 years now</i></p>	<p><i>Life can continue and life won't grind to a halt when you're diagnosed... and have a normal life. People are able to live normal lives really after they have been diagnosed with HIV and have, you know, quite positive life experiences</i></p> <p><i>There can be Life after HIV and you can still have kids and a partner</i></p>

Figure 13 You can live well with HIV

Medication to treat HIV is less complicated

In the **content analysis**, five of the women diagnosed prior to 2004, described challenges taking and tolerating taking HIV medication. Now on new and lesser medication regimes, they experienced corresponding improvements in their health and managing HIV. Two made reference to the large number of pills required in the early days, both currently on ‘three pills a day’ reflecting recent advances in treatment. In addition to requiring few pills or no medication, the women in the stories reported that the side effects were also considerably reduced.

More than half the stories made referenced only needing 1-3 pills a day. Two women did not disclose the amount of medication they took and two did not require medication. Jo who had been diagnosed age 59 in 2008, seven years before the publication, felt guilty that she did not currently need medication

From the **online reader feedback**, two posts referred to the number of pills required, the physically difficulty of taking them and their side effects. The information appeared to be second hand, with no time frame to indicate if this information was current or historical, although 414 people agreed. A third

post about medication also contradicted the theme. The currency of the knowledge is unknown and the statement in the post was inaccurate, but it was not fully supported.

The drugs just slow down process of HIV turning into full blown AIDS. Popping pills everyday, and living in pain and fear once the AIDs manifest is not a life worth living. (115 Likes/292 Dislikes)

From the **interviews**, both groups noted the message that these days medication for HIV involves taking a few pills: ‘yes I didn’t realise at this point 3 pills a day would do it. Last contact I had it was a little more complicated than that, so that was nice to read’ (A02X). Only one of the 18-35 group, with a health background, referenced the impact that ART has on ‘reducing the viral load’ (B07Y).

Complacency due to positive LWWHIV messages and ‘3 pills a day’

From the **content analysis**, by stressing that women can live ‘normal’ healthy lives after a diagnosis of HIV, some stories gave the impression that HIV is not serious disease and can be dealt with ‘with a few pills’ (Fig 15). Even women who had difficulty at first indicated that HIV wasn’t a big issue for them (op cit) and some stories gave the impression that ‘HIV has a minimal impact on your life’ (3-01). The tenor of all three stories in the Guardian, where the overarching article had a focus of presenting ‘life affirming stories’, came across, as blasé and that dealing with HIV was effortless. The stories were positive, with no emotive language. They were also short, so the information provided was limited.

Becky, in the Guardian, described not feeling any different physically, due to the ‘medication and the fact that I look after myself’. In the story, HIV did not appear to have changed anything in her life. However, she admitted that the diagnosis had been a ‘wake-up call’ (8-01). She shared her view that ‘HIV is not a huge deal’

I can’t say I was delighted when I was diagnosed, but I wasn’t totally freaked out (8-01)

Her story also appeared in the Daily Mail (7-03), which included “No longer a death sentence” in the heading. In that story, she described more of her symptoms, being a rash, feeling fluey and feeling drained. Also in that longer story, she made reference to the stigma people with HIV experience and explained that ‘my high fitness has really helped me deal with the treatment’, giving a more realistic picture of what she and others have to deal with.

The purpose behind two of Abby's six stories was to promote an 'upcoming' documentary (Nov 2014) about young people who are living with HIV, with a message of prevention. In sharing her stories Abby she wanted to make sure people know that 'you can live well with HIV':

*It's a really **manageable** chronic illness. You take a couple of pills a day. People live next to normal lives (noted in four of Abby's stories)*

However, in the stories that were particularly aimed at young people, Abby also noted concern that young people could become complacent and treat HIV like any other infection that can be treated. This was echoed by the young woman who was born with HIV (10-01). In several of her stories, Abby stressed the need by young people for greater awareness of HIV and prevention or protection.

I think young people are also complacent about their sexual health. There's an attitude that antibiotics can fix everything and people just aren't using protection'

I think, especially for younger generations, they couldn't even imagine knowing someone with the disease. They all sleep around, they don't care. They protect themselves, but that doesn't always help. They think nobody they know could ever have HIV. (10-01)

Generally the LWWHIV message in the stories was connected with the advances in medication, rather than a message of prevention, testing and early diagnosis.

This theme was echoed in the **online reader feedback** (Fig 15), where 388 readers *liked* posts that suggested the positive approach taken by the stories could be harmful, in that people will think HIV is 'not a big deal'. Those comments also referenced growing apathy and that 'just taking a pill' is not the answer to staying safe in the first place.

From the **interviews**, there was concern that young people, or even older women who return to the dating scene, may be complacent (A01X). This idea that young people may think that HIV, like other infections, can be 'fixed' by the GP using antibiotics, hence prevention not be considered, was then checked with the 18-35 group. All three felt that HIV is still a disease to be managed (see their comments in Fig 15) and not everything can be fixed with medication. The youngest felt that Cath's story was a 'super positive story for a really serious issue' (B08Y) and that 'three pills and everything will be ok' might be taken the wrong way as people may think that 'if you contract it you'll be totally fine'. Both

age groups felt that HIV is still an ‘incurable disease’. The first over 45 participant mentioned the significant advances in medication, but expressed concern that particularly women, and young women, may get complacent, recalling that after the Grim Reaper campaign ‘straight non drug-using women were more likely to be careful’ (A01X).

Content analysis 22 stories	Online Reader Feedback (3 posts)
<p><i>AIDS is a manageable illness and with the right treatment.....it's possible to live a long and fulfilling life</i></p> <p><i>Today I am happy, healthy and symptomless. I started taking medication last year, and it's just one pill a day.</i></p> <p><i>Because of the medication & the fact that I look after myself, my health is really good</i></p>	<p><i>Would have been good to see a story that wasn't so positive. There is a growing apathy fostering the attitude that it doesn't matter if I get HIV - I'll just take a pill - which isn't the whole story</i></p> <p><i>Hits it on the mark about the ignorance of people thinking that they are safe. That complacency will only harm you in the end</i></p> <p><i>This story could convince some people that HIV is no longer a big deal well, IT IS... STAY SAFE !</i></p> <p>388 LIKES//15 DISLIKES</p>
Interviews over 45 years	Interviews 18-35 years
<p><i>It did really used to be a death sentence um and now it's not and increasingly with all the various anti-retrovirals and things like that...but I guess what does still worry me a little about stories. That one of the reasons maybe why the rate of infection is increasing because people now go 'well that's ok'</i></p>	<p><i>I don't believe that everything can be fixed with medication</i></p> <p><i>I think there's a big: "it'll never happen to me" or "HIV is a thing of the past". I think that....I don't think that people think about those things. I think that people are more worried about chlamydia or gonorrhoea more so than HIV really</i></p>

Figure 14 Complacency due to positive LWVHIV messages and ‘3 pills a day’

The world is more accepting

From the **content analysis**, four women in the stories expressed that there had been a general shift in society with regard to changes in acceptance, awareness and attitude toward HIV/AIDS and people living with HIV (Fig 16). Even so, ‘women with HIV/AIDS are almost invisible’ (1-04)

Posts from **the online reader feedback**, echoed an overall change in how HIV/AIDS is viewed, with significant agreement (Fig 16). Three posts noted life expectancy, misconceptions, understanding treatment and that the situation is no longer hopeless, with acknowledgement that people are working together to a common goal. There were no references to changes regarding women with HIV.

From the **interviews**, participants in both groups expressed that things have changed over time (Fig 16). Each of the five participants over 45 recalled their past experience with HIV and three referenced having had ‘many discussions over the years about homosexuality with the family’ (A01X). One participant

noted that 25 years ago, when she worked in the field, ‘dozens of my friends died...but that is not the case now’ (A02X). One recalled the ‘scaremongering’ Grim Reaper campaign, which portrayed the disease as ‘the enemy’ (A01X), and one recalled the presentations at school that left her ‘petrified’ as a teenager (A05X). The first participant felt that things had changed culturally in the world and Australia. She referenced the current debate on same sex marriage (Sept. 2017), noted the acceptance of gender differences, especially with young people, and that the world is more accepting of people who are gay. She reminisced sadly that she no longer accompanies her gay friends to events (Fig 16). Her strongest example of change was her Mum (89 years), who did ‘a complete flip of where she was before – she now thinks ‘oh that just the way people are’ after being ‘quite affected by’ one of her friends who died of AIDS (A01X). She said ‘I think what younger people these days don’t understand is that at that time most gay men had to hide the fact that they were gay’.

The 18-35 group also felt that stigma has lessened over last 10 years. They noted that these stories would have been ‘different if written 20 years ago’ (B06Y) and that they are sharing information about something that not only has changed but also is ‘not well understood’ (B07Y). As mentioned, the dating apps Tinda and Grinder, released in the past 3-5 years, have also changed the way both women and men behave in seeking new relationships (B07Y).

Content analysis 22 stories	Online Reader Feedback (4 posts)
<i>I’ve been really surprised by how accepting & willing people are to put up with this virus. (in my job) I saw a lot of our former chairman.... a high-profile HIV-positive man.....I thought: maybe it’s not so bad these days. I know now that people know more about HIV/AIDS. It is not now a hush-hush thing. On TV there is AIDS awareness. People want to help others and care.</i>	<i>There is a change of attitude towards HIV positive people...communications like these dispel a lot of myths and fears. The world has come a VERY long way in the past 30 years.... 271 LIKES//11 DISLIKES Well done, this is such GOOD news.. Glad to see we’ve come so far. Just makes me so sad that our lost brothers and sisters (are not) alive to see it 2829 LIKES//0 DISLIKES</i>
Interviews over 45 years	Interviews 18-35 years
<i>...because he couldn’t take his partner with him. So I was sort of you know....the straight friend in the group who sometimes got to go to things and you know (laughing) I don’t get to go to those things anymore...so I certainly notice that</i>	<i>.....I suppose in story one (Nici) it’s portraying something that people don’t really understand and something that’s changed significantly over the last 20 years</i>

Figure 15 The world is more accepting

The perception of the message is affected by the presentation style

The aspects that were investigated in the **content analysis** included 1) the use of photographs and 2) links to adverts and other articles.

From the **interviews**, the audience reception of the photos was investigated. Participants were specifically asked *when you saw the full presentation of the two stories did it change any of the thoughts and feelings you had when you first read the stories?* They were also asked *If you had seen the full article first would you still have proceeded to read it?*

In the **online reader feedback**, two posts in the Guardian referred to the Daily Mail's sensational tendencies, which received 4,490 *like* responses.

The use of photographs

From the **content analysis**, the number of photos varied considerably across the publications. Each of the articles and each of the single stories had at least one photograph, some stories had none. Of the 22 stories, seven had no photograph nine had one. Three stories in the Guardian had one photograph and in the Daily Mail each of the three stories had four or five. Two of the four Herald Sun stories had one and two of the Women's Weekly stories had one photograph. The Mamamia single story was the only other publication with four.

The analysis investigated the relationship between stigma and either the number of photographs, or the amount of space the photos took in the story (% story that is photo). Of the 10 stories that described the woman's experience of stigma or discussed stigma as a broad issue, no correlation was found with either variable.

The subject matter of the photos was also investigated. In all but one story, photos of the women whose story was told were used. Consistently the photographs portrayed the women as looking well and healthy and participating in healthy activities. Some included the woman's new partner and her children or grandchildren. The four photographs in Mamamia, one of Abby's repeated stories, showed Abby appropriately as a healthy young woman. However, this story was not shown to the participants for comment. In the Daily Mail, Nici's five photos were mostly close up 'selfies' of her looking glamorous, sensual or with her partner; fitness teacher Becky's five photos all showed her in fitness outfits or with her bicycle; and Rachel's four photos were with her three children, her daughter and her partner.

