

Full title: Insights into the social context of living with a dual diagnosis of HIV and Cancer: A qualitative, thematic analysis of popular discourse in London newspapers

Short Title: HIV and Cancer: the social context

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Unstructured Abstract

As growing numbers of people living with HIV also develop cancer, a holistic understanding of their experiences is essential to the provision of patient centred care. Both conditions are linked to powerful beliefs in our society that may affect experiences. This study explored how HIV and cancer were represented in UK newspapers to gain insight into the social context of living with a dual diagnosis. We performed an initial content analysis of HIV articles and of cancer articles published in the free London newspapers, The Metro and The Evening Standard between 2012 and 2017, followed by qualitative thematic analysis and in-depth analysis of selected articles of exemplar cases. Both conditions were presented very differently. The underlying subtext was that cancer could happen to any of us. HIV was framed as a potentially dangerous, stigmatising phenomenon affecting 'others'.

Popular discourse about HIV within news media remains largely negative and stigmatizing. People living with a dual diagnosis of HIV and cancer may choose to prioritise the sharing of the more socially acceptable condition, cancer, in order to access support. The negotiation of cancer healthcare services is likely to be adversely influenced by the social burden of HIV related stigma.

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Main text

INTRODUCTION

Cancer is becoming a significant co morbidity for people living with HIV as effective antiretroviral therapy has improved long-term survival. Cancers traditionally considered as AIDS-defining (Kaposi Sarcoma, Non Hodgkins Lymphoma and cervical cancer) have declined in the era of effective HIV treatment but remain elevated in those living with HIV compared to those without (Franceschi et al, 2010). In addition to these virally driven cancers there is a growing incidence of more common cancers associated with lifestyle and ageing as people live longer (Shepherd et al, 2016; Lifson & Lando, 2012). With nearly 100,000 people living with HIV and receiving care in the UK, and over 7000 still undiagnosed (Nash et al, 2018), it is inevitable that an increasing number of people living with HIV will engage with cancer services and it is therefore timely to explore the experience of this dual diagnosis.

A dual diagnosis of HIV and cancer is the experience of two conditions loaded with their own distinct language and associated stigma. The social context surrounding both is a key component of understanding experiences. There has been renewed interest in developing more unified themes of stigma that transcend individual conditions and for this it is imperative to use a cross-cutting approach which considers wider contexts (Birbeck et al., 2019). Stories within popular newspapers form part of the social world that can impact upon behaviour, as demonstrated in a study which revealed the negative effect of increased newspaper coverage of HIV/AIDS on HIV testing behaviour (Stevens & Hornik, 2014). Popular representations of each condition have previously been explored separately in the literature as briefly discussed below, but it is important to look at both to properly understand implications for patient

experiences in the present day era of effective HIV treatment and the fast developing world of cancer therapies.

The literature emerging from the late 1980s and early 1990s featured negative and fearful associations with HIV/AIDS. Sontag's (1989) work on 'AIDS & Its Metaphors' was written at this time of moral panic and described the illness being linked to deviant behaviour. Then, being HIV positive was a relatively new and unknown condition, with little in the way of treatment and uncertainty as to how it might progress and spread. At that time the media reinforced feelings of fear by exploiting deep-seated anxiety about sex, disease and death with TV commercials featuring dire warnings and apocalyptic images of tombstones (Rhodes & Shaughnessy, 1990). Many popular newspapers sought to link the risk firmly with particular demonised groups such as drug users and gay men and disputed the relevance of health education campaigns to the heterosexual population (Clatts & Mutchler, 1989; Clarke, 1992; Beharrell, 1993). We live in a different era now with improved knowledge about transmission, and the development of easy-to-manage, effective HIV treatment has changed the medical landscape over time. It is important to explore whether these scientific developments are reflected in current popular representations.

