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Title	Sex, stigma and silence: the discursive construction of HIV in Ireland
Author(s)	Vaughan, Elena
Publication Date	2019-01-11
Publisher	NUI Galway
Item record	http://hdl.handle.net/10379/14994

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Sex, stigma, and silence: The discursive construction of HIV in Ireland

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Submitted 11th January 2019

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Abstract

Improvements to treatment mean that HIV is now a chronic, manageable illness. People living with HIV (PLHIV) have a life expectancy on a par with HIV negative individuals, and are non-infectious once the treatment goal of undetectable viral load (UVL) has been reached. In spite of such improvements HIV-related stigma continues to negatively impact the lives of PLHIV in complex ways and furthermore acts as a barrier to treatment and prevention efforts. In Ireland, the rate of new HIV diagnoses has grown considerably in the past few years, with the highest ever number of new diagnoses recorded in 2016 (HPSC, 2017).

This research examines the phenomenon of HIV-related stigma in the Irish context. Two studies were conducted. The first study explored the discursive construction of HIV in the Irish print media. 103 news articles printed in national newspapers over a ten year period were analysed using Critical Discourse Analysis (CDA), Limited Content Analysis and Technique Triangulation. The second study explored the experiences of stigma of 14 individuals with HIV from diverse cohorts. The interviews were analysed using Directed Content Analysis, utilising a conceptual framework developed as part of the review of the literature. This framework drew on existing conceptual frameworks for stigma, underpinned by readings of Bourdieu (1977) and Foucault (1984).

The findings indicate that HIV-related stigma is keenly bound up with discursive constructions of HIV that both shape and reflect deeply embedded cultural notions of sex, morality and health and illness. Analysis showed how such constructions mediate the embodied and enacted stigma experiences of PLHIV and how symbolic and structural violence are implicated in this process, working in tandem to negatively affect the health and well-being of those disproportionately affected by HIV. This study has implications for policy and practice and may be useful for informing stigma interventions going forward.

Acknowledgements

I would like to thank all the people who generously gave of their time to be interviewed for this study- thank you for sharing your stories with me. Thanks also are due to the staff of HIV Ireland, UISCE, AIDS West and the Cork Sexual Health Centre for supporting and facilitating this research.

I am extremely grateful to my supervisor Dr. Martin Power for giving me a chance and for believing in my work. Not to mention for the many, many coffees he sprung for during four years of 'living with PhD.'

Thanks also to my co-supervisor Dr. Jane Sixsmith for her support and kindness and to the members of my GRC- Dr. Catherine Anne Field, Dr. Vesna Malesevic and Dr Mary-Pat O'Malley.

I am lucky in my friendships- many thanks to all my pals for all their patience and generosity the past few years. A special mention is owed to Eamonn Day Lavelle for all his help with the website and graphic design work- thanks bud!

I would not have gotten far in this journey were it not for my family- to my Grandparents Jackie and Marian O'Grady for their love and support, to Mike O'Grady for feeding and watering me, to Shane O'Grady for his kindness, to Grace O'Grady for her gentle encouragement, to my brother Jack (*vulneratis non victus*), and my lovely sister Clare for giving me strength when I needed it most.

Lastly- to my mother Eily, who instilled in me a love of learning, and to my father Tom, who has long told me I could achieve anything I set my mind to. I am eternally grateful for all you have done for me. This is dedicated to you. xx

Chapter One: Introduction

The outlook for people living with HIV in Ireland (PLHIV), as in other Western countries, has shifted considerably in the past two decades. Access to antiretroviral (ARV) medication means that those diagnosed with HIV today are living long and healthy lives and have a life-expectancy on par with that of the general population (Hogg, 2013; May et al., 2014; Samji et al., 2013). Moreover women with HIV can safely give birth to HIV negative babies- indeed the success of prevention of mother to child (PMTCT) programmes has, within a short span of time, made mother to child transmission almost a thing of the past (Piot, Bartos, Larson, Zewdie, & Mane, 2008). Furthermore, as the 2008 Swiss Statement has highlighted, people living with HIV (PLHIV) are non-infectious when the treatment goal of undetectable viral load (UVL) has been reached (Vernazza, 2008). As such, the prospect of condomless sex for serodiscordant¹ couples is now a viable reality (Rodger et al., 2014; Rodger, Cambiano, Bruun, & et al., 2016; Vernazza, 2008). Crucially, this has led to an affirmation of the concept of treatment as prevention (TaSP) (Cohen et al., 2011; Cohen, McCauley, & Gamble, 2012). Indeed pre-exposure prophylaxis (PrEP)² has become an extremely significant prevention tool, reducing HIV infections in key affected populations by upwards of 86% (McCormack et al., 2016). These developments have opened up new possibilities for stemming the epidemic through a combination prevention approach that includes biomedical, structural and behavioural strategies (UNAIDS, 2010a, 2016a). Such progress has thus encouraged an optimistic outlook, leading Anthony Fauci, Director of the U.S. National Institute of Health, to declare in 2012 that ‘...an AIDS-free generation is indeed within reach’ (Fauci & Folkers, 2012, p. 344).

In spite of these immense advancements, however, myths and misinformation about HIV abound and stigma remains an entrenched problem which continues to hamper efforts to address the epidemic both in Ireland and globally (Ireland, 2017b; UNAIDS, 2007, 2010b, 2014b, 2018). Certainly, those at the coal face continue to highlight that people living with

¹ Serodiscordant is a term used to describe a relationship in which one partner is HIV positive and one is HIV negative.

² Pre-exposure prophylaxis (PrEP) refers to the use of the antiretroviral medication Truvada, or its generic iterations, as a preventative to acquiring HIV.

HIV in Ireland 'still have to walk in the shadows' (Coy, 2012, p. 2). In contrast to people living with other long-term manageable chronic illnesses, the stigma that surrounds HIV prohibits many from articulating their experience openly due to the 'negative beliefs, feelings and attitudes towards people living with HIV and/or associated with HIV' (UNAIDS, 2010b, p. 2). HIV-related stigma can lead to discrimination in healthcare settings, the community, and the workplace, whilst institutionalised discrimination is manifest in laws, policies and practices that result in unfair treatment of people living with or affected by HIV (Parker & Aggleton, 2003; UNAIDS, 2010b). In a human rights context, HIV-related stigma and discrimination are viewed as a violation of human and sexual and reproductive rights (Gruskin, Ferguson, & O'Malley, 2007; UNAIDS, 2007, 2010b, 2014b).

In addition to impacting the lives of PLHIV, stigma and discrimination have continuously been identified by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the European Centre for Disease Control (ECDC), among others, as one of the key drivers of HIV globally (ECDC, 2017a; UNAIDS, 2007, 2010a, 2010b, 2014b). For example, the stigma associated with HIV creates barriers across all levels of the HIV care continuum including accessing testing, treatment and engagement in care (UNAIDS, 2017). The impact is such that UNAIDS have stated that:

Reaching the 90–90–90 targets and ultimately ending the AIDS epidemic requires specific efforts to address stigma, discrimination and human rights violations at all levels...Service providers must know their obligations and be sensitized in order to reduce discrimination and stigma; key populations and people living with HIV must be aware of their rights and have the skills and knowledge to enforce them (UNAIDS, 2017, p.76).³

Ireland, however, has been identified of currently falling short of meeting the 90-90-90 targets, with significant gaps across the HIV continuum of care (ECDC, 2017c; Hurley, Lyons, O'Donnell, & Igoe, 2018). Of particular concern, Ireland is currently experiencing an unprecedented rise in the number of new HIV diagnoses. Since 2008 the number of new diagnoses has increased overall by over 20% and more than doubled among men who have

³ The 90-90-90 targets refers to objectives set out by UNAIDS and the global community that by 2020 90% of PLHIV will be diagnosed, 90% of those diagnosed will be on treatment and 90% of those on treatment will be virally suppressed (UNAIDS, 2014a).

sex with men (MSM) (HPSC, 2017b). In total, 8,341 cases of HIV have been diagnosed in Ireland to date (HPSC, 2017b).