From the **interviews**, discussing the full presentations of Nici (Story One) and Cath (Story Two), the participants commented a great deal on Nici's photographs. Those over 45 agreed that it was good to see how fit and healthy the women looked in the photos and that photos created 'more connection to the women' (A05X). The general feeling was that Nici's photos were personal, like 'selfies', 'sexual', 'glamorous', seemed 'self-indulgent' and that there were too many photos of her

The interesting thing was.....the first girl (Nici) headlined as 'The story of 3 women' and when I scrolled down there were 3 pictures of her and the first thing I thought about it was "god they managed to find 3 women who looked really alike" and it wasn't until I scrolled down further that I realised that was just her story and these were her pictures and there were other people after that (A03X)

I thought 'Oh for god's sake how many times do we need to see a photo of this woman?' (A01X)

One participant from each group were clear that the visual presentation of Nici's story had had an impact on them. They connected more with the text of Nici's story than Cath's, but found the opposite after reviewing the full publication online. Both said they might not have read it if they had come across the full presentation first

It was this kind of trashy magazine type of publication.....to me the presentation didn't fit the seriousness of the story. So, you know, I instantly connected less with that story. And story two (Cath) on the other hand looked quite serene and serious.....so when presented online, I connected more with story two. But when reading the content it was quite the opposite (A05X)

I was really like 'that's me, I relate', but if I had read Nici's story with the pictures and all of it together I may not have seen her in such, like, a great way (B08Y)

The incongruity of the presentation and content of the Daily Mail article was also noted by another over 45. She related to Cath's photo and story and would have read the story, but agree that the visual representations would have stopped her from reading Nici's story. However, she was attracted to the dot points about HIV at the start of Nici's story and felt that that would have caught her attention and interest enough to read it.

She (Nici) looked like a fit healthy young woman, which was good, but I didn't need to see all her head shot selfies.....it put me off her a bit, which is not fair..... because I'm interested in the subject matter..... if I just had been looking at the visual I probably wouldn't have [read it], but because it had....those headline facts that told me what it was going to be about, so I would have, but certainly not just from the visual I wouldn't have, but I would have with Cath (A01X)

She noted that 'party girl shots' and 'selfies' may be generational, in that they might appeal to and attract a younger audience. This was subsequently checked in the 18-35 interviews. The youngest participant, who was under 25, suggested that, although they would be attracted to the story, her generation would be inclined to judge the photos.

When I looked at pictures of her (Nici).....I'm not sure if this is a very nice thing to say about a woman, but I felt like some of the pictures were kind of like sexual, or something...which it's about HIV, but I just sort of thought that the pictures they chose for the second one (Cath) seemed respectful? Whereas for story one (Nici) I don't know....I probably wouldn't have chosen them for her if I was doing it (B08Y)

B06Y in the 18-35 group felt that the photos, especially being in colour, created more of a connection on an emotional level and, but that they did not change anything else for her. The third younger participant found that Nici's photos did not resonate with her. She felt the presence of the photos had made the story a little easier to follow than the text alone, which she found disjointed. However, she did agree with the over 45 group's reaction.

I'm not part of the selfie population....I don't think it really speaks to me, it seems a little bit.... not self-indulgent but it seems a little bit narcissistic to me, but the selfies don't resonate with me, maybe one would have been ok but not four or five (B07Y)

The way photographs were used in the presentation of Nici's story had an impact on the participants as the audience, potentially resulting in the story being bypassed and not read, even if the content was sound. It seemed that the subject matter had an impact across both age groups, which in turn made the number less acceptable.

Links to other articles

The **content analysis** investigated the inclusion of links to other articles, which could encourage the reader to follow and read them. The number and layout of the links and the appropriateness or sensational aspect of the articles varied considerably with the publication and some had none. The links and adverts were to articles with three types of content: 1) appropriate content 2) inappropriate and sensational (sexy or lurid) content in relation to women and 3) general, unrelated content.

As noted in Table 10, five of the articles (nine stories) had appropriate links and three articles (five stories) had links considered incongruous in relation to the subject matter. The Daily Mail, News.com and Cosmo, linked to articles that represented all three types of content

- 1) An example of an appropriate, congruous article in the Australian Women's Weekly read: *New tampons might protect women from HIV.*
- 2) Examples of inappropriate, sensational, lurid articles were found in the Daily Mail: *"I flash my t**s and give the boys an erection" by (TV star) in rap video after sexually explicit videos came out on line;* and in Cosmo: *A new women's only porn TV channel is here.*
- 3) The general unrelated links in the Daily Mail also had a sexist slant, objectifying women or with a focus on appearance.

Of the 10 stories that included both depictions of stigma (op cit), only 2 (20%) linked to articles with inappropriate content.

Layout and number of the links varied significantly across publications. The Herald Sun and the Guardian for example had none, leaving the text of the story clear and easy to read. However, Cosmo, News.com, Mamamia and the Daily Mail, followed the article/story with 10-18 pictures with links to other articles that occupied several pages after the woman's story finished. In addition, two of these had links and adverts down the side of the page with the story. News.com (2014) had a few adverts and links on the side of each page, while the Daily Mail, had 131 links at the side of its 25 pages, as well as up to three adverts to each page. Of interest, the Daily Mail, despite the sensational style, provided the largest amount of background information on HIV for the reader and referenced a number of resources.

From the **interviews**, the participants were specifically asked about the impact the links and content had on their reading experience. Of the two stories presented to the participants, Cath's Story Two, in the Women's Weekly, was presented simply, and Nici's Story One, in the Daily Mail article, contained many links to articles as described above. Most of the feedback relates to Nici's story.

Two participants over 45 group, both of whom had experience in the HIV field, and one participant in the 18-35 group, who worked in health, clearly said that 'no' the presentation style of the article and surrounding information would not have made a difference to their reception of the stories. They all indicated they had 'blocked' the extraneous information and could not state if it was appropriate or not.

Two participants (A04X and B08Y) did not follow the links. However, they explained they usually would have looked at and been distracted by any links. Following the instructions given with this task, they did not pay attention to the extra links or critique their content

Negatives for me is the sometimes the different type faces, the stuff that happens around the outside. I don't know whether is because I'm easily distracted but sometimes I think that takes away from the impact of the story..... probably not in this circumstance because I was on a mission.....but under normal circumstances – yes I would have (A04X)

Overall, three participants noted they would block, or tune out the 'extras' if not interested in them. Five others described them as distracting, annoying and said that they made it hard to concentrate. Participants from each age group noted that the adverts and links were annoying, not relevant and did not fit with storyline, being 'trashy' and about 'TV shows and pop culture'. They felt that the extra links and adverts did not fit with the seriousness of the story and would 'take away from the impact of the story'. The youngest participant felt that the adverts would appeal to young women, but she felt they were not appropriate.

Thinking about the adverts on the side it was all like 'vanity' adverts.....(looking) yes it's all about teeth and the Kardashians and stuff like that.....and even with this story (Nici) it definitely would have changed my opinion (B08Y)

One of the 18-35 group explained she reads stories like this on her phone, rather than her computer and felt an article would need to be 'built' for phones to ensure it was read

If there were pop-ups everywhere when I was reading it and I had to close the pop-ups in order to read it, I would probably find that really annoying. And likewise, if I was opening it and something started to play automatically, I'd probably find that really annoying.....(B07Y)

She described the presentation style, with all the ads and links on the page as ‘click-bait’, thus affecting the feeling of the story content being ‘trustworthy’

..just trying to get as many people clicking on something with a sensationalist title and then sell some ads (B07Y)

She also explained that an accessible, ‘cleaner’ story, ‘easy to read on her phone’, with ‘less distractions ‘flashing in the corner of my eye’, would be something she would ‘quite happily read after hours or late at night’. She did feel that the content of the extras was not relevant, perhaps appealing to younger women, but didn’t fit with the storyline.

Overall impact of the presentation style on the interview participants

The impact of the presentation style (Fig 17) showed that the 18-35 group preferred Cath’s Story Two was preferred. For those over 45 the drive to read was primarily based on interest.

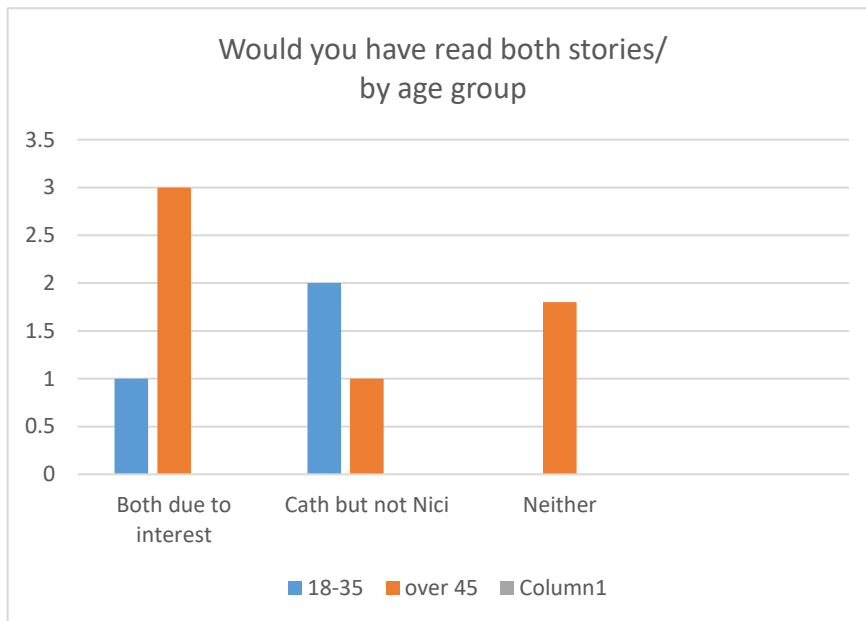


Figure 16 Impact of presentation on participants choice to read the stories

Ignorance about HIV still exists

From the **content analysis**, the women in the stories consistently expressed surprise at people’s knowledge about HIV and the ignorance that persists about women with HIV (see Fig 18). As discussed,

there was a particular focus in several stories that young people are unaware of their risk for HIV, ‘complacent when it comes to STIs’ (3-02), with the underlying attitude that ‘antibiotics can fix everything’ (4-01): ‘they think no-one they know could ever have HIV’ (10-01). One woman suggested it is time for another Grim Reaper type government campaign.

*The younger generation has to be told that it takes just one night of unprotected sex, so don't take the risk.....30 years on from the first HIV test and all the **hysteria** that followed, I'm in no doubt we need another Government awareness campaign (7-02)*

The **online reader feedback** (Fig 18) supported that ignorance about HIV is an issue. Two posts, which comprised 4,547 of those *likes*, supported this kind of information being shared by the media.

From the **interviews**, ‘*ignorance about HIV and a need to educate the community*’ was one of the five key messages in the stories identified by the participants. Two participants commented that people need to be educated to understand that HIV is not dangerous to the community. Five others noted that education is needed about HIV regarding ‘*misinformation about transmission*’ (Fig 18).

Content analysis 22 stories	Online Reader Feedback (5 posts)
<p>Women with AIDS are almost invisible in this country, we need to ...educate people about what living with HIV/AIDS really means. <i>It does amaze me how ignorant so many people still are though.</i> <i>I was stunned, but it's just ignorance, a lack of education.</i> <i>By now you'd think people would know a lot about HIV, but they don't</i> <i>People still don't have a clue about HIV</i></p>	<p><i>There is still so much ignorance about HIV... You can catch colds and tummy bugs from door handles, but not HIV. 450 LIKES//24 DISLIKES</i> <i>The public have such skewed ideas about HIV/AIDS the majority....are unaware and it's good to see media cover it. 3548LIKES//0 DISLIKES</i> <i>I remember Princess Diana shook hands with an AIDS patient and it went viral as nobody else had done it before. 42LIKES/ 2 DISLIKES</i> 5073 LIKES//34 DISLIKES</p>
Interviews over 45 years	Interviews 18-35 years
<p><i>People are still very ignorant about the disease. They still don't realise how difficult it is to catch, it's not one of those contagious diseases like measles um and so there's a lot of stigma about it</i></p>	<p><i>...was a call to arms about how we can educate people about how to prevent the transmission of HIV but also to reduce stigma as well in HIV and actual people's lived experiences and how we can all learn from very normal people about their experiences with...HIV</i></p>

Figure17|Ignorance about HIV still exists

Stereotype ‘who gets HIV’ does not include women, but anyone can.