Cancer, despite there being over 200 types, is often culturally constructed as one condition, 'The Big C'. It has been associated with powerful metaphors linked to industrialisation and the harmful effects of toxic chemicals (Weiss, 1997). Military metaphors such as a 'fight' or 'crusade' against cancer have been described in the literature (Sontag, 1983) and in popular discourse, but these can have the effect of suggesting that a failure of treatment equals a failure to fight hard enough (Reisfield & Wilson, 2004). Positive thinking in relation to cancer has been described by Wilkinson and Kitzinger (2000) as an idiom which is used by people with

cancer to conform to societal expectations that endorse this as appropriate and morally desirable.

Here we report an analysis of the representation of HIV and cancer in two free London papers from May 2012 to April 2017 to provide insight into how they are currently framed within British/Western popular discourse. An interpretive approach, utilising qualitative research methods was adopted as the most appropriate to explore the complexity of the social construction of each condition. As well as providing an understanding of how both HIV and cancer are framed separately within popular discourse, this analysis also provides insight into how the social context of both conditions might interplay and potentially impact upon peoples' experiences.

METHODS

The Metro and The London Evening Standard were selected as the key sources. They are both free of cost newspapers with a large circulation that are widely read by a broad demographic by virtue of their availability on the transport network where a large volume of people will pick them up to pass the time on their commute to work without making a conscious decision to select based on price or political persuasion. The messages they produce are therefore read by a mixed population in terms of cultural background, ethnicity and economic status. (Metro Readership and Distribution, 2019; Evening Standard Readership and Distribution, 2019).

Search strategy

A commercially available on-line database (NEXIS) of newspaper articles was used to retrieve articles using the broad search terms 'HIV' and 'cancer' in the five years prior to May 2017.

This period was selected to capture a representative range of HIV stories given that they occurred less frequently than articles about cancer. The broadly inclusive search yielded a total of 2551 cancer and 197 HIV articles. The search results were prepared for review by exporting a numbered list of full headlines containing links to the article text. The entire set of headlines were read and reference was made to the full text to aid the assigning of broad categories in an initial content analysis. As the process continued and familiarisation with the data grew, an iterative process of revisiting the categories and checking their suitability led to the refinement of the assignment and the development of initial themes. An overview of the search results and the category assignment was presented for cancer and HIV in tabular form see Table 1. The categories were then characterised in more detail using narrative description.

The content analysis and narrative summary made it clear that there were differences in the way the two conditions were presented. The next stage of analysis involved the development of themes and the creation of a thematic map. This process was conducted with the input of FS and MS to ensure that it was rigorous and of good quality. A number of articles were then selected for in-depth investigation based on a sampling strategy outlined by Miles & Huberman (1994). This sampling strategy incorporated three techniques: selecting apparently typical or representative examples of a theme; looking for negative or disconfirming examples of these themes and selecting exceptional or discrepant examples. A form was completed for each of the selected articles to tabulate the components of the analysis and included an examination of the context, the surface of the text, rhetorical devices, content and ideological statements and the overall discourse position and message of the article. This informed a narrative description which was written for each. The narratives aimed to compare representations of HIV and cancer between articles in order to identify the essential differences in the types of discourse presented. Finally, a synoptic analysis summarised the

themes and explored the potential impact that popular discourses around HIV and cancer might have on people who have a dual diagnosis.

THE RESULTS

An overview of the search results and the category assignment is presented for cancer and HIV in tabular form see Table 1

The Content Analysis

There were almost thirteen times as many cancer articles (n=2551) as HIV articles (n=197). This reflects the burden of cancer in the population but, as we shall see in the presented analysis, it was framed differently to HIV and this was reflected in the language and rhetorical devices used. Those categories which appeared in the results of both cancer and HIV searches were celebrity stories, 'human angle' stories, children, stories relating to funding and the NHS; and risk factors and awareness. There were also some categories unique to each condition. The main features and differences in representation are discussed below.

Cancer celebrity stories featured actors, singers, TV presenters and sports personalities who were interviewed about their personal experiences of having cancer. These stories often contained military metaphors with sixty headlines featuring the language of fighting and heroism. Stories featuring celebrities in connection with HIV were primarily linked to HIV charities rather than experiencing HIV themselves. Charlie Sheen was the only example of a commonly featured celebrity who was HIV positive identified in the search.