In this preliminary chapter I will set out the background and context to the study that was conducted for this PhD thesis. Firstly I will provide a concise account of the epidemiology of HIV in Ireland from 1983 to 2018. Next I will take a brief look at the history of AIDS, looking in particular at the early social and political responses to AIDS in the United States, the United Kingdom and in Ireland. Following this, I will lay out the policy and legal frameworks that govern the management of HIV in Ireland. A short section on the relationship between AIDS and the media serves as a prologue to the statement of the study rationale, research questions and aims. Lastly an outline of the subsequent chapters is provided.

Background and Context

Epidemiology of HIV in Ireland

1983-2000

The first cases of AIDS in Ireland were reported in 1983 among a small number of gay men (Seery, 1999). Throughout the 1980s and 1990s, however, the cohort most affected was people who use drugs (PWUD). Opiate addiction had emerged as a significant public health problem in the country during the late 1970s and early 1980s, particularly in working-class Dublin. The Jervis Street Drug Centre, for instance, saw its number of attendees increase from 294 in 1979 to 1,314 in 1983 (Dean, O'Hare, O'Connor, Kelly, & Kelly, 1985). By 1987 27% were testing positive for HIV (Dean, O'Hare, O'Connor, Kelly, & Kelly, 1987). By 1993, 45% of HIV diagnoses were among PWUD. Between 1993 and 1999 there was a shift however, and by 1999 PWUD accounted for 22% of new HIV cases (Seery, 1999). This was due in large part to concerted efforts to address the enormous drug issue in Dublin and through targeted interventions aimed at reducing harm from drug use (Seery, 1999). During the same time period, the rate of new transmissions among MSM remained relatively static, hovering around 27% in 1993 and 25% in 1998 (Seery, 1999). In contrast, transmissions among heterosexuals, grew steadily during this period- from 13% in 1993 to 21% in 1998, with women consistently representing around a quarter of all new transmissions (Seery, 1999).

2000-2016

In the early 2000s, new HIV transmissions continued to rise, with an increase of 22% in the overall number of new diagnoses in 2002, taking the number of new cases that year to 364 (Callelly, 2003). While throughout the 2000s numbers continued to increase, a shift occurred in the pattern of transmissions. In 2003, new diagnoses among heterosexuals made up the majority of new cases at 55% (222), whereas MSM represented 19% (n=76) and PWUD 12.5% (n=50) (HPSC, 2017b). Between 2003 and 2016 this trend reversed with the number of new diagnoses among MSM more than tripling to 51.4% (n=261), while PWUD decreased to 4.1% (n=21) and heterosexual transmission remained at roughly a quarter (n=140) (HPSC, 2017b). Between 2014 and 2015, there was a significant increase in the total number of new diagnoses recorded- 30%- although this was partly due to changes to notification protocols (HPSC, 2017b). Since then, there have been 5% increments both in 2015 and 2016 (HPSC, 2017b). The highest number of new diagnoses to date was recorded in 2016 at 508 cases (HPSC, 2017b).

2017-present

In 2017 the number of new diagnoses remained relatively static hovering around 500 (HPSC, 2018).⁴ Currently it is estimated that there are 7,205 people living with HIV in Ireland, with approximately 12.9% (n=929) undiagnosed (Hurley et al., 2018). This represents a diagnosis rate of 10.7 per 100,000 of population, which is considerably higher than the EU average of 6.3 per 100,000 (HPSC, 2017b). There is a clear gender divide, with males (77%) more than three times more likely to be diagnosed than females (22%) (HPSC, 2017b). People born in Ireland make up 25% of new diagnoses, whilst 66% were born abroad (HPSC, 2017b). The median age of diagnosis is 35 years, with the majority of diagnoses occurring in the East of the country (Dublin, Kildare and Wicklow). This concentrates the rate per 100,000 to twice the national average in this region (HPSC, 2017b).

There is also a trend of relatively late diagnoses in Ireland at 56%, which contrasts with the European average of 47%. Indeed 19% of people were diagnosed at an advanced stage of HIV infection, meaning they had a CD4 count of less than 200 and/or an AIDS-defining illness (Adler, Mounier-Jack, & Coker, 2009; ECDC, 2017c; HPSC, 2017b). A further

⁴ This figure is based on provisional data from the Health Protection Surveillance Centre (HPSC, 2018).

37% were classed as late presenters, meaning they had a CD4 count of less than 350 or an AIDS-defining illness. Heterosexual women, heterosexual men, people over the age of 39 and people from sub-Saharan Africa were most likely to be late diagnosed (HPSC, 2017b). These figures suggest particular barriers to testing and screening among these cohorts (Kall, Smith, & Delpech, 2012). Late diagnosis is of particular concern as it is associated with an increased risk of co-morbidities and opportunistic infections such as TB, and is associated with increased mortality (Adler et al., 2009; Chadborn, Delpech, Sabin, Sinka, & Evans, 2006; Kall et al., 2012).

A Brief History of AIDS

AIDS first came to attention in the United States in 1981, with reports of young gay men presenting with pneumocystis carinii pneumonia (PCP) and Kaposi sarcoma in Los Angeles, San Francisco and New York (CDC, 1981). Physicians were perplexed. Previously healthy young men were becoming sick and dying from relatively rare cancers and infections. Early theories about what was causing the syndrome frequently centred around 'life-style' factors of gay men, including use of amyl nitrate (poppers), multiple sex partners and even adverse reactions to semen (Greene, 2007). As the first cases were appearing predominantly among gay men, the condition was originally referred to as GRID-Gay Related Immune Deficiency- the first of many acronyms in the history of HIV and AIDS (Garfield, 1988; Shilts, 1988). It soon became apparent, however, that the condition was not confined to gay men. As reports began to increase in incidence and cases were showing up in other cohorts the Centre for Disease Control (CDC) began using the term AIDS (Acquired Immune Deficiency Syndrome) from September 1982 (CDC, 1982). The emergence of the syndrome was not confined to the United States- early cases of AIDS were identified in the UK, Belgium and France, countries which had strong colonial links with Africa, where the virus is believed to have originated (Shilts, 1988).

Initial doubts that AIDS was caused by an infectious agent soon gave way. The idea that this new disease might be caused by a pathogen intrigued those working in the field. Research on infectious diseases had fallen out of fashion somewhat during the 1970s, as the successful development of vaccines had engendered the belief 'that epidemic diseases caused by microbes, including viruses, no longer posed a threat in industrialized countries' (Gallo & Montagnier, 2003, p. 2283). In 1983, HIV was isolated in the Pasteur Institute in

Paris, by Françoise Barré-Sinoussi and Luc Montagnier, and, separately, in Bethesda, Maryland by Robert Gallo (Gallo & Montagnier, 2003). Following a dispute between Gallo and Montagnier over the ownership of the discovery and the ensuing right to name the virus, the International Committee of the Taxonomy of Viruses ultimately recommended on naming the virus HIV in 1986 (Gallo & Montagnier, 2003; Greene, 2007; Shilts, 1988).⁵

Etiology of HIV

The human immunodeficiency virus (HIV) is a retrovirus that affects the immune system. The virus affects a type of white blood cell involved in the immune response called a CD4 cell- known alternatively as a T-cell, T-lymphocyte or T-helper cell. HIV uses the CD4 cell in order to replicate copies of itself, by extracting DNA from the host cell. The newly created copies of the virus are then released from the depleted CD4 cell into the bloodstream in order to find other CD4 cells in which to begin the replication process once more⁶ (Greene, 2007). As the virus progresses and more and more CD4 cells become depleted, the body's immune function begins to decline, and this leads to an increased susceptibility to opportunistic infections such as PC pneumonia and cancers such as Kaposi's sarcoma. This is what is known as Acquired Immune Deficiency Syndrome (AIDS). Antiretroviral medications work to reduce the amount of virus in the bloodstream by halting the replication process at various stages of the viral life-cycle.