From the **content analysis**, in each story as expected, the women did not fit the stereotype of a person who they and others thought were at risk for HIV (Fig 19). The stereotype included: ‘gay men and injecting drug users’ (6-04) and those who engage in ‘risky behaviour’. Other characteristics to indicate that the women did not consider themselves at risk included being ‘white’, ‘Australian’, ‘married’, ‘heterosexual’, a ‘woman’ and ‘not promiscuous’. As a result, across all publications, in 13 of the stories the women experienced shock in reaction to their diagnosis of HIV, including feeling ‘suicidal’.

The women’s knowledge about HIV changed over time. As the women came to terms with their diagnosis and they gained more understanding, recurrent themes came through the stories that ‘HIV doesn’t discriminate’, ‘HIV doesn’t define who you are’ and that ‘anyone can get HIV’.

From the **online reader feedback**, only a few commented on this theme. Two posts with a few equal responses held opposing views about which group were most at risk: gay men or heterosexuals (Fig 19). One post noted that ‘a high percentage of the worldwide HIV positive population is female’, the only time that was mentioned.

From the **interviews**, some over 45 recalled the Grim Reaper campaign, after which ‘*straight non drug-using women were much more likely to be more careful*’ (A01X), a group that prior to the campaign may not have understood they were at risk. They felt that HIV is a disease that anyone can contract (Fig 19) including ‘normal everyday women’ (A05X) and ‘ordinary people’ (A01X). One participant noted that since anyone can get HIV, ‘you may not know you have it’.

Content analysis 22 stories	Online Reader Feedback (4 posts)
<i>I was from a regular middle class family. I’d been to uni. I was a young woman, HIV couldn’t affect me. Women don’t meet the stereotype of the so-called typical person who’s going to contract HIV.... Not high risk, I was a married women</i>	<i>All those still thinking these diseases are only applicable if one is a junkie or (gay), are putting their children at risk 34 LIKES//8 DISLIKES HIV only affects gay men - heterosexuals are low risk 34 LIKES//0 DISLIKES</i>
Interviews over 45 years	Interviews 18-35 years
<i>.....they’re nice girls aren’t they, they’re nice girls. They’re not drug users, they’re not prostitutes they’re, you know they’re not the sort of people who would get HIV (softer) um, so both of them are quite sympathetic characters I think..um and that’s fine. I thought it came across as a disease that.....an everyday person could be infected with</i>	<i>I think that the main messages were: anyone can be diagnosed with HIV....so it was kind of challenging the traditional perspectives on.... people with HIV, how they present and what society previously told us about them...and how their experiences contrast to the....social stigmatised version...and what we’ve been told previously about how HIV kind of presents</i>

Women don't know the risk for HIV as it relates to them

From the **content analysis**, 11 (73.3%) of the women knew nothing about the implications of having HIV on diagnosis, even though some were young adults when HIV/AIDS was first in the public eye. The year of diagnosis and age of the woman on diagnosis is outlined in Table 16. That women of all ages had little or no knowledge of HIV as it might relate to them, was unexpected. Since the Grim Reaper advert was published in 1987 and the first HIV testing and diagnosis occurred in 1985, there was an expectation that those born on or before 1972 would have some knowledge. They would have been 13 years or older when HIV/AIDS came into the public eye. Six women were in that age group, however, only one knew that HIV could be contracted through unprotected sex and none understood the risk as it related to them (women). Of the six in the younger age group, born after 1982 who would have been aged 3 years or less when HIV/AIDS came into the public eye, one was born with HIV and one contracted HIV from her partner with haemophilia. This younger group grew up in an era where HIV existed and confronting adverts and information about HIV/AIDS were not the norm. Again none knew the risk as it related to them. Both Abby and Becky (8-01) searched on Google to match their symptoms to a potential disease.

Table 16 Age and year of diagnosis of the women, related to HIV/AIDS first public announcements

Story code	Year/age at Diagnosis	Born before 1972		Born on or later than 1982	Knew nothing (NIL) Researched (R)
1-01	2005/ d/k		1974		Not known
1-02 and 6-04	1994/25	1972			NIL
1-03	1989/20	1969			NIL
1-04	2012/42	1970			NIL
1-05 to 5-01 (6 stories 1 woman)	2013/23			1990	NIL – R
6-01	1998/21		1977		NIL
6-02	2012/28			1984	NIL
6-03	1994/40	1954			NIL
7-01	1997/19	1968			Knew safe sex
7-02	2007/39	1968			NIL – R
7-03 and 8-01	2012/37		1975		NIL- R
8-02	2006/22			1984	NIL
8-03	2008/18			1990	NIL
9-01	2004/20			1984	
10-01	1986/01			1985	

From the **online reader feedback**, only one woman made a reference to this theme. From her handle (Angie1963) she may have been born in 1963, making her 51 at the time of the post and born before 1972. Her post gained 77 likes.

Oh my days! When I think of how foolish I was when I was young, I count my blessings.

In the **interviews**, there was little reference to a difference in knowledge related to age demographic.

GPs do not recognise that women are at risk for HIV

From the **content analysis**, the aspect of the GP not recognising the woman's risk of HIV, or misdiagnosis resulting in delaying testing, was raised in nine stories. However, those nine stories only represented four of the women: Nici diagnosed 1997, Becky and Diane diagnosed 2012 and Abby diagnosed 2013. Abby's story was repeated in six publications from 2014 to 2017. She also had visits to the emergency department and was diagnosed after she insisted on being tested. In addition, her story references that 'sexual health screens for women do not include a test for HIV'.

In addition to the women in the stories (op cit), some GPs also held the stereotype that people at risk of HIV does not include women. Abby's GP, in response to her request for an HIV test, in all six of her stories, is described as saying:

...you're an Australian woman, the chances of you having come into contact or contracting HIV are so slim that doing the test probably isn't necessary (4-01)

One of Becky's two stories noted that she visited her GP several times, being tested after she went online and researched her symptoms. Diane had frequent visits to her doctor and was initially misdiagnosed

I'd been suffering a number of illnesses and my immune system wasn't functioning at all. I'd had this lump on the side of my neck that wouldn't go away and although I'd been going to the doctors to get help, I'd been misdiagnosed (1-04)

The most recent publication featuring Abby's story was in News.com (2017). It had the headline "*HIV misconceptions leading to delayed diagnosis for some women*" and statements from the AIDS Action

Council of ACT and the Council's women's network: *'Testing is not only not on women's minds but also [not on the minds of] health care practitioners and some GPs'*

The three examples described above occurred in the four women who had been diagnosed since 2012. In addition, since the article published in 2017 included credible experts in the field provided supporting information, there is support to include 'misdiagnosis by the GP due to stereotype that women are not at risk' as a current issue, even though it was underrepresented across all 22 stories.

There was only one example in the stories of misinformation about living with HIV, from health practitioners to the woman (1997). Twenty years ago Nici, tested as a result of her boyfriend's diagnosis of AIDS did not experience misdiagnosis due to gender. The misinformation she was given from the health practitioners, relates the proliferation of stigma and poor knowledge about HIV, rather than misdiagnosis

I was told I'd die in four or five years' time, but the worst part was being told I could never have children or a partner, which upset me more than having any disease.....All the information I was given at the beginning by the doctors was so incredibly wrong!.....My mum has been told by an HIV adviser to wash my clothes separate to theirs and store my toothbrush on the other side of the sink, habits I assured her weren't necessary (7-01)

The **online reader feedback** nor **interviews** did not address GP knowledge

However, from the **interviews**, two mentioned the misinformation given to Nici. One over 45 noted the fact that Nici was diagnosed in 1997 may have contributed (A01X). The youngest participant felt she would have been someone who believed that you had to separate clothes and toothbrushes and commented that she would have been in the stigmatizing group had she not read the story.

...not that I didn't fully know about HIV and stuff but even I would have thought, like, having a toothbrush of someone with HIV, I didn't know that you can't catch it like that. I would have thought that you could. So it was kind of cool in that way (B08Y)

Accurate sources of information

The **content analysis** showed that any background information about HIV in the stories was appropriate and contained accurate information about HIV and available resources. All the articles were published with a purpose, for example 'provide information to women and young people', 'highlight late and under testing for HIV in women', often in conjunction with a major event such as AIDS conferences, or anniversaries of first HIV diagnosis. The purpose and context of the articles, i.e. the related event, influenced the story perspective and focus. For example the National Day of Women Living with HIV, now annually in March, was established in 2016 to celebrate women with HIV and to combat stigma. Two of the single stories (ABC online; News.com) were published in March 2017. They discussed 'under-testing' in women, that 'stigma still exists' and that women with HIV are 'invisible'.

The amount of background information varied considerably across the publications. Four of the single story publications had none, nine stories, across three publications, including Women's Weekly and the Guardian, had just a few lines of introduction. Nine stories had a significant amount of background information, including the Herald Sun and the Daily Mail.

Background was organised differently with each publication. The Guardian had a brief introduction to six stories of men and women, followed by nine pages of moderated reader feedback. The Herald Sun had a page of background followed by four stories, with a small amount of reader feedback. The 2014 News.com article started with half a page of video promoting an HIV documentary and half a page of information. The ABC's four pages of larger sized font interspersed the story, background information and expert testimony, in a similar presentation style to the March 2017 News.com article. The Daily Mail had the most background content of all the publications. It started with a list of 10 dot points, followed by six lines of expert testimony and a video. After the stories, 13 lines of commentary, half a page of expert testimony and a timeline of the "*History of AIDS from 1908 to the present day*", was followed by with three pages of reader feedback.

Within 13 of the stories, across eight publications, the reader was referred to resources, or websites of credible organisations that provide information or support about HIV. Some included videos that started automatically. As a result, when viewed online, the video played without requiring the reader to 'click' on the video to start it. Resources for the reader to follow up were included in 11 (73.3%) of the 15 stories where the woman's experience of stigma was discussed and in 10 (55.6%) of the 18 stories that discussed stigma as a broad issue.

The **online reader feedback** posts did not reference the background information on HIV

From the **interviews**, two participants in the over 45 group noted that the intention had been for the publications to provide good and accurate information. One noted that one of the articles had included stories of women diagnosed at different times which gave a valuable perspective

you could get a slightly different perspective on what it had been like for each of them to be diagnosed in different periods.... and what treatment was (A02X)

I thought that they tried to give sensible and clean information. In telling the story (Nici)...doing the comparison between the bad information and the good information (A01X).

Stories are valuable tool to share information

From the **content analysis** of the stories, the women's own lack of knowledge of HIV and their observations about other people highlighted for them a need for education. They all expressed a desire to share information and support other women and work in roles and projects with support organisations, write in networks or take time to speak to community groups

I've made it my mission to dispel any myths around HIV, to help others understand the reality of the condition (7-01)

She is passionate about community awareness of HIV and now works as a support co-ordinator at PWV⁷ (1-03)

Becky, diagnosed in 2012, appeared on TV to share her story, even though this meant that everyone she knew would be aware of her HIV status

I decided to go on Daybreak that November, which meant that everyone I worked with, old friends, everybody knew my HIV status. Apart from the sense of relief at being completely open, I really saw a value in putting myself forward to help change those lingering misconceptions so many people have.

The value of stories as a useful mechanism to share information and connect with others was repeated across the stories (Fig 20). Addressing isolation through support networks was noted as one way

personal stories were shared. They wanted to share their story to prevent others contracting HIV and to speak out about issues with issues of diagnosis and stigma. The women’s courage to share their stories and desire to help others, by reflecting on their own situation, helped others deal with their situation.