The cancer human angle stories were often personal in nature and featured important life events such as birth and marriage reported with emotive language. Thirty stories featured weddings, thirty-seven featured babies with thirty-two of these being about mothers with

cancer. Language such as ‘miracle’ babies and ‘dying groom’s last wish’ created a fairy tale like discourse with the protagonists pitted against cancer. Human angle stories in HIV were different in tone, often featuring the potential danger of HIV transmission. Apart from four first person accounts of living with HIV that were designed to inform and educate, many of the stories were about court cases relating to transmission or healthcare staff who were HIV positive.

There was a striking difference between the reporting of stories relating to children, with just one story in the HIV group compared with 147 articles about children with cancer. The language in the cancer stories served to eulogise the children and lend them idealised qualities, as exemplified by the headline ‘Tinkerbell has taken your hair, mum and dad tell brave Alisha’. Phrases such as ‘can do more good things from heaven’ and ‘his spirit lives on’ lent religious overtones to these representations. In just one result, the children living with HIV appeared almost incidental to the portrayal of the main benevolent protagonist, a visiting Western dance teacher.

For those stories relating to funding, 41 of those about cancer featured accounts with a personal angle where treatments had been approved or alternatively rejected for use within the NHS. Debate over the NHS funding for PrEP (pre-exposure prophylaxis for people at high risk of HIV) was a prominent feature of HIV articles and these stories always featured debates about whether funding was deserved.

There were a myriad of speculated risk factors for cancer such as food, drink, pollution or stress, and an apparent appetite for discussing these in newspaper articles in an inclusive discussion which invited the reader to consider their own risk factors. Stories about the risks of

HIV transmission made a clear link with perceived deviant behaviour such as gay sex and promiscuity and an assumption that infection could be controlled by modification of behaviour.

There were two categories which were a feature of articles about cancer but not HIV, they were 'cancer scams' and diagnosis and presentation. Cancer scams included stories about people faking cancer to raise money or stealing charity funds and implied a level of outrage that cancer should be cynically used for financial gain. Diagnosis and presentation featured articles about cancer screening and stories about individuals' experiences of misdiagnosis which reflects the variety of presenting signs and symptoms and screening methods for cancer. The one category in HIV stories which did not exist for cancer was HIV Commentary. These featured longer individual opinion pieces in the Evening Standard providing views on issues such as the possibility of the end of an 'AIDS defining era' and criticism of 'this new gay hedonism'.

The thematic analysis

The first stage of the thematic analysis involved the creation of a thematic map which represented those themes developed from further exploration of the category content analysis. It illustrated two overarching themes in relation to the two conditions: Cancer could happen to you and HIV happens to others. Cancer was not framed as infectious. Diagnosis was generally presented as free from blame (except for particular lifestyle examples such as smoking and lung cancer) and something that the reading audience could relate to. HIV was framed as dangerous, infectious and associated with sexual behaviour and therefore blameworthy. Not only did it appear as a condition which affects 'other' people who are outside of the readers' experience, there was an additional (misguided) fear of transmission

which overshadowed perceptions of it. Other themes are represented in constellations around these two main conceptual groupings (See Figure 1). The search results were then revisited with the thematic map to check that the themes worked well and that nothing had been omitted.

Selection of articles for in-depth analysis

A sample of articles were selected for in-depth analysis to enable further exploration of the themes represented in the map. These are presented in Table 2. Ten articles were selected as typical or representative examples of one or several of these identified themes. One cancer and one HIV article was chosen from the same initial category with the articles matched as closely as possible so that the detailed language, rhetorical devices and context could be compared between the two conditions. Negative or disconfirming examples of these themes were also sought.