Early responses to AIDS- social, political and historical context

Early responses to AIDS are widely regarded to have been negatively impacted by the prevailing social, political and ideological environment at the time (Garfield, 1988; Shilts, 1988; Treichler, 1987b; Treichler, 1999; Watney, 1997). The emergence of AIDS in the early 1980s coincided with the contemporaneous resurgence of a particular brand of social conservatism on either side of the Atlantic (Watney, 1997). The politics of both Margaret Thatcher in the UK and Ronald Reagan in the US were keenly aligned with the religious right and both leaders were elected to power on a platform that promoted traditional Christian 'family values,' while also emphasising neo-liberal notions of individual responsibility (Dardot & Laval, 2017). In Ireland, politics and religion had long been intertwined, and the

⁵ For a detailed account of the early days of the AIDS epidemic in the US and the controversy surrounding the naming of HIV see Shilts, 1988

⁶ For an accessible explanation of the HIV life-cycle, see <http://www.aidsmap.com/HIV-lifecycle/page/1044602/>

influence of the Catholic Church held considerable sway on political considerations (Ferriter, 2009). The early association of AIDS with gay men and drug use thus presented a problem to the authorities tasked with dealing with the epidemic, particularly in Ireland where homosexuality was still illegal and condoms were not freely available (Ferriter, 2009; NASC, 1992; Seery, 1999).

Against this socially conservative political climate, the response of the Irish State to the burgeoning AIDS crisis was sluggish. Initial public information and education initiatives were carried out by grassroots movements such as Gay Health Action (GHA), founded in 1985, and gay alternative media such as OUT magazine (Kerrigan, 2017). During the early days of the epidemic, Out, like its counterpart Gay Times in the UK, was the only available public source of information on AIDS. In the absence of a State response GHA published the first AIDS information leaflet in 1985, with the assistance of a small grant from the Department of Health (Seery, 1999). Subsequent efforts by GHA to obtain further assistance from the Department of Health however, were met with silence. OUT reported that authorities 'had not answered any letters, agreed to any meetings, nor accepted telephone calls' (quoted in Kerrigan, 2017, p. 6).

In 1987 the Irish government produced a mass media public information campaign, the message of which aligned closely to that of similar campaigns in the UK, such as the infamous tombstone and iceberg campaigns. A TV advertisement was produced and released by the Health Education Bureau in 1987 to promote the message that 'casual sex spreads AIDS' (Seery, 1999). The ad depicted scenes of gambling, downplayed the effectiveness of condoms in protecting against transmission and asserted that 'just one act of intercourse may give you AIDS' (Bureau, 1987). More saliently, particularly for the Irish context, the ad omitted any mention of the potential for the virus to be transmitted via intravenous drug use. The subtext of the advertisement was clear and had been designed to be as palatable as possible for Catholic ideologues- heterosexual monogamy or celibacy were the only options. Indeed, during the Lindsay Tribunal (2002), a Department of Health official acknowledged that stiff opposition from 'right wing Christian or Catholic' groups made it difficult to promote safer sex messages and further stated that to advocate for condom use would have caused 'murder' (Melia, 2001).

State responses to the AIDS crisis elsewhere during the 1980s were also characterised by official silences and a reluctance to acknowledge the reality of AIDS, particularly in regard to the specific impact it was having on communities of gay men. Ronald Reagan infamously did not utter the word AIDS publicly until a press conference on the 17th of September 1985, four years into the AIDS epidemic in the United States (Shilts, 1988). Furthermore, he did not address the issue in earnest publicly until the 31st of May 1987 during a speech to the American Foundation for AIDS Research (Reagan, 1987). The speech pointedly made no references to gay men, thousands of whom had already died from the illness by that time. Margaret Thatcher was similarly ill at ease with dealing with or discussing the issue. Indeed archive materials from Downing Street indicate that Thatcher and her advisors were extremely wary of AIDS. A memo from Mrs. Thatcher's private secretary to her diary secretary gives insight into the worries advisors had about the public relations implications for Mrs. Thatcher of engaging with the AIDS crisis: 'My own feelings on this is that the Prime Minister should stay clear of AIDS (!), even when it is a question of opening laboratories to help innocent victims' (Addison, 1985).

In both the UK and the USA then, as in Ireland, initial efforts to inform people about AIDS emanated not from the State but from grassroots groups and charitable organisations. In the USA grassroots gay organisations such as Gay Men's Health Crisis (GMHC) and ACTUP were disseminating health information about AIDS from 1982. In contrast, The Surgeon General of the USA did not address the issue until 1986 (Shilts, 1988). In the UK, similarly, the Gay Switchboard and community publication 'The Gay News' were instrumental in disseminating information about AIDS to the community from the early 1980s. The death of Terry Higgins led to the establishment of the eponymous Terrence Higgins Trust by a group of his friends in 1982. The following year the Trust published the first health information leaflets on AIDS in the UK, drawing on pamphlets circulated by GMHC and ACTUP in New York. The leaflets described the symptoms of AIDS, what people should look out for and advised anyone experiencing them to seek immediate medical advice from a gay-friendly doctor (Garfield, 1988).

Up to this point in the UK, the public's information about AIDS had been limited to lurid and increasingly hyperbolised accounts in red tops and a small number of news and documentary programmes that were often heavily editorialised for popular consumption

with a broadly white, middle-class and heterosexual audience in mind (Watney, 1997). The lack of knowledge about AIDS and the communities it affected was such that in exploring for ways in which to get the right information to the target audience, officials were obliged to seek inspiration from less than orthodox sources. For instance, the then Minister for Health Norman Fowler was obliged to smuggle copies of American gay magazine 'The New York Native' into London in diplomatic bags in order to avoid them from being seized by customs (Garfield, 1994).

Against the growing backdrop of the crisis, the UK Ministry of Health published a national newspaper ad on AIDS in 1986. This did not occur without much hand-wringing among cabinet members about the language used. A hand-written annotation by Mrs. Thatcher on a letter from the Department of Health shows that she remained 'against certain parts of the advertisement' (Thatcher, 1986a). Mrs. Thatcher was particularly opposed to the inclusion of language about sex. 'Do we have to do the section on risky sex?' she queried in another handwritten note (Thatcher, 1986b). Mrs. Thatcher was especially concerned that openly discussing sex in a national newspaper would cause 'anxiety on the part of parents' and be detrimental to 'teenagers who would never be in danger of AIDS' (Thatcher, 1986a).

If Mrs. Thatcher's concerns could be described as prudish, in Ireland in 1985, the crisis was seen by Minister for Foreign Affairs Peter Barry as an opportunity to reinforce a defence in the case being taken against the State by David Norris challenging the laws against homosexuality. Minister Barry had been advised by the Attorney General that 'homosexual acts as such cannot cause the disease' and had been warned by medical experts that sanctions were not an appropriate response as continued criminal sanctions would 'reduce the likelihood of possible Aids (sic) victims coming forward' (Gatland, 2015). Nonetheless, Minister Barry maintained that the epidemic could provide a basis to justify retaining the legislation. He argued that the laws 'might help counter the spread of Aids' and that this was in the interests of 'the morals, the rights and freedoms of others and health' (Gatland, 2015).

The lethargic response of the Irish State became ever more unsustainable in the face of persistent activism from often disparate groups. For example, in 1987 the Irish

Haemophilia Society conducted a survey of the 106 people known to have acquired the virus through infected cryoprecipitate products/blood plasma and published the document 'AIDS, Haemophilia and the Government' (O'Mahony, 2013). The report outlined the unmet health and social care needs of Irish haemophiliacs and was submitted to the Department of Health along with a detailed proposal that a trust fund of €400,000 be established to meet these needs going forward. Again, there was no response from the government and the Haemophilia Society was thus forced to embark on a campaign of intense lobbying to have their case heard. Ultimately it would not be until the early 2000s and the advent of the Lindsay Tribunal, that people with haemophilia would have their day in court- by which time many had already died.

Nonetheless, the lobbying by the Haemophilia Society saw some success to their efforts. In 1989, over 800 people had been diagnosed HIV positive, 88 cases of AIDS had been reported to the Department of Health and 36 people had died (O'Hanlon, 1989). Brendan Howlin, then a Labour Party back-bencher, brought forward a bill to the Oireachtas (Parliament) that reflected the calls of the Irish Haemophilia Society to establish a trust fund for haemophiliacs with HIV. Mr. Howlin further called on the then government 'to ensure that every public health facility is made available to all AIDS sufferers' (Howlin, 1989). While the then Minister for Health Rory O'Hanlon acknowledged the need for facilities for all AIDS victims, he rejected the idea of a special fund for haemophiliacs, arguing that this would set haemophiliacs apart from other people with HIV and thus create the false impression of 'guilty' and 'innocent' AIDS victims. 'It was important,' he said, that 'sufferers are not made to feel as if they were outcasts in our society' (O'Hanlon, 1989). Mr. Howlin countered that the Minister's words 'would stand up to better scrutiny if the situation in St. James's Hospital...was not as it is,' pointing out that 'in the unit which treats AIDS victims there is one consultant, one junior hospital doctor, one nurse, one counsellor and one social worker paid by the State...Our treatment of all AIDS sufferers is inadequate' (Howlin, 1989).