From the **interviews**, three participants saw the women as inspiring in sharing their stories to help others (See Fig 20). The 18-35 group felt that the stories were a good way to learn from people not typically expected to have HIV about their experiences. They also noted that anyone can be diagnosed and that the stories

Stories are good vehicles to show what happened to others when ‘they didn’t think it would’ (B07Y)

Raising these issues in this lighter way through stories may be a way to reach them (A01X)

From the **online reader feedback** over a dozen posts in the Guardian supported the use of stories and articles in the media to dispel negative perceptions, ignorance, stigma and misconceptions, attracting 10,353 likes (see Fig 20).

Content analysis 22 stories	Online Reader Feedback (13 posts)
<p><i>My family and friends believed my story can make a difference, to influence the decisions people make</i></p> <p><i>If my story stops one woman contracting HIV then I’ve achieved. By talking about it, I hope to empower other women to share their stories</i></p> <p><i>Going to the support group was one of the best things I did...I wasn’t a victim...most importantly that I wasn’t alone, other women were dealing with this too.</i></p> <p><i>Connecting with other people and being really inspired by what they’re able to do with their lives has been key</i></p>	<p><i>Fascinating read, the public have such skewed ideas about HIV/AIDS it's important for the media to portray the reality of the illnesses.....the majority of people are unaware and it's good to see media cover it 3536 LIKES //0 DISLIKES</i></p> <p><i>There's plenty of negativity out there regarding HIV. I think this article is refreshing for shattering this myth that people with HIV lead hideous lives 2829 LIKES //0 DILSIKES</i></p> <p><i>Interesting read, brilliant, educational, dispels prejudice, stigma, myths and fears.</i></p> <p><i>Interesting, informative, diverse stories. Thanks for sharing. 3989 LIKES //0 DISLIKES</i></p>
Interviews over 45 years	Interviews 18-35 years
<p><i>(Cath) has made it a bit of a mission to change you know what’s happening to her has meant that she had also decided that she’s going to do something for others</i></p> <p><i>She’s trying to educate about HIV so really she’s aware that it’s out there</i></p>	<p><i>I thought that (Cath) seemed quite inspiring and the fact that she’s going around, you know...a highly sought after speaker who goes out to community groups. I mean.... she sees herself as a stigma warrior</i></p>

Figure 18 Stories are valuable tool to share information

Safe sex and early testing needs obvious message

From the **content analysis**, the women were clear that it can be awkward for young people and women to raise the topic of safe sex and that young people in particular need education and support (Fig 24).

The stories were analysed to see if safe sex and testing were mentioned in the storylines and to determine if the stories advocated or encouraged safe sex and/or early testing for women (Figs 22, 23).

The topics of testing and safe sex were raised in stories aimed at young people although they did not strongly educate about, or advocate for, safe sex and testing.

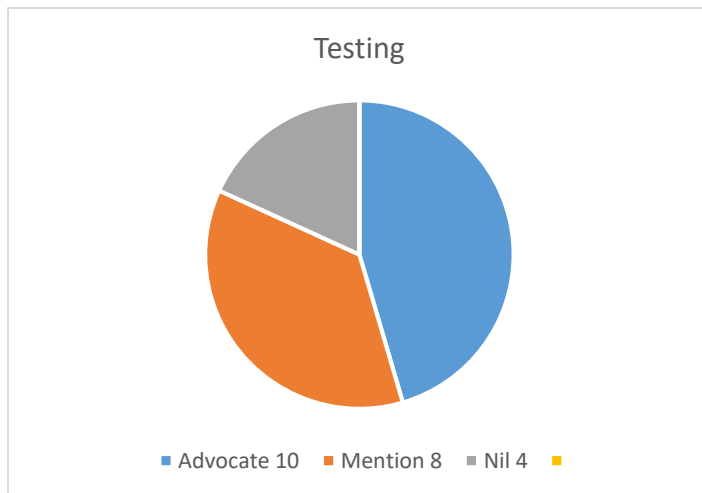


Figure 19 Testing included in the storyline of 18 (81.8%) of the stories

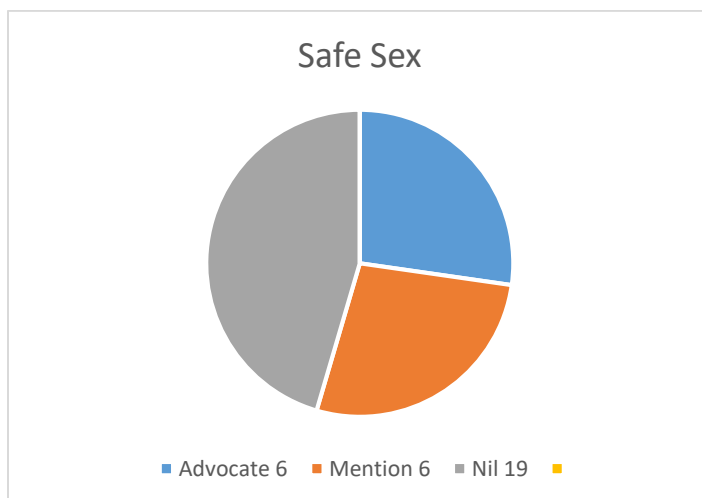


Figure 20 Safe Sex included in the storyline of 12 (54.5%) of the stories

Inclusion in the story line and advocacy for both testing and safe sex were measured and compared with publishing source and target audience (Appendix 7). Only two (9.1%) stories did not mention safe sex or testing at all. Three publishers did not advocate for safe sex or testing: eight of the ten stories in the Herald Sun, Daily Mail and the Guardian. However, all of the single story publications (Abby's story) included advocacy for either safe sex or testing or both, with Cosmo, News.com and Mamamia mentioning, as well as advocating for, both safe sex and testing. All but one of the five Women's Weekly stories (80%), including Abby's story, advocated for either safe sex or testing. The purpose of the story generally matched the story content. All those aimed at young people mentioned or advocated for safe sex and testing. Three of those both included them in the storyline and advocated for safe sex and testing.

In contrast, seven of the 10 stories that were aimed at a general audience did not advocate for safe sex or for testing. They did not fit the purpose which instead included: to show that 'people can live well with HIV'; that 'HIV is not a death sentence'; and that 'women with HIV are not alone'.

Stigma can be a reason for delayed testing, in that women will not disclose or be tested for HIV due to a fear of stigma. As mentioned 18 (81.8%) of the 22 stories mentioned testing. A similar proportion, 12 (80%), of the 15 stories that had discussed stigma also discussed testing. Advocacy and encouragement for women to be tested was mentioned less often, being six times in the 15 stories (40%). Of the 18 stories where stigma was discussed as a broad issue, 10 (83.3%) of the stories mentioned testing, with nine (50%) advocating for testing.

As mentioned, 12 (54.5%) of the stories referred to safe sex. A similar proportion of references to safe sex was found in stories that had also discussed stigma. Safe sex was mentioned in eight (53.3%) of the 15 stories that described the woman's experience of stigma and in nine (50%) of the stories that discussed stigma as a broad issue. Again, like testing, safe sex was discussed more often than it was encouraged or advocated for. Safe sex was encouraged in 33.3% (five) of the 15 stories that described the woman's experience of stigma and encouraged in 22% (four) of the 18 stories where stigma was discussed as a broad issue. Testing was included more often than safe sex in the storylines.

From the **online reader feedback**, the responses, which were in publications aimed at the general public and not young people, did address safe sex and the messages were clear. There were three main ideas about safe sex: 1) that you get HIV/AIDS from having unprotected sex with a partner who has HIV/AIDS and who you may or may not know; 2) that the safe sex/use a condom messages aren't as readily

accepted or acted upon on in heterosexual relationships; and 3) that if the purpose of the stories is to promote safe sex then the message in the story needs to be much clearer (Fig 23).

From the **interviews** the participants agreed that the stories did not strongly advocate for safe sex and testing. There was reference in both groups to a need to educate people in the community with regard to preventing transmission and reducing stigma. One 18-35 participant agreed that an obvious message is needed to have an impact in an educational way. Another felt that ‘learning from real life’ was the stronger message, and that the stories made you think about that (Fig 23).

Content analysis 22 stories	Online Reader Feedback (8 posts)
<i>I know so many girlfriends who've had unprotected sex because they feel it's awkward to bring up a condom in the heat of the moment, but at the end of the day it's you who has to live with the consequences Young people aren't receiving adequate education about the risk of STIs or the importance of safe sex...</i>	<i>Get HIV/AIDS from having unprotected sex with an infected partner regardless of how/where you met the person 1009 LIKES//187 DISLIKES More nuanced safe sex message needed 1213 LIKES//0 DISLIKES</i>
Interviews over 45 years	Interviews 18-35 years
<i>(Cath's story) stressed the importance of knowing your status Do you take your partner to have him tested and then open the results together?</i>	<i>(it was) about how we educate people about transmission of HIV, also to reduce stigma as well What worked the best in reading both of the stories was...real life situations that you've probably been in.....not just like thinking about safe sex and HIV If you want to encourage testing it needs to be a bit more explicit</i>

Figure 21 Safe sex and early testing needs targeted message

Magazines are read online

From the **content analysis** all the stories were obtained online.

From the **online reader feedback** the topics of how people read magazines was not addressed

From the **interviews**, the participants purchased neither hard copies of magazines, nor online subscriptions. However, all over 45 said that they would ‘always’ pick up a magazine and read it if they were in a waiting room, or similar. Two reported they would search online to find a topic of interest. Of the 18-35 group, two reported they might occasionally look at a hard copy magazine but would likely read that type of publication on their phone or read articles on Face Book. The youngest participant said she might get articles like this forwarded to her with her study and does see magazines occasionally, but prefers to avoid them if possible as they do not promote feelings of self-worth

I actively avoid it. I get really frustrated with tabloid magazines and reality TV, like it really bothers me. I try not to be judgmental of anyone or anything, but I think I find for myself, after reading things like that I don't really feel as great about myself..... So the long winded answer to that question is - I normally avoid like tabloid related things (B08Y)

Intent to share the stories

This was a question of interest in the study. In the interviews, the participants were specifically asked 'Would you share either of these stories with family or friends? Online reader feedback also recorded the extent to which article had been shared electronically.

From the **content analysis**, the women shared their personal story as a means of 'making a difference'.

In the **online reader feedback** the articles that contained posted comments and responses, also had the capacity to Share the whole article electronically (Table 13). The three stories in the Daily Mail, including stories in the Guardian, including 54 moderated posts and thousands of like/dislike responses, were shared 3,212 times.

From the **interviews**, three participants in the over 45 group had discussed 'issues of HIV and infection' (A02X) with family over the years and felt there was 'nothing in these stories that was any different to things already discussed' (A01X), but that they might 'if it were to come up' (A02X) or if there was 'a new medical breakthrough in HIV' (A03X). All the 18-35 group would discuss with friends and family and two already had by the time we held the interview

Yes, discussed Cath's story and used her experience to start the ball rolling with my Mum (who recently started dating, encouraged her to get checked) (B07Y)

I told my mum as soon as I read it and my best friend today – we talk about sexual health stuff. My friend is squeamish, but Mum always wants to know (B08Y)

Of interest, one of the over 45 group who said she would likely not share the articles, did notify me that she had sent the links to her daughter after all,

After we hung up (Skype call), I decided to forward my daughter the links to the two articles. So yes, I guess the discussion with you affected me(A02X)

During the interview, all three the 18-35 group and two out of five in the over 45 group (five or 62.5%) expressed an intention to share the stories with family and/or close friends. This became six participants or 75% of the over 45 group after the post interview communication.