The two celebrity stories contained very different portrayals of the main protagonists and the presentation of their conditions and the detail of the analysis can be found in Table 3. The cancer article featuring Victoria Derbyshire's breast cancer treatment implied that the TV presenter's decision to share her experience was prompted by a desire to help other people. Uncomfortable details about her side effects were enveloped within a positive start and finish, thus conforming to acceptable conversational idioms and protecting the reader from the need to dwell upon them. The HIV story featuring the actor, Charlie Sheen, was by contrast a sensational account, full of language about sex-workers and drug use which intended to grab the attention and shock rather than promote reader identification and sympathy. The actual impact of HIV on Sheen's health, the fact that the virus undetectable in his blood and therefore

untransmissible was not mentioned. The suggestion was that this story was a spectacle remote from the reader; HIV was a concern of 'others'.

In the cancer 'human angle' stories and those featuring children, the language depicted idealised human behaviour such as a romantic wedding of 'sweethearts' and a child who was uncomplaining and selfless. In contrast the 'human angle' HIV story used a terse and factual reporting style to describe a court case in which a man had been accused of deliberately infecting a 'string of male lovers with HIV'. It was presented as a criminal act with no acknowledgement of this being a controversial or complex issue. The story featuring children with HIV presented Kenyan children in an orphanage as passive recipients of a Western ballerina's benevolence.

Funding stories in both conditions were more neutral in their language but the main area for comparison between the two was the indirect signposting of the issue of deservedness in the story about PrEP by the juxtaposition of prevention of HIV with the mention of an implied threat to the funding of children's health services. The cancer scam article described a financial fraud in which the protagonist lied about his daughter having cancer and used emotive language of the victim feeling 'violated' and the fraudster having 'groomed' his targets to imply a transgressive nature to the act. The HIV commentary piece used the language of blame and judgement towards the behaviour of sections of the gay community who in the opinion of the writer inhabited the 'soulless and empty world of hedonism' and were 'partly to blame for the spread of HIV'.

DISCUSSION

Principal Findings

This examination of stories in London free newspapers between 2012 and 2017 showed that discussion of cancer in these newspapers differs considerably in the tone and type of stories presented from that of HIV.

Overall, cancer stories did not include much information about the physical realities of the condition or side effects of treatment. There was also a moral component in that people with cancer were portrayed as largely innocent and deserving of sympathy. This popular discourse may translate into the everyday by enabling talk about cancer diagnosis, with associated sympathy and support. It may, however, mean there is a felt pressure to earn this support by conforming to the framing of experiences in terms of a brave struggle characterised by a positive attitude. In this way statements about positive thinking reflect media representations as well as conforming to pervasive societal norms (Wilkinson & Kitinger, 2000) and are taken as evidence of a 'fighting spirit' which is considered to be a good mental adjustment to cancer.

HIV appeared much less frequently than cancer in newspaper stories and the nature of the reporting was clearly different. A lot of the existing literature on the media representation of HIV and AIDS came from the late 1980's and early 1990's when HIV was a new disease without effective treatment. In our work, 25 years on, it is striking that elements of this representation remain, despite huge progress in the medical management of the condition and attempts by healthcare professionals to present HIV as a 'normal' chronic illness. The sensational language around the behaviour and lifestyle of Charlie Sheen, the depersonalised portrayal of an HIV positive individual and link with criminality which was a feature of the selected human angle story, and the issue of deservedness when related to the funding of treatment are all factors

that continue to present HIV as a condition of 'others'. For the most part the reader is not invited to identify with the protagonists on a personal level in the same way as in cancer stories.

Strengths and limitations of the study

The selection of articles from free newspapers in London ensured that the reading audience came from a broad demographic in terms of culture, ethnicity and economic status; the tabloid style of both meant that the stories leaned towards the popular and sensationalist. By not including broadsheet publications it is likely that those media perspectives which challenged HIV stigma and included scientific and medical research developments more in line with health education messages were missing from the analysis. The greater volume of stories about cancer gave a wider selection from which to choose examples and understand nuances.