The government ultimately lost the vote in the Dáil. In the wake of the defeat the government was dissolved and lost a considerable number of seats in the subsequent election. For the incoming government it was clear that there was a need to address the AIDS epidemic in earnest. The trust fund for haemophiliacs was established and the National

AIDS Strategy was subsequently formed to begin formulating a coherent policy framework for the HIV response in Ireland.

Policy and legal frameworks for HIV in Ireland

In 1992 the government established the National AIDS Strategy Committee (NASC) in order to coordinate the response to the HIV epidemic. This committee was composed of four sub-committees with responsibility for surveillance, care and management, education and prevention and discrimination (NASC, 2000). The NASC was quick to report, publishing its first document in 1992 and this formed the basis for actions throughout the 1990s (Seery, 1999). At this time there was no effective treatment for HIV and, in the context of the time, the focus of much of these recommendations was directed towards prevention and education. This was problematic, however, given that condoms were not widely available, sex between men was still illegal and there were 'difficulties in acknowledging that drug use and sex occurred between some men in prison' (NASC, 2000, p. 28). Recommendations were made with respect to the provision of social welfare support for PLHIV unable to work and respite and palliative care. The NASC suggested that between 7 and 8 infectious disease consultants were necessary to meet demand and recognised the on-going work of voluntary and non-statutory organisations in the roles of education, prevention and health promotion. There was a clear focus in the document on issues that were particularly reflective of the era, concerning segregation of prisoners, the decriminalisation of homosexuality and the use of body-bags for the deceased. Furthermore, recommendations were made for non-discrimination of PLHIV in healthcare and other settings (NASC, 1992).

In the mid to late 1990s, continued increases in HIV diagnoses, changes in the epidemiology of HIV in Ireland and the development of ARV medication in 1996 prompted a review of existing policy and practice. In 2000, the 'AIDS Strategy 2000,' policy document was published and was comprised of four distinct reports from each of the NASC sub-committees. Despite the NASC's earlier recommendations, there were only four Infectious Disease consultants in the country- one in Cork and three in Dublin. Moreover, one of the Dublin consultants was shared between the Mater and Beaumont hospitals. This meant

that people living outside of Cork or Dublin were required to travel to attend clinics.⁷ In light of this the strategy recommended that services be expanded across Ireland and that additional infectious disease consultants be appointed as a matter of urgency. The strategy reaffirmed the need for a cross-sectoral approach to education and prevention and recommended that a review be conducted to examine the adequacy of funding and resources, the establishment of an antenatal screening programme, and that national media campaigns be conducted to challenge stigma, raise awareness of new treatments and underscore the importance of prevention. This strategy also acknowledged the structural barriers of poverty, stigma and discrimination and their impact in driving the epidemic, with specific recommendations for interventions directed towards those most vulnerable- for example, young gay men (NASC, 2000). In 2011, HIV was made a notifiable illness by Statutory Instrument 452 following recommendations from the National AIDS Strategy Committee. This changed from a previous voluntary case based system of reporting. By this time there were three adult infectious disease clinics and one paediatric ID unit in Dublin. Outside of the capital there are ID clinics in Cork, Limerick and Galway.

In 2011, at the height of the recession that followed the 2008 economic crash, a new Fine Gael/Labour coalition was elected and a new programme for government, emphasising reform of public services, was implemented. During this time period the overall health budget for the country was cut by 22% (Burke, Thomas, Barry, & Keegan, 2014; HSE, 2013). The NASC ceased to function or meet from 2012 and responsibility for HIV policy and governance was transferred in effect to the Crisis Pregnancy Agency, which was re-named the Sexual Health and Crisis Pregnancy Programme (SHCPP). In 2015, the government published the first National Sexual Health Strategy (NSHS), a comprehensive document outlining goals and objectives for the delivery of sexual health services, sexual health promotion and prevention. The strategy comes under the existing Healthy Ireland governance structures and responsibility for implementing the policy lies with the SHCCP, which is part of the Health and Well-being division of the HSE. As part of this strategy a National Clinical Lead and a National Programme Lead were appointed. The function of the clinical lead is to 'ensure standardised and effective sexual health services' and the function

⁷ 10-15% of patients at Beaumont and the Mater were from outside the greater Dublin area (NASC, 2000, p. 57)

of the programme lead is to develop an implementation plan and coordinate actions to implement policy (DOH, 2015, p. 20). The Department for Health has responsibility for oversight and monitoring.

The NSHS outlines three main goals:

Goal 1- Sexual health promotion, education and prevention: Everyone living in Ireland will receive comprehensive and age-appropriate sexual health education and/or information and will have access to appropriate prevention and promotion services.

Goal 2- Sexual health services: Equitable, accessible and high quality sexual health services that are targeted and tailored to need will be available to everyone.

Goal 3- Sexual health intelligence: Robust and high quality sexual health information will be generated to underpin policy, practice, service planning and strategic monitoring

(DOH, 2015, pp. 17-18).

A review of the implementation of the NSHS is currently underway and the SHCCP is engaged at present in conducting several evaluations of services and programmes. These reports are not yet available however, and, as such, it is difficult to give a precise outline of the activities and achievements of the programme (Deely, 2018). Nonetheless, a number of actions have been taken that have specific relevance to HIV, including the development and implementation of clinical practice guidelines for HIV testing and screening and an audit of HIV testing, use of antiretroviral therapy for prevention and STI testing and management (HSE, 2017). In addition, a mapping and needs assessment of STI services has been undertaken and a multisectoral working group on PrEP was convened and is to make recommendations to the NSHS implementation group⁸ (HPSC, 2017a).

AIDS, culture and the media- the discursive construction of HIV

In exploring AIDS as metaphor, Susan Sontag (1988) places AIDS within the context of plagues as a cultural phenomenon which has historically played on people's fears of

⁸ PrEP has been available to purchase in Ireland since December 2017.

Otherness. Sontag outlines how plagues, as a 'mythological menace,' have been exploited by those with particular ideological, religious or social agendas as proof of divine punishment for collective and individual moral transgressions (Sontag, 1988, p. 148). AIDS was no different. Given the initial association of the illness with gay men, much of the early coverage of AIDS characterised the epidemic as a 'gay plague' (Treichler, 1987; Watney, 1997). Emerging at a time when the world was becoming ever more inter-connected and the forces of globalisation and free-market capitalism were re-shaping societies, AIDS was the first pandemic in human history to reach a global audience via mass media. The ascendancy of the New Right embodied by Ronald Reagan and Margaret Thatcher had re-invigorated a social conservatism which, aligned with the Christian Right, endorsed a potent anti-gay message. The media, particularly the tabloid press, were eager to capitalise on AIDS to further this renewed ideological agenda. Roy Greenslade, assistant features editor at the Sun newspaper in the UK from 1981 to 1986 recalled that among executives at the Sun 'the consensus that informed the debate, such as it was, was that all homosexuals are perverts. Flowing from that, AIDS appeared to be just desserts for being involved in deviant sexual behaviour' (Garfield, 1995, p. 44-45).

While the media certainly inflamed anti-gay sentiment with its coverage, it was also reflective of a social and cultural environment that was already deeply suspicious, if not openly hostile, to gay men and women (Watney, 1997). The American Psychological Association (APA) had only removed homosexuality from DSM-II in 1973 and despite the increased visibility of gay people as a result of the gay liberation movement, homosexuality was still widely regarded as 'unnatural' (Drescher, 2015). Those working in the fields of medicine and science were not immune to such cultural influences and initial responses to the AIDS crisis by physicians and research scientists reflected this (Treichler, 1999). The use of the term GRID at the outset of the epidemic helped in part to construct future conceptualisations of the illness as a disease that was intrinsically linked to gayness. This was reinforced by early medical speculation that AIDS was caused by something particular to gay life-styles (Greene, 2007). Indeed, even after it had been established that a pathogen was the cause of the disease, scientific and medical perspectives on AIDS in many quarters were still inflected with a culturally embedded homophobia.