Impact of the Stories

From the **interviews** there was agreement in the 18-35 group was that these stories would help someone deal with the situation if they had HIV, or help reduce stigma, but might not prompt someone to practice safe sex or get tested. They felt the stories would have an impact on other people and that they had also resonated with the stories. The response of the 18-35 participants was:

In their interactions with people with HIV, and at a later stage if that young woman as diagnosed with HIV as well, they might remember the story and not feel so fearful of the diagnosis. I think if you want to encourage testing it needs to be a bit more explicit. The stories address stigma (B06Y)

I think the stories would resonate with others my age. Young people under 30 are resonating with Instagram now... personalitiesThey link to brands or hyperlink to stories or websites (B07Y)

Especially as it's a first-hand story. They have a huge impact on me. If I'm in the same situation in future, I'll think 'I know someone that happened to' (B08Y)

The response of those over 45 included that stories in magazines may be a reminder to women to protect themselves; that the online environment may be a better way to reach people than hard copy magazines, which was reinforced by the participants reading habits; and that the messages need to be reinforced in other ways and not solely rely on magazines as a vehicle:

If someone read them they would have good information and better knowledge (A03X)

Stories like this – lighter in magazines not serious, are probably a good thing to protect yourself and relevant to women my age as well. Also need reinforcement, not only in magazines (A01X)

Online stories would have more of an impact – get them into on-line media rather than magazines. Not sure who reads magazines anymore (A04X)

Chapter 7 Discussion

The findings of this study build on the available research that describes the way women with HIV are portrayed in stories in popular media. In addition, it builds on existing research about the use of narratives or stories crafted using the principles of message design to communicate about health. This study looked at personal stories of women with HIV, published online from 2014-2017. It showed some similarities and differences to reports in the literature, which describe stories in the media dating back to the 1990s. This study has findings that have added to stigma, feminist and story theories embedded in the literature. Investigating the online environment as a vehicle is not entirely new, but investigating the audiences' reception, as well as using content analysis, provides new insights into the use of stories as public health messages. This study includes evidence based tools to investigate the potential for stories to effectively communicate a message. Overall, the study aimed to contribute to current understanding of the use of stories to share public health messages; while considering the online environment and its potential as a vehicle to reach a wide audience.

Findings from the Combined Data Analysis and the Transformative measures

The data from investigation of the stories about women with HIV were organised into two main sections: first, the Combined Data Analysis, including content analysis and audience reception; and second, the measures and audience reception of the transformative effects of the stories, transportation, and story structure. Data collected in relation to these 2 sections provide insight into the three research questions stated earlier.

From the findings in the Combined Data Analysis, which included the descriptive content analysis and two types of data representing audience reception, there was considerable agreement across the data sets for a number of the themes (for detail see: Main Themes Appendix 5). The following discussion of the combined data analysis has two main aspects: first, that of looking at the experiences of women with HIV and how they are portrayed (related to research question, including firstly how the stories were written, how the women and HIV were depicted and the knowledge of the women and others about HIV); and secondly, gaining insight into the way the stories were received by an audience; including key messages, how the women in the stories were perceived, the effect of publication style on audience reception and the expressed intention to share the stories (related to research question 2).

How are both women and HIV portrayed in stories about women with HIV in magazines and online news?

This study was conducted on 22 personal stories of 15 women with HIV, written by journalists, published in magazines and news sites online between 2014 and 2017. Although the focus in this study was on stories, or narratives, previous research has described a *journalistic* style of newspaper reporting about people with HIV (Lupton, 1992; Lupton et al., 1993; Lupton, 1999). Despite some the differences between a news story and a published personal story, findings from previous research were deemed appropriate for comparison.

In this study, the women in the stories were consistently portrayed in a positive light without the underlying stigmatization that had been a feature in some earlier news stories (Lupton et al., 1993). Lupton (1993) described a shift to a more empathetic portrayal by the journalists, whilst still attributing blame to the person with HIV often relating to how they contracted the virus. This is in contrast to this study. In this study, positive language, including words like 'brave', 'strong' and 'courageous', was used to describe the women across all the stories. Lupton (1992, p147) described language as the 'layer of signification lying beneath the obvious... surface'. This consistent use of positive language across all stories in this study may reflect society's attitude to people with HIV, with a further shift toward empathy. The interviewed participants in this study also observed that the women in the stories had faced difficult situations and had overcome difficulties. Lupton (1999a) described three archetypes of HIV/AIDS used by the press: victim, survivor and carrier. The women in the stories in this study were described using the archetype of 'survivor' so that, along with the positive language, they are seen in a favourable light and more likely to be well received by others.

Stigma surrounding the women's HIV status was included in the storylines, a factor suggested by the interviewed participants as raising awareness of and acting to reduce stigma. Researchers have noted that stories promote empathy which can lead to a reduction in stigma (Barbour et al., 2016; Rappaport, 1995). In these stories, stigma was included either by describing stigma generally, as something that people living with HIV experience; or by describing the stigma the women experienced immediately after diagnosis. One recommendation in the Stigma Audit Community Report (Slavin, Brenner et al., 2007) was that people with HIV should not be seen as passive receptors of stigma, to be pitied. The way the women were presented across the stories does support that approach.

The stigma the women had experienced on diagnosis took the form of *othering*, being seen as a 'feared other' or as having 'deviant' traits (Goffman, 1963), with some describing extreme stigmatisation, as found in this investigation. The fact that most of the women in the stories acknowledged that other people experience stigma, suggests that stigma persists. This is supported by the Stigma Audit (Slavin, Brenner et al., 2007). However, the women consistently claimed that they personally did not experience stigma due of their HIV status. This was a new theme, that 'stigma happens to others but not to me' and the women were adamant that by being 'open' about their HIV status, they avoided the stigma that others experience. This attitude may be a form of *passing*, that is dissociating with others who are stigmatised because it is a difficult issue. This has been reported in the literature (Slavin, Batrouney et al., 2007).

The women were shown across all the stories as living well with HIV, a theme in line with the reported purpose of some of the articles. Photos showed them as healthy women and they were described as having happy productive lives. This depiction was supported positively by the online audience with over 5,000 responses and the interviewed participants agreed. Reasons provided, for living well after a diagnosis of HIV, included advances in medication and that the women were taking good care of themselves. To broadcast a consistent message across all sources that most people live well with HIV is a new emerging theme in this study. Previously, when news stories described people with HIV as a 'survivor', it was selective, and their strategies of self-care portrayed them as responsible and with an 'intention to reform their ways' (Lupton 1999a, p49). In this way, the person with HIV was seen to be containing the infection and was therefore regarded in a correspondingly good light, in contrast to the other two archetypes. However, with the strong focus on the women with HIV in the stories all living well came a new theme of concern from the audience. One younger interviewed participant felt that one woman's story was too positive for such a serious issue. Others observed that people might become complacent and not take steps to protect themselves, if they saw HIV being described in an overly positive way, or as easy to manage. They felt that this would belittle the seriousness of the virus and the need to be alert. In particular this was raised in relation to potential for complacency in young people, although several participants noted the current trend for older women now to be in the 'dating scene' and commented on the fact that HIV and STDs are rising in women. Lupton and co-workers (1993) suggested that the mainstream popular press should be monitored by health educators, for the underlying messages being shared with the general public, as they may need to be countered. In this study, even though the stories were written with good intentions, such as to de-stigmatise HIV or to

show that people can live well with HIV, they may have had an unintended consequence, an underlying message that potentially HIV is no longer a real issue to be concerned about.

Reluctance to disclose their status can lead to isolation for women with HIV and subsequent depression (Morrison et al., 2002). Even though the incidence of depression and reluctance to disclose in this study was lower than expected, a large number of the women (60%) experienced feelings of isolation due to HIV. Many of the women reported that attending support groups and hearing stories about other women with HIV were key factors that alleviated their feelings of isolation. This is a strategy recommended to manage stigma in women (McDonald, 2012; Ho & Holliday, 2015). The women also received support from family, friends and organisations that support people with HIV. This suggests the potential value of sharing personal stories, in which people may have faced similar difficulties, and that social support is also important.

The findings from my study supported previous research (Koelmeyer et al., 2012), in that the women in the stories related strongly to their maternal role and faced not only their own health issues but also felt responsible for the health of their children. Several women were pregnant or breastfeeding when they were diagnosed and the fear they felt for their children was evident whilst waiting for their test results. Surprisingly, despite the fact that a number of the women had children after diagnosis, including two who previously had a child born with HIV, none of the women reported 'unwarranted disclosure from health practitioners' or receiving 'less favourable treatment at health services', where clinicians face the dilemma in managing the health of both mother and child (Koelmeyer et al., 2012 p9). Neither were they described as failing in their role as a mother, which is a theme in the literature (McDonald, 2012; Amaro, 2001). The maternal role plays a large part in women's identity and the desire of women with HIV to have children is now assisted by advances in ART (antiretroviral therapy). The interviewed participants accepted that women with HIV would have children. The youngest expressed surprise that women with HIV could have a child and was very keen to learn more. The stories portrayed that a component of a woman's identity, to have a child, is still possible with HIV, but they failed to show the potential stigma that women with HIV may face if they have, or choose to have, children. After diagnosis, the women gained an understanding of HIV as it related to them as women. In the same way that the women demonstrated personal agency in negotiating safe sex with any new partners, the women were portrayed as negotiating a choice to have children in relationships with partners who were accepting of their HIV status.

The gay informed approach to negotiating safe sex and use of condoms has not been adopted as a key strategy in heterosexual relationships. There was interesting feedback across the data sets. In the stories, the women described negotiating safe sex after the diagnosis, but not prior. There was a lot of support in the online feedback for women to be pro-active in safe sex at all times, with one online posted comment noting that heterosexuals have not adopted the regular use of condoms. That post was well supported with many responses. Interestingly, whilst supporting the practice of safe sex one participant from each age group noted that some situations do not support women negotiating safe sex and it is not simple to suggest that option. This is supported by the literature. Although the use of male condoms is a valuable strategy, protection from transmission of the HIV virus should not solely focus on women's insistence on the use of condoms, or assume people are free to make a rational choice to use a condom (Amaro, 2001). Any strategy needs to be multi layered and include men in the solution (Higgins et al., 2012).

Consistent with the literature the women in the stories in my study contracted HIV from their long-term partner and were tested for HIV after their partner became sick (Cameron, 2012; Koelmeyer, 2012), and this generated audience interest. One interviewed participant focused on this as a significant issue, raising the dilemma of trusting your long-term partner or not, and what to do about that? One online comment suggested that people should not be relying on (trusting) their partner to keep them safe. That post garnered a large supportive response. Women in a long-term relationship may not consider themselves at risk and therefore may not insist on condom use for their male partners. Also, women are often in relationships where there is male-controlled sexual decision making (Amaro, 2001). These are significant issues given women primarily contract HIV from men and raises questions about how women protect themselves from HIV in long-term relationships. The stories portrayed the women as unknowingly contracting HIV from their partner, without providing a sense of a different outcome. One younger participant commented that she was surprised that one of the women in the stories had not been aware of her partner's risky behaviour. The youngest participants felt that she could easily see that 'people lie all the time'. This was supported by a post indicating 'online dating' to be a source of people who don't tell the truth, whilst noting that others believe them. If women are more aware of their potential risk for HIV and that being in a relationship is not a safety factor, their behaviour may change. As mentioned, for one interviewed participant, who had not previously considered that this might happen to her, reading the stories brought this fact home to her.

In relation to contracting HIV from their partner, a new and disturbing theme was voiced. A number of the women thought they had been deliberately infected by their partner; Lupton's (1999a) third archetype of 'carrier'. The current position in Australia is that it is a criminal act if a person with HIV does not disclose they have the virus, prior to a sexual act (Cameron, 2012b). However, it is difficult to argue the criminal intent to harm a woman, by her partner with HIV, since there are a several ways there could be a 'betrayal of trust' in a relationship. It is also problematic, if a woman seeks justice and, for example, takes the position of 'victim of a man', since this would disempower and stigmatise her, leading to further health issues (Cameron, 2012b p 34 &35). Putting aside acts of deliberate intent to harm, Cameron (2012b) points out the difficulty for heterosexual men to disclose their HIV status, when even the use of condoms has not been adopted as a norm. For the general public, this comes back to the issue of awareness raising and creating opportunities for more discussion and negotiation between men and women.