Implications for clinicians

The results demonstrate that popular discourse in the news media still retain many of the negative and stigmatising connotations which are likely to make people with a HIV diagnosis feel inhibited sharing their experience and accessing support. Those with a dual diagnosis may therefore choose to prioritise the sharing of information about their cancer diagnosis as an acceptable condition in order to gain support from others. This selective disclosure has been reported in the literature in those with a dual diagnosis of HIV and TB and HIV and Hepatitis C (Daftary, 2012; Lekas et al, 2011). Awareness of societal judgemental attitudes about HIV expressed in the language of danger and high risk behaviour is likely to worsen internalised stigma which has been shown to have an impact on health related factors such as seeking healthcare and adhering to treatment (Ware et al, 2006). Within a dual diagnosis the impact is

likely to be felt as an additional burden to manage information about an HIV diagnosis and add to emotional distress when dealing with a potentially life threatening and debilitating cancer diagnosis with challenges of its own, in an unfamiliar healthcare environment. An understanding of this burden, particularly among oncology healthcare professionals, is essential in order to provide compassionate, patient centred care for this group of people.

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Authors contributions

EH conducted the database search, extracted the data, performed both the content and thematic analysis of the data and wrote the manuscript

MS contributed to the development of the methods used within the study, contributed to the thematic analysis and interpretation of the findings and commented on all versions of the manuscript

FS contributed to the development of the methods used within the study, contributed to the thematic analysis and interpretation of the findings and commented on all versions of the manuscript

Declaration of interests

There are no conflicts of interest for any of the authors

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Table 1 Search results & category assignment

Cancer articles identified by Nexis Database Search May 2012 – May 2017		HIV articles identified by Nexis Database Search May 2012 – May 2017	
Evening Standard	n = 937	Evening Standard	n = 88
Metro	n = 1695	Metro	n = 144
Total cancer articles	n = 2632	Total HIV articles	n = 232
Total duplicates*	n = 81	Total duplicates*	n = 35
Total without duplicates	n = 2551	Total without duplicates	n = 197
Thematic categories		Thematic categories	
Cancer Awareness/ Risk	n = 243	HIV Awareness/Risk	n = 10
Cancer Fundraising	n = 245	HIV Fundraising	n = 5
Celebrity Cancer	n = 510	Celebrity HIV	n = 53
Cancer 'The Human Angle'	n = 331	HIV 'The Human Angle'	n = 40
Cancer advances in treatment/Medical interventions	n = 271	HIV advances in treatment/Medical interventions	n = 22
Cancer Figures	n = 87	HIV Figures	n = 9
Cancer Funding & the NHS	n = 160	HIV Funding and the NHS	n = 19
Children with Cancer	n = 147	Children with HIV	n = 1
Cancer Business/Industry	n = 49	HIV Business/Industry	n = 3
Cancer an Incidental Mention	n = 399	HIV an incidental mention	n = 16
Cancer Scams	n = 36	Category did not exist for HIV	
Cancer Diagnosis & Presentation	n = 73	Category did not exist for HIV	
Category did not exist for Cancer		HIV 'Commentary'	n = 19