A now infamous editorial by John Langone in the popular science magazine *Discover* in 1985 is emblematic of the sort of cultural bias against gays that was often brought to bear on scientific thinking about AIDS (Casselmann, 2005). The editorial titled 'AIDS: The Latest Scientific Facts' claimed that women were anatomically precluded from becoming infected with HIV because female genitalia, described as 'the rugged vagina,' rendered women less biologically vulnerable to acquiring the virus that caused AIDS (quoted in Treichler, 1999, p. 18). Against 'the rugged vagina' he contrasted the 'vulnerable anus,' claiming that rectal cells were 'easily invaded.' Ultimately the piece identified anal sex as 'the essential element in the AIDS story' (Casselmann, 2005), asserting that 'AIDS...is now and is likely to remain-largely the fatal price one can pay for anal intercourse' (quoted in Treichler, 1999, p. 18). Twenty years after its publication, in an article that omitted some of the more eyebrow raising statements in the piece, the magazine acknowledged the error it had made. It claimed the editorial was based on interviews with 'more than a dozen leading epidemiologists in the United States, Britain, and France' and stated that Langone's position reflected 'the latest scientific thinking at the time and cultural biases' (Casselmann, 2005).

Early accounts of AIDS such as this are indicative of how even the seemingly value-free pursuit of scientific inquiry may be compromised by underlying cultural and ideological biases. As those such as Treichler (1999) have argued, this points to the 'circular relation between truth, the systems of power that produce and sustain it, and the effects of power that it induces and that it in turn reconfigures' (1999, p. 139). A consequence of this is the formation of 'common sense' assumptions that soon become so deeply embedded in the way we think and talk about things that we regard them as almost a priori truths. Treichler (1999) further asserts:

Truth in this sense, is already power: we can forget the fight for or against a particular truth and instead interrogate the rules at work in a society that distinguishes "true" representations from "false" ones. Media accounts of AIDS conform to such regimes, they come to seem familiar, true, because they simultaneously reinforce prior representations and prepare us for similar representations to come (p. 139).

Almost four decades since the AIDS crisis began, there is by now a wealth of prior representations. The vast coverage of AIDS has produced a multitude of discourses that have inscribed AIDS into the collective cultural memory. By means of this discursive palimpsest effect, the HIV positive body has acquired a symbolic significance, becoming the object through which broader societal fears and anxieties about sex, sexuality and issues of morality and social order are mediated and negotiated.

Understandings of HIV as a socio-political, cultural and linguistic construct have implications, however, that go beyond academic or philosophical inquiry. Language as a symbolic and a structuring instrument has the power to mould a subjective reality. As a discursive construction, HIV offers a potent example of the potential for rupture between the subjective reality that is constituted through language and the lived experience of those living with or affected by HIV. This can have tangible implications for people living with HIV in the way in which erroneous attitudes and beliefs about HIV are reproduced and reinforced. It is only by interrogating such ruptures that it becomes possible to ‘understand AIDS dual life as both a material and a linguistic reality...and formulate intelligent interventions’ (Treichler, 1999, p. 18).

Rationale, Research Questions and Aims

Given the consistent emphasis placed by UNAIDS, among others, on the vital need to address stigma as part of the response, this study comes at a timely moment (UNAIDS, 2007, 2010b, 2014b, 2018). In addition to the dramatic increase in new infections, there is a considerable dearth of research on HIV-related stigma in Ireland. Indeed, this is the first study of its kind in Ireland to conduct in-depth qualitative interviews with people living with HIV on diverse stigma experiences across a mix of cohorts and the first to explore PLHIV’s experiences of stigma in a variety of health-care settings. Furthermore, it is the first study in Ireland to investigate the ways in which culture and discourse are involved in reproducing and reinforcing HIV-related stigma. Such information, accompanied by a deepened understanding of the mechanisms, effects and outcomes of stigma, is crucial for researchers, policy-makers and HCPs to better design and inform stigma-reduction interventions, policies and practices in order to respond to the HIV epidemic.

The research questions underpinning this research are thus:

- 1) What discourses exist in relation to press coverage of HIV in Ireland today and how do the print media frame people living with HIV?
- 2) How do these discourses frame understandings of HIV and the nature of the HIV epidemic in the Irish context?
- 3) How do these discourses mediate reported stigma experiences?

The aims of the research are thus:

- 1) To identify and analyse the dominant discourses of HIV that exist in the print media in Ireland.
- 2) To investigate how discourses of HIV are negotiated, internalised and/or resisted by PLHIV.
- 3) To identify the specific contexts in which stigma is experienced by PLHIV.

Structure of thesis and outline of chapters

Including this chapter, the thesis is divided into six chapters in total. The chapter that follows this one reviews the literature relevant to the study. This includes an overview of HIV-related stigma, the existing studies that have been conducted in Ireland specifically, an examination of conceptual frameworks for stigma and an exposition of the conceptual and theoretical framework guiding and informing analysis.

In Chapter Three I lay out the methodological approach taken, covering research design, participant recruitment, data collection, choice of methods used and analytical steps and procedures. In addition I discuss some of the strengths and limitations of the approaches taken.

Chapter Four sets out the findings of the analysis of the newspaper data, looking at how discourses of HIV in the print media circumscribe subject positions for PLHIV and how the epidemic in the Irish context is dominantly framed.

Chapter Five is divided into two sections to explore the analysis and results of the interviews. The first section looks at context specific experiences of stigma and the second section looks at stigma experiences by placing them within the conceptual framework that was developed as part of the literature review and further developed through analysis of the interview data.

Chapter Six discusses the analysis and results, comparing findings with other studies and situating the discussion within the theoretical and analytical frameworks laid out in Chapter Two. Discussion centres on the mechanisms, impact and outcomes of stigma, as well as analysing factors involved in the on-going HIV epidemic in Ireland.

Conclusion

In this preliminary chapter I have set the background and context to the study. As a prelude to the statement of the study rationale, aims and research questions, I have given an account of the epidemiology of HIV in Ireland, a brief history of the emergence of AIDS, early political responses to the disease, an overview of the policy and legal frameworks that govern the management of HIV in Ireland and a short introduction to the relationship of AIDS and the media. The following chapter will lay out in greater detail the some of the theoretical frameworks that inform this thesis, as well as reviewing the extant literature on HIV-related stigma and stigma more broadly.

Chapter Two: Review of the literature and theoretical frameworks

Introduction

In this chapter I review the literature both on HIV-related stigma specifically and stigma more broadly, in addition to providing an overview of the theories on discourse, power and society that informed the analysis of the data gathered for this research. Firstly I provide an overview of HIV-related stigma, outlining the effects of stigma on the health and well-being of people living with HIV (PLHIV). Next I give an account of the existing stigma studies that have been conducted in Ireland and identify the gaps in knowledge around stigma in the Irish context. Following this I review the literature on stigma with specific reference to the conceptual frameworks and approaches that have been employed in studying stigma over the past 30 years. The evolution of scholarship on stigma is further explored in the sub-section titled 'Paradigm Shift,' to show how stigma scholars have more recently incorporated a structural as well as a symbolic dimension to the conceptualisation of stigma.

Increased understanding of stigma has shown how it manifests in discrete ways and these are examined in the sub-section on 'Stigma Mechanisms.' Following this, I discuss the critical cultural turn that has emerged in public health scholarship over the past 30 years and how this has prompted a closer look at the role of discourse, the media and culture in shaping understandings of health. This leads to an exposition on the theories of discourse and power that inform the theoretical underpinnings of this research. Specifically I draw upon the work of Pierre Bourdieu and Michel Foucault and, to a lesser extent, the writings of Louis Althusser, Judith Butler, Ernesto Laclau and Slavoj Zizek. Finally, I articulate my understanding of stigma and my approach to analysis, integrating the extant scholarship and conceptual frameworks for stigma with the theories of discourse, power and society previously elaborated upon.