Across all data sets, there was strong agreement that ignorance about HIV still exists. The stereotype of who is at risk for HIV affected the women in two ways. Firstly, some of the women were not seen as being at risk of HIV, which can delay diagnosis and the start of treatment. Secondly, the women experienced being stigmatised on diagnosis, which included assumptions of being a drug user or prostitute. In addition to the general public, GPs may not consider HIV in relation to women presenting for diagnosis of unusual symptoms. This may be because the National HIV Strategy 2014-2017 and the new guidelines for physicians on prescribing PreP ART, do not include women as being at risk for HIV (Department of Health, 2014; WHO 2015). It has been said 'Women with HIV are invisible' (Amaro, 2001; Koelmeyer, 2012) and that may be so if they are not expected to have HIV. It is valuable to raise awareness, not only in the general public, but also among health professionals, that, although there are some people who are considered at higher risk of contracting HIV, all sexually active people are at risk.

In summary, sharing stories is valuable. Stories need to be written that are realistic and positive, and use supportive language. They need to discuss the problem of women living with HIV being stigmatised, and to raise awareness without attaching blame on women. Personal stories can describe how women with HIV can be living well, with enough information for the reader to understand the implications of having HIV. They can include alternatives for people to consider, including messages of protection, including safe sex or abstaining from sexual activity, as well as encouraging discussion and negotiation of safe sex with a potential sexual partner. Women can be educated about testing for HIV and encouraged to request that as part of regular health checks and they can be made aware that partners do betray

women and that being in a relationship does not protect against HIV or any other sexually transmitted disease.

How are the stories received; how does the audience experience the stories?

There was strong agreement across the data sets that stories are a valuable tool to share information and messages such as those about women with HIV. This finding was supported from the point of view of the two audience groups, as well as the women in the stories. The value of narratives to engage the reader, persuade and affect belief has been shown in the literature (Green and Brock 2000). One online comment, that it was good to see stories shared via the media, received a large number of supportive responses. Several women in the stories described the value of sharing in support groups and hearing other people's personal stories. They felt that this addressed their feelings of isolation. LaBonte et al. (1999), noted that stories in a woman's voice are better received by women as women perceive the story is true to their own experience. These comments both support the literature that stories help people make sense of their experiences (Lee et al., 2016) and the premise of this study that magazines are a potential vehicle to share personal stories.

In addition to the impact of the stories on the reader, two aspects of presentation were investigated to determine if they affected the reception of the stories: photographs and links to other articles. The two stories discussed in the interviews provided examples of a busy, scandalous style of presentation, with over a hundred links and five photos (Story One) and a simple conservative presentation with one photo and no links (Story Two). There was strong agreement across the data sets that the full presentation of the stories affected the reception of the story and hence how the participants related to the story and the women. This was a key finding. The participants firstly read the text of the stories, without the influence of photos or links, and scored their level of transportation. Transportation scores for the text of Story One indicated a reasonable story structure and reasonable message features, sufficient to engage the reader. In support of that, the participants on the whole, expressed an empathetic opinion of the text of Story One and most engaged with the woman in the story.

On viewing the full presentation, the participants described the inclusion of photos in general as positive, describing a better connection with and relating to the women. They were pleased to see them looking healthy and happy. However, they agreed that five photos of the woman in Story One looking 'sexy' was both too many and incongruous with the storyline. They found the large number of links to 'trashy' articles, such as a Woman's-only porn site and 'unsubstantiated social rubbish' distasteful and

off-putting. Some cited these as reasons they would not have read the story, others found them distracting enough to stop reading and two said they usually would be distracted and follow the links. It is important that stories about and for women are presented in a culturally appropriate way (Lupton, 1992) and in order for a narrative to be persuasive, readers must identify with them and see them as realistic and relatable (Barbour et al., 2016; Lee et al., 2016). Despite initial engagement, corroborated with a validated score, most participants actively changed their mind about Story One when they saw that the woman and her story did not relate to them, had inappropriate content for the storyline and as several noted, it was 'annoying'. Interestingly, initially Story Two had a lesser transportation score but participants reported better engagement and identification with the full presentation.

Most of the communication literature discusses the construction and content of the story or narrative, not the overall presentation or vehicle used to carry the message. Therefore, this new finding is important. It suggests that care is needed in choosing a publisher or magazine as a vehicle for a story written with the intention to carry a health message, regardless of how well crafted the story is. The main reason for a magazine to have a scandalous ideology would be to attract attention, or to provide 'click-bait', which is defined as: '(on the Internet) content whose main purpose is to attract attention and encourage visitors to click on a link to a particular web page'¹⁹. This type of presentation is designed to attract the reader away from the story, for commercial gain.

There were differing amounts of background information written by the journalist included with the stories. This varied from 2 lines to several pages. From the content analysis and participants, the background information across all stories was deemed appropriate and was accurate information about HIV, potentially useful for the reader, if they needed more information about reading a sensitive topic such as HIV. Ironically, the Daily Mail article provided the most, background information about women and HIV, and HIV in general, which was noted by the participants as useful information.

The interviewed participants felt that the main messages of the two stories they were given to read were: 'not a death sentence'; 'HIV affects anyone/ordinary people'; 'there is life after HIV/living well with HIV'; 'ignorance/need to educate the community'; and 'help/empower people with HIV'. However, the purpose of the articles and stories was not specifically to promote safe sex and early testing for women. Of interest, both safe sex and testing were included in the storyline of the stories that were aimed at younger people, potentially raising awareness, although there was not strong advocacy for either. A comment from one participant (echoed online with 1,213 supportive responses) suggested that

if the purpose of the story is to share a specific message, then the message needs to be clear and obvious.

Of interest in this study was the intention of the reader to share a story they had read with others. As mentioned, this may indicate that the story was significant to or may have had an impact on the reader. Barbour and co-workers (2016, p830) found that when a participant in their study read a narrative message, they expressed 'higher intentions to share the message either interpersonally or via social media'. When the interviewed participants were asked if they would share the stories with family or close friends, six expressed an intention to share them. This was true for all participants in the younger age group. Two had already shared the stories prior to the interview and one shared afterwards. The study also included electronic sharing of the stories, via the online reader feedback and capacity to share the articles. Two of the articles, each containing three of the women's stories in the study, were shared in their entirety: the Daily Mail to 2,412 people and the Guardian to 3,212 others online. As noted, the act of 'sharing' in itself may reflect the importance of the story to the reader, or its narrative properties and would be an important reason for using a narrative approach to stories with the purpose of carrying a health message.

In summary, sharing stories is valuable in varied settings. Choosing a suitable vehicle, with ideology and presentation style that compliments the public health message is likely to be important. Include accurate background information. If there is a specific message to communicate, it needs to be clear.

Findings on the transformation effects, transportation and story structure

Are stories about women with HIV in magazines and online news sites transformative?

Using the Transformational Story Template (Fig 5), eight of the 22 stories, were transformational. This means they would have also been written incorporating message features that produce a persuasive effect (Appendix 1). All the stories were written by journalists, who understand story structure and how to write narrative messages. Nevertheless, some stories did not contain sufficient message design features to create a story that was fully identifiable, relatable and persuasive. If personal stories of women with HIV are to be shared via magazines, it would be important to ensure that not only the information about HIV is accurate, but that also the stories are written in such a way as to be persuasive.

Level of transportation relates to the belief a reader has in the conclusions of the story (Green & Brock, 2000) and is an aspect of a transformative story. The participants' scores for their level of transportation on reading the two stories prior to interview, measured using the validated Transportation Scale (Table 7), were neither high nor low. This indicated that the participants would have experienced some, but not a high level of transportation in the stories. Again, this indicates that if the purpose of a personal story in a magazine was to absorb the reader sufficiently affect their beliefs, more attention is required in crafting the story to ensure there story includes message features that are transporting. The scale also included measures of story structure and perception. The majority of scores for both stories were in the higher range, showing that both stories were structured well. It was the transportation effect of the stories that required more development.

Of interest the text-only of Story One was found to be more transporting by both age groups, than that of Story Two. However, participants' experience of Story One changed when the story was read in context of its full busy and lurid presentation style. This point is important. A story may be well written, containing elements that will engage and transport the reader, but if the presentation affects the reception of the story, the potential for health communication will be missed.

Although the participants did not report a high level of engagement with either story, they mentioned some of the message features thought to be key in transformational stories. Their perception included: they were true stories, the women had overcome difficulties, they were written in the first-person by the women, the participants were willing to read stories to the end. The younger participants felt the stories would have an impact, for example to reduce stigma and all those over 45 related to the descriptions of HIV in the 1980s, showing relevance.

For this vehicle to be successful may require collaboration between publisher, journalist and health expert, with reflection prior to publication to ensure not only accuracy but also the inclusion of transformative message features.

Strengths and Limitations of the design

Trustworthiness of the research was supported in a number of ways. Firstly, the style of content analysis was chosen to suit the investigation. As described by Hsieh and Shannon (2005 p1281), this was a 'directed' content analysis of recent documents (2014-2017). It was built on existing theory, with

opportunity to extend and add from the more recent stories. The relational template used (McCormack, 2000) assisted to organise that narrative data using deductive themes that could be flexible, enabling concurrent analysis as themes were added and cross checked (Nakkeeran & Zodepy, 2012). Secondly, there was prolonged interaction with the data due to the hermeneutic cycle of reading, re-reading and reflection. Thirdly, there was continuous checking and constant comparison (Bowen, 2009 p 37) with each data set to ensure the excerpts fit the coding in the templates. If a new idea was noted, all other data sets and raw data was reviewed retrospectively, to add the new theme if needed, or to understand why it was not there. As a result, data collection and analysis occurred simultaneously (Colorafi & Evans 2016). Fourthly, the study design incorporated both data triangulation and investigator triangulation of interpretations.

The content analysis was also descriptive, which can be limiting as it relies on what is there. In this case the women's experience could only be analysed from what was presented in the stories and there may have been experiences left out. In that way, an assumption that something did not occur could not be made simply because it was not included in the story. It may have been a journalistic choice. The, the range of publications found and the variety in purpose of each story helped to provide some variety about the various issues, nevertheless what was left out is unknown.

The quantitative and qualitative methods complimented each other and supported the overall qualitative approach. The qualitative approaches looked for patterns in the data to seek explanation and interpretation (Morgan, 1993) and the quantitative counting of data, provided insight into the extent to which a theme or variable existed across the stories. Incorporating evidence based assessment of transformative features and validated measures of transportation effects and readability scores provided confidence in the outcomes regarding the persuasive nature of the stories. For example, the participants provided some information in the interviews about their engagement with the stories, but the measurements enabled interpretation.

A limitation noted in the content analysis was the unsuitability of analysing the whole data set statistically. For example the EpiData base was set up with variables that could have been analysed for prevalence in magazines in general. However, there were 22 stories, about 15 women across six data sets and ten different publications. To interpret statistically across the whole data set of stories was not realistic, as the prevalence of any variable had more meaning when it was related back to the publication or women.

The study involved a large amount of narrative data which can be unwieldy to manage. By deductively setting up a relational template, using a validated approach (McCormack 2000), cross referenced with the theoretical perspectives, the narrative data could be populated into visual templates. Additional themes could be added. As a result, the themes, the women, the story codes, the publications and any repeated stories could be seen clearly and patterns observed. The template acted a visual coding method, supporting the analysis (Contandriopolous et al., 2018). Similarly, templates were set up to organise excerpts from the interview transcripts and the online feedback, both based on themes identified in the content analysis and literature. This visual mechanism for coding enabled patterns to be seen in the data and for the various data sets to be cross referenced. Again, there was extensive immersion in both the data sets and the raw data, as themes were checked, resulted in prolonged exposure to the data, increasing confidence in the analysis.