Table 2 Articles selected for in-depth analysis

Themes	Illustrative Quotes	Initial category	Source	Headline	Date
Bravery, battles & positive thinking	Described as 'brave & honest & raw & inspiring'	Cancer celebrity	Metro	<i>BBC Victoria shares brave film diary of chemo battle</i>	12-Nov-15
Shame, blame. Sexual behaviour. Potential danger of transmission	'extortion by friends & prostitutes', 'meltdown' due to 'roid (steroid) rage'	HIV Celebrity	Metro	<i>Sheen reveals his HIV agony to be free of blackmailers</i>	18-Nov-15
Fairy tales. Idealised human behaviour	romantic language such as 'sweetheart' 'wished to wed' and 'tied the knot' 'now we are complete'	Cancer the 'Human Angle'	Metro	<i>Mad rush to tie knot for cancer sufferer</i>	08-May-15
Reporting at a distance. Sexual behaviour (criminality)	'accused of deliberately infecting a string of male lovers'	HIV the 'Human Angle'	Metro	<i>26-year-old accused of infecting lovers with HIV to stand trial</i>	27-Feb-17
Fairy tales. Sharing personal stories. Idealised human qualities. Bravery, battles & positive thinking	'never complained, never wallowed in self pity' 'wise beyond her years' 'will be looking down smiling'	Cancer and Children	Evening Standard	<i>My dying daughter inspired my own cancer battle; mother's moving tribute to 11-year-old who was 'wise beyond her years'</i>	07-Mar-17
Reporting at a distance. The overarching 'HIV happens to others'	'orphaned children in the biggest slum in Africa' 'in desparate & desolate conditions'	HIV and Children	Evening Standard	<i>It's really touching to see the joy ballet can bring to African orphans</i>	03-Mar-17
Cancer funding is deserved	Neutral, scientific language 'clinically effective' 'good reduction in the size of their tumours'	Cancer & the NHS	Metro	<i>Last-chance lung cancer drug offered on the NHS</i>	04-Oct-16
HIV funding is a subject of debate	'potential impact on the provision of other services including hearing implants for children...children aged two to five who have cystic fibrosis'	HIV & the NHS	Evening Standard	<i>NHS loses appeal over drug that prevents HIV</i>	10-Nov-16
Idealised human qualities	'the lowest of the lowest' victim of fraud felt 'violated' and 'groomed'	Cancer Scam	Evening Standard	<i>I feel violated by friend who conned me out of £178,000 says jeweller</i>	10-May-16
Blame, shame. Sexual behaviour	'the gay scene today seems obsessed with drugs.' Obsessed with sex. Unable to take responsibility for its part in the spread of HIV. Inhabiting a soulless and empty world of hedonism'	HIV Commentary	Evening Standard	<i>This new gay hedonism is not what I fought for; In a provocative view, a leading gay rights campaigner says obsession with drugs and sex is blighting the cause</i>	28-Jun-13

Table 3 Fine Analysis of Celebrity Stories

Title	Sheen reveals his HIV agony to be free of blackmailers 18-Nov-15 Metro
Context	Reports on the news that actor Charlie Sheen revealed to the public that he was HIV positive
Surface of the text	Headline contains emotive language 'HIV agony' 'blackmailers'. Short article starts with reporting how Sheen 'told the world' on the Today Show in US, moves on to give background of blackmail, mentions that he had unprotected sex twice but that both partners were 'under the care of my doctor'. Finished with his doctor stating that he is healthy
Rhetorical means	The language around his situation before he went public describes an intolerable situation. He was in a 'prison' and under an 'onslaught and barrage of attacks and sub-truths'; 'extortion by friends and prostitutes' and had 'paid out millions'. References to 'extortion', 'blackmail', 'prison' suggest a shady underworld. He denied that his condition was related to the 'meltdown' that led to him being fired from an earlier TV show which he attributed to 'roid (<i>steroid</i>)rage'. This language adds to the sensational portrayal of someone out of control
Content & Ideological Statements	Sensational story revealing a murky world where a celebrity paid millions and withstood an onslaught of blackmail rather than reveal his HIV diagnosis. This gives the idea that society would not be supportive of a celebrity revealing their HIV status and implies it has potential to ruin their career
Discourse position and overall message of the article	An HIV diagnosis is something to be hidden, harmful to a celebrity who is prepared to endure blackmail to keep it secret
Title	BBC Victoria shares brave film diary of chemo battle 12-Nov-15 Metro
Context	Reports on Victoria Derbyshire sharing a video diary of her experience of having chemotherapy for breast cancer on her BBC show
Surface of the text	Headline marks this out as a story about bravery. Short descriptive story on her experience of chemotherapy and its side effects. Final section quotes others praising her honesty and strength.
Rhetorical means	The language of 'brave' and 'battle' in the headline implies that the decision to share her story is courageous. The content describing the video is factual without rhetorical devices, it contains quotes of her feeling 'increasingly queasy and drained'. The final section details praise she has received on Twitter in response to the diary describing her as 'brave and honest, raw and inspiring' and 'a wonderfully strong lady'
Content & Ideological Statements	This article commends the brave decision to share her story
Discourse positions and overall message of the article	Sharing information about cancer experience is praiseworthy; dealing with cancer is brave