HIV-related stigma- an overview

Since the advent of antiretroviral (ARV) therapy in the mid-1990s, HIV has become a life-long manageable condition rather than the terminal illness it once was. In the intervening years, improvements both to existing medical therapies and the knowledge base mean people living with HIV (PLHIV) now have a life-span approaching that of those without

the virus and indeed are more likely to die from a non-AIDS illness (Hogg, 2013; May et al., 2014; Samji et al., 2013; Weber et al., 2013). In spite of such welcome changes stigma remains a widespread and almost intractable problem that negatively impacts on prevention efforts and treatment of HIV (Brickley, 2007; Carr & Gramling, 2004; Heijnders, 2006; Pachankis et al., 2015; Sharp, 2010; UNAIDS, 2014b). HIV-related stigma is, for example, associated with decreased rates of testing and higher life-time risk of acquiring HIV, whilst stereotypes about HIV are known to decrease perceptions of risk (Earnshaw, Smith, Chaudoir, Lee, & Copenhaver, 2012; Karim et al., 2008; Pitpitan et al., 2012). Adherence to ARV medication is also negatively affected by HIV-related stigma, resulting in adverse health outcomes for PLHIV as well as having implications for onward transmission of the virus (Dlamini et al., 2009; Katz et al., 2013; Kingori et al., 2012; Konkle-Parker, Erlen, & Dubbert, 2008; Kumarasamy et al., 2005; Murray et al., 2009; Sabin et al., 2008). Experiences of stigma further contribute to adverse mental health outcomes for PLHIV, as stigma is significantly associated with higher levels of PTSD, depression and suicidal ideation across all age-groups and cohorts (Bennett, Hersh, Herres, & Foster, 2015; Breet, Kagee, & Seedat, 2014; Ferlatte, Salway, Oliffe, & Trussler, 2017; Martin & Kagee, 2011; Murphy, Garrido-Hernansaiz, Mulcahy, & Hevey, 2018; Neigh, Rhodes, Valdez, & Jovanovic, 2016; Stutterheim et al., 2011; Stutterheim et al., 2009; Turan et al., 2017).

In addition to health specific issues, the stigma associated with HIV can have an adverse impact upon other aspects of life, with PLHIV reporting higher levels of social exclusion, loneliness and lower levels of quality of life (Fekete, Williams, & Skinta, 2018; Logie et al., 2018; Nobre, Pereira, Roine, Sutinen, & Sintonen, 2018). This is especially the case for those that experience intersecting stigmas related to gender identity, sexual orientation and race (Logie et al., 2018; Slater et al., 2013). Indeed for some PLHIV it is stigma, rather than HIV itself, that has the most negative impact upon their quality of life of (Holzemer et al., 2009).

Instances where HIV status can constrain life choices are apparent with employment and travel. Access to employment can be affected by a person's HIV status, with many employers reluctant to hire a person they knew was HIV positive (Annequin, Lert, Spire, & Dray-Spira, 2016; Annequin, Lert, Spire, Dray-Spira, & Grp, 2015; Barrington, Acevedo, Donastorg, Perez, & Kerrigan, 2017; Corrigan & Fong, 2014; Corrigan, Tsang, Shi, Lam, &

Larson, 2010; Liu, Canada, Shi, & Corrigan, 2012; Pena Longobardo & Oliva-Moreno, 2018; Rao, Angell, Lam, & Corrigan, 2008). This is problematic, given that secure employment has been linked to higher quality of life, adherence to medication and improved health outcomes generally for PLHIV (Degroote, Vogelaers, & Vandijck, 2014; Nachega et al., 2015). The freedom to live and work in certain places is also limited by HIV status, with countries such as Singapore, Jordan, Qatar and the UAE still imposing complete travel bans (hivtravel.org). Moreover, criminalisation of transmission laws exist still in many countries, with significant prosecutions of people living with HIV in Canada, the USA, the UK and Germany, among others (Hernandez, 2013; Mykhalovskiy, 2011, 2015). In the United States in particular, prosecutions have occurred against HIV-positive individuals even where transmission of the virus did not occur, essentially criminalising the sexual expression of individuals living with HIV (see HIVjusticenetwork.net). Meanwhile, in 2018 in Ireland, the first prosecution for transmission of HIV resulted in a prison sentence of ten years for the convicted individual (Nic Ardghail, 2018).

Stigma in the Irish context- Existing studies and gaps in knowledge

In 2008, as part of the government-funded 'Stamp Out Stigma' campaign, two surveys were conducted to assess attitudes, knowledge and beliefs of the general public and, separately, PLHIV's experiences of stigma and discrimination. The final report (SOS, 2008) found that people with HIV are the third most likely to suffer societal discrimination in Ireland, after drug-users and Travellers. This report illustrated the prevalence of misunderstandings about HIV transmission among Irish society. For example, almost 25% of respondents in the general public survey said they would have concerns about eating a meal prepared by a person living with HIV. The consequences of such misunderstandings were clearly manifest in the reported stigma experiences of PLHIV surveyed, with 49% reporting having experienced discrimination by friends, 37% by a doctor and 34% by a dentist. Additionally, 28% of PLHIV had experienced discrimination from their family as a result of their HIV status, while 43% had experienced stigma in the community. Lesser levels of discrimination were reported in the workplace, with one fifth of respondents reporting issues. This was attributed, however, to non-disclosure of status. Overall, the report highlighted that stigma and discrimination were a problem for PLHIV in all walks of life, including within the family, in healthcare, the education system and employment.

The primary recommendation of this report was for research to be conducted that would 'separate out and examine experiences' in order to better 'understand the impact of HIV-related stigma and discrimination on the population of PLHIV' (2008, p. 19). This echoes the recommendations of the 2008 HIV/AIDS Education and Prevention Plan that was commissioned by the sub-committee for Education and Prevention of the National AIDS Strategy Committee (NASC). This plan similarly called for research to be conducted 'to explore the needs of HIV positive people in the Irish context,' since 'qualitative research is needed to complement existing surveillance data and programme evaluation findings' (Barry & O'Higgins, 2008, p. 53 & 37).

In spite of such calls, a similar dual survey conducted by HIV Ireland (Ireland, 2017a, 2017b) nearly ten years later showed a comparable picture. Amongst PLHIV (n=168), 30% reported feeling stigmatised by family, 27% by health professionals and 23% by friends (Ireland, 2017a). In addition, over half stated they were offended by language used about HIV on social media and 33% by language used in the print media, with particular exception taken to the terms 'clean' and 'dirty' (Ireland, 2017a, p. 7). More saliently perhaps, anticipated or perceived stigma was reported to be relatively high, with 61% having not disclosed their status at some point for fear of being judged or treated differently (Ireland, 2017b).

Amongst the public (n=1013), this survey revealed a troubling deficit in knowledge around transmission of HIV, with 70% believing HIV can be transmitted via biting or spitting and 24% believing transmission via kissing was possible (Ireland, 2017b). This knowledge deficit was most pronounced among young people, with 20% of 18-24 year olds believing that transmission via public toilet seat was possible, compared to 10% of the overall sample. Almost the same proportion of young people (19%) believed that HIV could be transmitted via coughing or sneezing (Ireland, 2017b). Of the total sample, 17% agreed they would not have sympathy for PLHIV who acquired infection via unprotected sex (HIV in Ireland, 2017a, p. 6).

Peer reviewed studies on stigma and HIV in the Irish context are sparse, with only seven identified, undertaken between 2001 and 2018. Of these, four were qualitative and three were quantitative. Four studies had mixed cohorts and three were centred on MSM.

Research on HIV-related stigma in Ireland has tended to centre on the impact of stigma at the level of the individual, with the effects of internalised stigma on mental health and disclosure experiences the topics given most consideration (Foreman & Ní Rathaille, 2016; France et al., 2015; Murphy & Hevey, 2013; Murphy et al., 2018; Murphy, Hevey, O'Dea, Ní Rathaille, & Mulcahy, 2015b; Murphy, Hevey, O'Dea, Ní Rathaille, & Mulcahy, 2015a; Surlis & Hyde, 2001).