Krippendorff et al., (1989) suggested that in mass media, certain people are written about or quoted more than others, in their example they noted that this relates to celebrities. This can lead to statistical bias in the analysis, as some opinions are over-represented. That had the potential to occur in this study as one women's story was published across six different publications in three years. An advantage to a visual coding system was that for each theme or topic that her story was coded against, it was clear that it was her story, as the coding system used labels, shading and colours. An example where this could have resulted in an inaccurate interpretation of the data is described in the study, that of misdiagnosis by her GP.

With the exception of one, in person, the interviews were conducted via Skype, with the two stories and Transportation Scale provided via email. Return of the Transportation scores by each participant ensured that the stories had been read prior to the interview, which was crucial.

Chapter 8 Conclusion

Findings and the Implications

HIV in women is increasing in Australia. Online magazines have the potential to raise awareness about women with HIV by publishing personal stories that reduce stigma and isolation and provide information about prevention and testing. They are accessible and potentially have a wide reach. Considerations include: creating stories with message design features that promote transformation and publishing them in magazines that have a compatible publishing ideology, with attention to language, context and overall presentation.

Three main aspects were investigated. These included: understanding the way that women with HIV were portrayed and the level of knowledge that they and other people had about HIV; determining how the stories might be received by the potential audience; and the extent to which the stories were written in a way that engaged and influenced the reader, to enable belief and potential for behaviour change. An overall qualitative approach was taken, including qualitative and quantitative methods, supported by theoretical perspectives of hermeneutic phenomenology and narrative enquiry. The investigation comprised a directed, descriptive content analysis; focused interviews with women who do not have a diagnosis of HIV (audience); online reader feedback (audience); and assessment of the stories for transformational and transportation message design features.

It was interesting to find that the women with HIV in the stories had been consistently portrayed in a positive way across all the stories. None of the journalists had used the women's diagnosis or past behaviour as a headline 'grab', as had been previously noted. Nevertheless, aspects of the story were used in headlines to attract attention, but the shock factor often lay in something the women endured, for example that under testing occurs in women. The only exception to that would be the gendered language used to show incongruity, as described in the example Rachel the grandmother in the study.

The limitation noted of relying on what a document provides in a content analysis may have an impact when the women were all shown to have overcome difficulties and were living well after their diagnosis of HIV. It was interesting that all the stories agreed, they were printed over three years by different publishers, but the purpose of all the publications was focussed on showing that there is life after HIV. This is admirable and may contribute to the ability of the stories to have an impact to reduce stigma, there was an underlying feeling that they weren't telling the whole story and that readers did need to

know that if they contracted HIV, that it was a serious health issue. This was reflected across the audience feedback, that an overly positive portrayal, that HIV is easily managed, could result in complacency and disregard of a need to protect against the virus.

There was a clear message that ignorance still exists with regard to HIV transmission and who is at risk; the stereotype of gay men, drug users and sex workers, and does not include women in general. This had some impact on the women with regard to delayed diagnosis by their GP and being initially labelled as deviant by people who related them to the stereotype. Education is required on many fronts. Firstly, women need to be aware of their risk, so they can act with personal agency regarding protecting themselves, negotiating with partners or seeking testing. Secondly in general, people need to understand that since anyone can get HIV, a diagnosis does not mean you are in a class of deviants, nor does it mean they will catch HIV from casual contact. Finally health practitioners need to be reminded that although some people are at high risk, anyone they treat could have HIV and that women with HIV have as strong a desire to have children as anyone else.

The stories in the study did not show that those women who considered or had children after diagnosis encountered unwarranted disclosure from health practitioners, although one interview participant, a young health care worker expressed that she felt this view persists. The investigation supported the literature that GPs may still hold opinions that women are not at risk for HIV. Treatment and prevention strategies focus on the groups of people considered to be at high risk and, as such, are not aimed at women. Given women are not encouraged to test routinely for HIV, and test after their partner is sick, contributes to a potential delay in diagnosis and treatment of HIV in women, as reported in the literature (Cameron, 2012a)

The data supported that the gay-informed approach, of negotiating safe sex and using condoms, has not been adopted by heterosexuals (Brown, G. et al., 2014). Although the women contracted HIV through heterosexual contact (Cameron, 2012a) as expected, condoms are not necessarily under a woman's control. Adding this to the concern raised about trust in relationships, it is clear that a simple 'use a condom' strategy is not the most appropriate. As feminist theory suggests, there needs to be discussion among men and women about finding a solution. At least if women are aware they can begin to act with personal agency, as they were able to do after diagnosis.

It was clear across all the data sets that sharing and hearing stories about women with HIV was important factor, not only to the women for support, but also as a mechanism for others to be familiar

with and understand the issue. The unexpectedly low incidence of depression, for example, appeared to be due to social support and sharing stories and there was agreement that stories may help reduce stigma. It was important to investigate how the stories were received. The participant interviews and online feedback provided insight into reception of the stories themselves as well as the additional information and presentation style, showing what might have an impact on reception in addition to story content. The audience was also clear that if specific messages need to be carried in the stories, they need to be explicit and clear.

Communications literature has shown that narratives are more likely to be shared by the reader. This was specifically investigated, with agreement found across both forms of audience data. When asked, most of the interview participants indicated they would share the stories with family or close friends and three reported they had done so. Two of the online articles, each with three stories about women and HIV were shared in their entirety with over 5,000 others electronically.

The stories generally followed story structure, but investigation of message design and the inclusion of transformative message features showed that, even though the stories were written by communication professionals, journalists, only half had the capacity to strongly persuade the reader. This suggested that to achieve effective communication of public health messages and engage and persuade a reader, more effort is required in constructing the stories. This would potentially require the co-operation of suitable publishers, communications professionals such as journalists and health promotion experts. As with any health promotion campaign, one single publication or approach would not be enough. To date stories were published in line with significant national events to take advantage of additional publicity. However, since available public health resources for HIV prevention may be directed in preference at high risk groups, sharing stories in magazines may be a mechanism that could be cost effective.

Sexually transmitted diseases are increasing, as noted by one participant who works in a health field, with concern expressed that this increase may be related to the rise in use of dating applications, not only by young people, but by older people returning to the dating scene. The prevention and safe sex message is a message for all sexually active people.

Potential future research

The content analysis results demonstrated a potential impact on the reduction of isolation in the women with HIV, although this was not specifically measured. Reducing stigma and isolation in women with HIV has the potential to have an impact on the burden of disease in women with HIV, including depression.

Therefore, it would be valuable to investigate the use of stories as a mechanism to help resolve the problems of stigma and isolation in women with HIV.

The strategy of male condoms as the main mechanism for women to protect themselves has flaws, as it assumes this strategy is under a woman's control. The stories would need to address other aspects of protection including abstinence, although this still leaves women at a potential disadvantage. The research to date has generally omitted men in the prevention efforts for women and does not take note that men should also be aware of their risk and take steps to protect themselves and their partner. Feminist theory suggests that men be included in the solution. In line with this study, perhaps the potential to publish personal stories about people with HIV in men's magazines could be investigated. This approach could include topics of prevention and protection, but also discuss the issue of trust in relationships.

The impact of presentation on the reception of the message warrants further investigation. However, this preliminary finding was cautionary, in that this study found that a well crafted message still has the potential to be ineffective if used in a context that negates or contradicts the health communication. In addition, although appropriate context and language has been suggested as a requirement for many years, gendered and critical descriptions of some of the women was still seen in the stories. Interestingly, this was used by both female and male journalists.

Online magazines have a large readership, are easily accessible and remain accessible after publication date. However, Instagram was suggested by one participant. Instagram is a social media platform that supports people described as 'influencers' with large followings, who have the ability to share stories via a weblink for example, or encourage certain behaviours, often related to consumerism.

Finally, in the face of an increase in HIV in women in Australia and the dearth of prevention messages that include women; in light of the backdrop that HIV prevention is focused on high risk groups and the premise that public health resources may also need to be focused on those at high risk; the mechanism to address women and HIV through the publication of personal stories in magazines is worth continuing. The use of stories to raise awareness of HIV in women, using written message features that are known to be effective in changing beliefs in accordance with the story content, is valuable. Using a mechanism with a wide reach to a general population appears to be a strategy worth continuing. Ideally it would require the collaboration of a publisher, and working with communications and health promotion experts.

Appendices

Appendix 1: Features of Transformational Stories

Variable	Shepard ¹⁶	Zac ¹⁷ and Barbour (et al 2016)	Green & Brock (2000)	Hinyard & Kreuter (2007)
Reflective* Character is introspective	Recognise own position re change. Know oneself. Build power within. May facilitate action	Innocent, seek to right the wrong, find courage to be a better person – Hero’s journey*		Perceived Realism* Identify with character Personal experience*
Believable character* (Unforgettable character)	Real life situation. Gives emotional power, authenticity. Relatable. Something in common with, or can care about. Only need 1-2 things to tell us who they are. Not perfect, learn	Believable, suspend disbelief. Relatable. Personal relevance (Barbour et al 2016)	Seems like real life* Strong feelings toward characters	Real Life, relatable, relevant, identifiable (Bond 1997)
Emotion*		Emotionally resonate with the character - we feel the emotions* (also Barbour 2016)	Emotional involvement*	Personal involvement
Engage all senses*	Descriptive, imagery, engage senses	Increases empathy and transportation when hear/see - holds attention	Mental imagery*	Attention, imagery, feelings*
Struggle* Plot	Conflict or struggle the character goes through (short story =1 conflict)			
Tension* Plot	Rising action	Increasing tension holds reader’s attention – hook - keeps reading, want to know what happens. Capture attention and transport into characters world	Feelings of suspense* Cognitive attention* Lose awareness of surroundings*	Suspense
Turning point* Identify significant moment of change, (dramatic point)	Turning point (resolution). Give new insights, perspective - learns as solve problem. The way story goes after change determines how audience engages	Reader may relate, realise have to face difficulties, may have something to learn – leads to empathy and narrative transportation*		
Easy to read				Literacy scale
Clear story		Story structure (Barbour	Yes	Yes

curve		et al 2016)		
Theme grows out of the story	Reader feels - learned it for themselves. (Don't need to state the moral)			
Well-chosen setting	Interesting familiar time/place			Familiar/unfamiliar affects reception – may accept falsehood if not familiar
Tense	One i.e. present or past			
Person	1 st person is most powerful (Winterbottom 2008)			1 st or 3 rd (insufficient evidence)

Items noted with * contribute to Transformational story template (Fig 5: methods)

Appendix 2: Background data for descriptive content analysis (EpiData).