The core-beliefs related to internalised or 'self-stigma' was the topic of one qualitative study, which found that participants became most distressed or emotional when discussing the impact of stigma on their sense of self, rather than how they were viewed by others (France et al., 2015). This would seem to corroborate quantitative research that found that internalised stigma tends to be associated with adverse mental health outcomes (Murphy & Hevey, 2013; Murphy et al., 2018). Internalised stigma- in the form of a rejection of a HIV positive identity and holding stigmatising or stereotyped beliefs about other HIV positive gay men- was furthermore implicated in non-disclosure in a study of men who have sex with men (MSM) in the context of casual sexual encounters (Murphy et al., 2015a).

Difficulties around disclosure were a common theme in many HIV-related stigma studies conducted in Ireland. Anticipated or perceived stigma were commonly cited as factors involved in such difficulties, with disclosure decisions often mediated by expectations of differential treatment and fears of negative reaction (Foreman & Ní Rathaille, 2016; France et al., 2015; Murphy et al., 2015a; Murphy et al., 2015b). Worries about sexual and social exclusion, for example, were identified as a motivating factor for non-disclosure to casual sexual partners by men who have sex with men (Murphy, et al., 2015a).

Some evidence for stigma intersectionality was apparent from a couple of studies (Murphy & Hevey, 2013; Surlis & Hyde, 2001). Surlis and Hyde (2001), for example found that the experiences of HIV positive patients in a hospital setting varied depending on mode of transmission, with people who inject drugs reporting greater levels of enacted stigma than other cohorts. Murphy and Hevey (2013) reported that higher levels of stigma resilience were observed in those that acquired HIV through heterosexual transmission than

homosexual transmission. Similarly, one study with a majority heterosexual cohort (France et al., 2015) found that community involvement was an important mechanism for coping with stigma. In contrast Murphy et al., (2015b) found that closer community attachment was associated with lower levels of disclosure, with the authors suggesting that this may be due to increased exposure to stigmatising attitudes towards HIV among peers. The prevalence of HIV-related stigma in the gay community was also further remarked upon in another study, with the authors noting the relative frequency with which they encountered ‘anachronistic discourses of depravity and infectiousness’ among interviewees (Murphy et al., 2015b).

Coping strategies, stigma resistance and stigma resilience were notable features to arise in a number of the studies (Foreman & Ní Rathaille, 2016; France et al., 2015; Murphy & Hevey, 2013; Murphy et al., 2015a). Peer support was identified as an important mechanism in coping and resisting stigma, especially in the context of a lack of formal support structures and counselling services within clinical settings (Foreman & Ní Rathaille, 2016; France et al., 2015).

In sum, research on HIV-related stigma in Ireland has been limited and has tended to focus largely on internalised stigma, issues of disclosure and mental health. Consequently, two main gaps in knowledge arise. Firstly, while a couple of studies have explored HIV-related stigma in specific contexts- such as disclosure to sexual partners and in a hospital setting- these have been limited to a singular focus (Murphy et al., 2015a; Surlis & Hyde, 2001). As such, few have investigated the ways in which stigma affects specific aspects of people’s lives- at home, in the community, in healthcare settings, and in work, for example. Indeed, the only study to have explored experiences of stigma in a healthcare setting was conducted seventeen years ago and thus may have limited relevance today (Surlis & Hyde, 2001). This limits the ability to design and implement interventions to reduce stigma. Secondly, studies on HIV-related stigma in Ireland have largely been limited to the exploration of stigma experiences at the individual level and as such have omitted analysis of the broader socio-cultural and structural influences in the reproduction of stigma. Such an analysis supported by empirical evidence would be useful for policy-makers and HCPs in designing and planning services.

Approaches to the study of stigma- perspectives and conceptual frameworks

Within the literature on HIV-related stigma and the phenomenon of stigma more broadly, the breadth and variability of definitions of stigma is consistently remarked upon (Earnshaw & Chaudoir, 2009; Link & Phelan, 2001; Logie & Gadalla, 2009; Parker & Aggleton, 2003). This is hardly surprising given the interest in this subject from disparate fields and disciplines, and the specific and distinct approaches undertaken by researchers in those fields to conceptualise, understand and/or measure what is a complex and multi-faceted social phenomenon. Although the concept of stigma is not new, scholarly interest in stigma as a social process that has a significant impact on health, well-being and social justice has grown considerably over the past three decades (Gilmore & Somerville, 1994; Hatzenbuehler et al., 2014; Link & Phelan, 2014; Link & Phelan, 2001; Parker & Aggleton, 2003; Scambler, 2006, 2009; Weiss, Ramakrishna, & Somma, 2006).

In much of the early work on HIV related stigma, specific conceptual definitions of stigma are often not provided (Herek, 1999; Herek, 2002; see also Mahajan et al., 2008) Rather, Goffman's (1963) definition of stigma is without doubt the one most frequently reached for and is certainly the most commonly cited in the literature in general (France et al., 2015; Smith, Rossetto, & Peterson, 2008; Surlis & Hyde, 2001; Weiss et al., 2006). Within this, stigma is explained through the characterisation of the stigmatised individual as having a spoiled identity. This spoiled identity is a result of the assignation of an attribute that is 'deeply discrediting' (Goffman, 1963, p. 13), which is used to explain 'his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those of social class.' (Goffman, 1963, p. 13-15). Goffman's (1963) definition of stigma was situated within the theoretical framework of symbolic interactionism which underscores the constitutive effects of micro-level interactions in the construction of self-hood, and which uses the allegory of 'dramaturgy' to explain how individuals 'perform,' the subjectivities they assumed (see Scambler, 2009).

Goffman (1963) contended that 'a language of relationships, not attributes, is really needed' to describe stigma (p. 13) and that it is not necessary to possess a negative attribute to be negatively affected by it. Indeed Goffman (1963) insists that negative or positive assignations to attributes are mutable- an attribute that may stigmatise one

individual 'can confirm the usualness of another' (p. 13). This assertion of stigmatisation by association is an important one in the context of HIV-related stigma where some cohorts historically have been stigmatised for their perceived association and increased susceptibility to HIV (Shilts, 1988). Certainly, the four H's identified as significant risk groups- heroin addicts, homosexuals, Haitians and haemophiliacs- were routinely viewed with a high degree of fear and suspicion during the early days of the epidemic (Feldman & Bayer, 1999; Shilts, 1988).

While the ubiquity of Goffman's (1963) framework is undeniable, it has nonetheless drawn critique for its singular emphasis on the effects of stigma on micro- level interactions rather than emphasising the broader structural and cultural factors upon which stigma is contingent (Scambler, 2006). Additional criticism has centred on the shifting of responsibility upon the individual whose task it is to manage their 'spoiled identity' (Link & Phelan, 2001, Parker et al., 2003). Furthermore, others have drawn attention to Goffman's (1963) use of anachronistic language, the broad range of phenomena to which his definition applies and the limited cross-cultural applicability, as shortcomings which may curtail its usefulness as a conceptual framework for work on health-related stigmas (Weiss et al., 2006). Nevertheless, Goffman's work was extremely impactful, not least of all in catalysing and furthering interest in the subject in the fields of sociology and social psychology. According to Scheff (2003), one of Goffman's great achievements lay in providing 'a vocabulary for describing the micro-world' (Scheff, 2003, p. 52).

A former student of Goffman's, Scheff (1974) applied the underlying principles of Goffman's (1963) work on stigma to the study of mental illness. The Labelling Theory of Mental Illness (Scheff, 1974) asserts that mental illness is, in large part, socially constructed. This occurs when labels of mental illness are applied to people who exhibit behaviours outside of cultural and social norms. Labelled individuals draw on extant stereotypes and culturally dominant paradigms for what it means to be 'mentally ill,' construct an identity around this and 'perform' their label. This cognitive process, accordingly, is reinforced and mediated by micro level interactions between the labelled individual and others in society. The responses of others to the labelled individual affect and inform future behaviour so that the application of a label of mental illness becomes a self-fulfilling prophecy and can lead to chronic mental illness.