<ul style="list-style-type: none"> • Name of website • Type of website – category (type of publication) • URL • Date • Photo stock used • % photo • Size of headline • Sensational headline • # of advertisements • Type of advert and relation to storyline • Total Length – pages • Lines of text • # of words • Age of woman • Partner status • Job 	<p>From Bowen (2009)</p> <ul style="list-style-type: none"> • Purpose of the document (article) • Reason produced • Target audience • Information about the author/byline • Original source of information • 1st hand experience or written from secondary sources • Un/solicited • Un/edited • Anonymous • Context specific
	<p>Active Listening – McCormack (2000)</p> <ul style="list-style-type: none"> • Point of view – 1st or 3rd person • Gender/age • Who are main characters • What are main events • What is researcher position re stories

Appendix 3: Final EpiData Data Form

Story code / Website name / author
Source of story / Year published / Target audience
Woman's name / Woman's age / Partner status
adverts / # of adverts / adverts' topics
size of headline / is headline sensational
photos in story / % story which is photo / Photo source
FI Reading ease / KS Grade Level / # words in the story
1st or 3rd person / estimate of year of Dx / estimate age at Dx
HIV from ex partner (Y/N/DK)
 How did the woman contract HIV – select contact
Story mentions testing (Y/N/DK)
 Story advocates for testing (Y/N/DK)
Story mentions safe sex (Y/N/DK)
 Story encourages safe sex (Y/N/DK)
Stigmatising text directed at woman (Y/N/DK)
 Story mentions stigma (Y/N/DK)
Does fem theory contribute to understanding the story (Y/N/DK)
Article has purpose (Y/N/DK) / what is purpose _____
Does article have a context _____
Resources to assist noted (appropriate, not, both, d/k, none)
Article contains links to other articles (Y/N/DK)
Story is transformative (Y/N/DK)

Appendix 4: Qualitative Content Analysis Template

LENS 1 – Language	McCormack’s Lenses/ theoretical perspectives/ excerpts	story code
How is woman portrayed		
Level of support – isolation		
LENS 1 – language		
Tenor: drift/Latent meaning i.e. subtext (part of language sub-set)		
LENS 2 Context		Story code
Context of publication		
Cultural context - Social, political, historical		
Social context – partner		
Context of personal agency		
LENS 3 Moments		
Turning point		
LENS 4 Narrative persuasion		
Transformative stories (stage one data)		
Other		
Safe sex		
Issues with GP and Dx		
Testing		
Pregnancy, breastfeeding, children after HIV and mothers role		
Courage to share story		
Expressed a desire to help or actively working to help others		

Story code	Source	
1	Women’s Weekly	5 stories (Abbey 1-05)
2,3,4,5	News and magazines on-line	all Abbey– 5 stories (4 sources)
6	Herald Sun	4 stories
7	Daily Mail	3 stories
8	Guardian	3 stories
9 and 10	Health info sites	2 stories, 2 sources

Colour coding for publication, story and repeated stories by Abby

Colour coding is consistent throughout

Appendix 5: Summary of Main Themes from Combined Data Analysis mapped across data sets

	Theme from Combined Analysis			
Lit Review	Content Analysis	Interviews		Online reader
			Likes	DisLikes
	Women portrayed empathetically, as brave or strong	Yes	1653	12
	Women experienced stigma, written stories not stigmatizing	Yes	5118	348
	Women acknowledged stigma, denied was happening to them	-		-
Yes	Some women reluctant to disclose their HIV status	-		-
	Isolation after diagnosis alleviated by support networks	-		-
Yes	A Women feels responsible for the health of her children	-		-
	Women want children despite HIV	Yes	36	3
	Women with HIV are described using gendered language	-		-
Yes	Women contract HIV from long-term partner	3/8		-
Yes	Betrayal of trust in long-term relationships	Yes	46	32
	Sub: Should not rely on partner to stay safe (<i>only in online feedback</i>)*	-	1,281	7
	Women negotiated safe sex – after diagnosis	-		-
	Sub: for women negotiating safe sex (<i>only in online feedback</i>)*		910	56
	Sub: Contexts don't support women negotiating safe sex (<i>only in interviews</i>)*	2/8		-
	Sub: 'Condom' message doesn't carry same weight for heterosexuals*	-	1,123	0
	You can live well with HIV (TENOR)	Yes	5,316	22
Yes	Medication to treat HIV is less complicated	Yes	529	292
	Complacency due to positive LWWHIV messages and '3 pills a day'	Yes	388	15
	The world is more accepting	Yes	3,100	11
	The perception of the message is affected by the presentation style	Yes	4,490	0
	Ignorance about HIV still exists	Yes	5,073	34
Yes	Stereotype 'who gets HIV' does not include women, but anyone can	Yes	34	42
	Women don't know the risk for HIV as it relates to them	-	77	1
Yes	GPs do not recognise that women are at risk for HIV	-		-
	Accurate sources of information	2/8		-
	Stories are valuable tool to share information	Yes	10,353	0
	Safe sex and early testing needs obvious message	Yes	1,213	0
	Magazines are read online	Yes		-
	Intent to share the stories	Yes		5,612 Shares
	Impact of the Stories	Yes		

Appendix 6: Transformational Story Assessment (results from Fig 7)

Answer = Yes/No/DK/Partly/Several (note Abbey's six stories all single plus Women's Weekly)

Story code	101 TWO	102	103	104	105 Rpt	601	602	603	604	701 ONE	702	703	801	802	803	901	10 01
Character reflects on their situation	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	D/K	N	N/Y	Y	y/n	y
Uses the woman voice	3 RD	3 RD	3 RD	3 RD	3 RD	1 st	1 st	1 st	1 st	1 st	1 st	1 st	1 st	1 st	1 st	1 st	1 st
character believable?	Y	Y	Y	Y	Y	Y	Y	Y	Y	D/K	Y	N	Y	Y	Y	Y	Y
Identifiable and relatable	Y									N			Y				
emotional connection-	Y	Y	Y	Y	Y	Y	Y	Y	Y	D/K	Y	N	N	Y	Y	Y	Y
engage all senses	Y	Y	N	Part	Y	Y	D/K	Y	Y	Prt/Y	Y	N	N	N/Y	N	Y	Y
engaging	Y									N							
one key struggle	Y	Part	Y	Y	Y	Y	Y	Y	Y	Y/N	Y	N	N	N	N	N	N
Tension	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	Y	N
rising tension										no						no	
turning point.	Y	D/K	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N
easy to read	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
moral	Y	Y	Y	Y	Y	Y	Y	Y	Y	D/K	Y	Y	Y	Y		D/K	D/K
story curve	Y	N	Y	Y	Y	Y	Y	D/K	Y	N	Y	N	N	N	N	N	N
Transformative	Y	N		Y	Y	Y	Y	Y	Y	N	Y	N	N	N	N	N	N
Co-coded	YES									YES					YES		

Story code (All Abbey)	105 Rpt	201	301	302	401	501
Character reflects on their situation	Y	Y	Y		Y	D/K
Uses the woman voice	3 RD	3 RD	1 st	3rd	3 RD	3 RD
character believable?	Y	Y	Y	Y	Y	Y
Identifiable and relatable						
emotional connection-	Y	Y	Part	N	N	Y
engage all senses	Y	D/K	D/K	N	N	N
engaging						
one key struggle	Y	Y	sevl		sevl	Y
Tension	Y	D/K	Y		N	N
rising tension		no	no	no	no	
turning point.	Y	Svl	D/K		Y	Y
easy to read	Y	Y	N		N	N
moral	Y	Y	Y		Y	Y
story curve	Y	D/K	N		N	N
Transformative	Y	N	N		N	N
Co-coded						

Appendix 7 Publisher and the inclusion of/advocacy for testing and safe sex

Publisher	Purpose/ context	Audience target	Mentioned testing & safe sex & advocacy for both	Advocated for either testing or safe sex	Did not advocate for testing. Nor for safe sex	Did not mention or advocate for safe sex or testing
Aust. Womens Weekly (AWW)	De-stigmatise HIV Targeted information	Young women		101		
AWW		Women		102, 104		
AWW		Women				103
AWW – Abbey		Young women		105		
Cosmo – Abbey	Inform – prevention HIV high in youth	Young women	201			
News.com – Abbey	Inform – prevention HIV high in women	Young women	301			
News.com – Abbey	Under testing/ New National WLWHIV day	Women		302		
Mamamia – Abbey	Inform – prevention AIDS conference	Young women	401			
ABC – Abbey	Under testing/ New National WLWHIV day	Women		501		
Herald Sun	WLWHIV not alone AIDS conference	General Public				601
Herald Sun		General Public	602			
Herald Sun		General Public			603, 604	
Daily Mail	HIV not a death sentence 30yr since 1st HIV test	General Public			701, 703	
Daily Mail		General Public	702			
Guardian		General Public			801, 802, 803	
NHS Choices	Inform	Health Info		901		
Web MD	Inform	Health Info				

Appendix 8 Interview Guide

Interview guide for structured interviews (*stage two*)

I'm interested in your experience of reading the two stories so you can refer to both of them.

When you read the texts of the 2 stories what was your general impression

What do you think the main messages are? The main messages that they wanted people to take away?

Why do you think that? (prompt)

From the stories, was there something you didn't know about HIV, or something different than you had thought?

Can you say what that was?

What are your thoughts about the two women whose stories were told?

Why do you think that?

How do you feel the women were portrayed in the story?

Do you feel there were aspects in the story that stigmatised either of the women?
When?

What are your thoughts about how HIV is portrayed in the stories? (same kind of question)

Tell me a little more about that?

(Did the stories give you any sense of how HIV is stigmatised today?)

You read the text of the stories and then looked at a link to their original articles – did you manage to do that?

What was your impression when you saw the full magazine style/online presentation?

Did it change any of the thoughts or feelings you'd had when you first read the stories?

Can you say why?

Did you click on anything to take a look?

Do you have any comments or thoughts about the photographs or images used in the stories

Do you read magazines or stories online, even occasionally such as in a waiting room?

How do you access this kind of article or story?

If you had seen the full version of the stories in a magazine. Would you stop at these stories and read them, or keep flicking the pages

Why is that?

Would either of these stories be stories that you would share or discuss with other members of your family or close friends?

Why is that?

Would coming across these stories in a magazine format or on line make an impact on you as a young woman today

Would it make them think about safe sex or testing

Did it give sense “Oh well its not an issue because it can be fixed with medication” or ‘the doctor will fix it’

Were you surprised by anything you read?

I’m interested in your experience of reading these stories. Is there anything else you would like to add or comment on that I haven’t asked or touched on?

Questions are bold

Prompts are italic

Participant code _____	Date _____	Time _____	Place _____
H.Nikolas			

Footnotes

- 1) https://www.afao.org.au/media-centre/media-releases/2016/australians-need-to-work-together-to-end-hiv-as-nation-marks-extraordinary-progress-against-aids#.WBrne_I96yI0
Sourced 6.30pm 3rd Nov 2016
- 2) Source: Mapping HIV outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia UNSW <http://www.acon.org.au/wp-content/uploads/2015/04/Mapping-HIV-outcomes-in-Australia-KIRBY-2010.pdf>
- 3) <https://www.aids.gov/hiv-aids-basics/just-diagnosed-with-hiv-aids/treatment-options/overview-of-hiv-treatments/> sourced 1 Dec 2016 3.30pm
- 4) <https://www.afao.org.au/about-hiv/the-hiv-epidemic/hiv-statistics-australia#.WEeKgTuO5xg>
- 5) <http://emedicine.medscape.com/article/1533218-overview>
- 6) <http://www.aww.com.au/latest-news/real-life/australian-women-living-with-hiv-21865> sourced 6.23pm 3rd Nov 2016
- 7) Positive Women Victoria website www.positivewomen.org.au
- 8) <http://www.dailymail.co.uk/femail/article-2979005/Three-HIV-positive-women-share-incredible-stories-living-disease-no-longer-death-sentence.html> sourced 3.00pm 28December 2016
- 9) <https://www.medibank.com.au/livebetter/health-matters-with-ita-buttrose/>
- 10) <http://www.starobserver.com.au/news/national-news/former-health-minister-says-australias-success-in-early-days-of-hiv-would-not-be-repeated/125604>
- 11) Adelaide, S. Aust. : Australian Health Promotion Association, South Australian Branch, 2002. National Library of Australia online catalogue. <https://catalogue.nla.gov.au/Record/3699082>
- 12) <https://www.theguardian.com/media/2013/feb/14/measuring-magazine-readership-abcs>
- 13) <https://mumbrella.com.au/publishers-agencies-need-change-magazine-audience-conversation-440989>
- 14) <http://www.roymorgan.com/industries/media/readership/magazine-readership>
- 15) Source Template.net <https://www.template.net/business/word-templates/plot-diagram-template/>
- 16) Aaron Shepard. What makes a good story. www.transformationalstory.org/SupportingResources
- 17) How Stories Change the Brain - Paul J. Zak, syndicated from Greater Good, Mar 03, 2014
www.dailygood.org/story/659/how-stories-change-the-brain-paul-j-zak/
- 18) www.websearch.com.au

- 19) <https://www.google.com.au/search?q=click+bait&oq=click+bait&aqs=chrome.0.69i59j0l5.4482j0j8&sourceid=chrome&ie=UTF-8>
- 20) Oxford dictionary www.oxforddictionaries.com

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