While Labelling Theory has been criticised for over-stating the constitutive effects of the labelling process in directly producing mental illness, it was nonetheless drawn upon subsequently by Link et al. (1989) to further elaborate the impact of stigma in exacerbating mental illness and, more importantly perhaps, the effects stigma has on eliciting certain behaviours in stigmatised individuals (Link et al., 1989; see also Scambler, 2009). Modified Labelling Theory articulates that upon diagnosis with mental illness, individuals internalise the negative beliefs and attitudes towards mental illness that they have acquired as a result of socialisation (Link et al., 1989). This cognitive process commonly triggers the stigmatised individual to engage in a number of coping mechanisms, including withdrawing from certain social interactions, concealment of their condition and any instances of hospitalisation, and attempts to covertly educate others about their condition. The anticipation of a negative reaction will furthermore cause the stigmatised individual to engage in avoidance strategies, such as not seeking a promotion-for fear of a medical exam or asking for a date. Such strategies may often further isolate the individual and damage their self-esteem, in such a way that the person's previously held negative beliefs about their illness or what it means to live with that illness can adversely impact upon health and increase vulnerability to future mental health problems (Link et al., 1989).

Paradigm shift

Increased medical-sociological scholarship on stigma in recent years has seen a move away from the socio-cognitive paradigms for stigma favoured by social psychologists towards approaches that integrate a structural as well as a symbolic dimension (see Hatzenbuehler & Link, 2014). Link and Phelan's (2001) conceptual model of stigma for instance, shifted the paradigm to focus less on the constitutive effects of individual cognitive processes catalysed by micro level interactions towards a framework that emphasises the effects of relations of power. This conceptualisation acknowledges the effects of stigma on reducing life chances of affected individuals and the function this serves in reproducing an asymmetric social order (see Parker & Aggleton, 2003). Link and Phelan (2001) identified five inter-related components that must be present for stigma to occur: 1) distinguishing and labelling of difference; 2) linking of labelled individuals to negative stereotypes via dominant cultural beliefs; 3) 'Othering' of labelled individuals and the creation of an 'us' and 'them' dichotomy; 4) labelled individuals must experience loss of status and discrimination

that negatively affect outcomes; 5) the process is contingent on access to social, political and economic power. Thus it is argued that stigma becomes manifest 'when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold' (Link & Phelan, 2001, p. 367).

It is not sufficient, therefore, that a label and a negative stereotype are assigned. For instance, although politicians, bankers and lawyers are groups that are routinely labelled and negatively stereotyped, they are not stigmatised because: 1) membership of these groups does not confer a loss of status that would lead to social exclusion or significantly endanger membership of society in general; 2) they are not discriminated against in a way that affects the distribution of their life chances; and 3) they hold access to power and to institutions of power that confer privilege and advantage. In contrast, membership of a stigmatised group has been shown to reduce a person's interpersonal influence, and specifically in relation to HIV infection has been shown to have negative outcomes for physical and mental health and is furthermore associated with low social support, social exclusion, lower levels of income and increased mortality (Chadborn et al., 2006; Hatzenbuehler et al., 2014; Katz et al., 2013; Logie & Gadalla, 2009; Logie, James, Tharao, & Loutfy, 2013; Phelan, Lucas, Ridgeway, & Taylor, 2014; Rabkin, 2008; Stutterheim et al., 2011).

The shift towards an integrated symbolic-structural approach has had a particularly significant impact on the study of HIV-related stigma (Cook, Purdie-Vaughns, Meyer, & Busch, 2014; Farmer, Nizeye, Stulac, & Keshavjee, 2006; Logie et al., 2018; Miller, Varni, Solomon, DeSarno, & Bunn, 2016; Misir, 2013; Parker & Aggleton, 2003; UNAIDS, 2010a). Parker and Aggleton (2003) drew on the work of Bourdieu (1977) and Foucault (1976), to generate a conceptual framework specifically for HIV and AIDS-related stigma and discrimination. This framework critiqued existing approaches to HIV-related stigma and argued for the need to reframe how stigma and discrimination are understood in order 'to conceptualize them as social processes that can only be understood in relation to broader notions of power and domination'(Parker & Aggleton, 2003, p. 16). This model affirms the strategic deployment of stigma and the concepts of symbolic violence and cultural hegemony as being fundamentally implicated in the reproduction and legitimisation of social inequality. Indeed they state that it is:

at the point of intersection between culture, power and difference...that it becomes possible to understand stigma and stigmatization not merely as an isolated phenomenon, or expressions of individual or of cultural values, but as central to the constitution of the social order (Parker & Aggleton, 2003, p. 17).

This symbolic-structural approach highlights the link between the symbolic violence exerted upon stigmatised and marginalised individuals via cultural apparatus- for example, language, art, religion, political ideology- and the structural violence- such as, policies, systems of power, institutional practices and legal frameworks- that is inflicted through embedded systems of power, which determine access to resources, legal recourse, political power, and essential services such as health and education (Bourdieu, 1991; Farmer et al., 2006; Link & Phelan, 2014; Parker & Aggleton, 2003).

This integrated symbolic-structural approach has gained considerable traction among researchers interested in the relationship between health and stigma, leading to the articulation of the relatively new concept of structural stigma (Angermeyer, Matschinger, Link, & Schomerus, 2014; Farmer et al., 2006; Hatzenbuehler, 2016; Hatzenbuehler et al., 2014; Hatzenbuehler & Link, 2014; Lukachko, Hatzenbuehler, & Keyes, 2014; Miller, Grover, Bunn, & Solomon, 2011; Miller et al., 2016; Pachankis et al., 2015). Structural stigma has been defined as encompassing a set of socio-cultural norms and practices, and institutional policies that implicitly disadvantage the stigmatised (Hatzenbuehler & Link, 2014). Put simply, 'stigma has affected the structure around the person, leading the person to be exposed to a host of untoward circumstances' (Link & Phelan, 2001, p. 373).

Link and Phelan (2014) have expanded on the structural stigma concept to articulate the theory of Stigma Power. Similar to Parker and Aggleton's conceptualisation (2003), the Stigma Power theory (Link & Phelan, 2014) draws on the Bourdieuan concept of symbolic power as a power that is exercised unconsciously and which is tacitly accepted as the natural order of things or the way of the world (Bourdieu, 1991). Link and Phelan (2014) argue that stigma functions to maintain a hierarchical social order by acting to keep 'other people down, in or away' (Link & Phelan, 2014, p. 24). Symbolic power, they argue, provides a conceptual rationale for the manifestation of 'internalised' or 'self-stigma,' in accounting for the way in which stigmatised individuals 'misrecognise' and thus endorse the legitimacy

of dominant cultural norms of shame and blame (see also Scambler, 2009; Scambler & Paoli, 2008).

Stigma mechanisms

In addition to conceptualisations of structural stigma, Link and Phelan (2014) distinguish two other distinct stigma mechanisms in which discrimination can operate on a largely hidden basis. Firstly, interactional stigma, which affects the way stigmatisers interact with and behave around the stigmatised and in turn impact on the way in which the stigmatised person responds; and secondly, discrimination operating through the stigmatised person- referring to the way in which a stigmatised person is cognisant of their stigmatised status and thus self-regulates and modifies their behaviour accordingly (Link & Phelan, 2014).

These discrete stigma mechanisms have also been articulated and defined in other ways in the literature (Earnshaw & Chaudoir, 2009; Emler et al., 2015; Peltzer & Ramlagan, 2011; Scambler & Hopkins, 1986; Turan et al., 2017). Scambler and Hopkins (1986) articulate the differences between enacted and felt stigma, whereby the former refers to explicit discrimination on the grounds of difference and social unacceptability, and the latter refers to a sense of shame and the fear or expectation of overt discrimination. Scambler and Hopkins (1986) found that felt rather than enacted stigma had a more disruptive effect on a stigmatised person's life, due to the anxiety that resulted from concealment of the stigmatising condition (Link et al., 1989; Link & Phelan, 2001; Murphy et al., 2015a; Scambler & Hopkins, 1986).

More recently, felt stigma has been articulated as anticipated or perceived stigma (Earnshaw & Chaudoir, 2009; Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Peltzer & Ramlagan, 2011; Turan et al., 2017). Earnshaw and Chaudoir's (2009) framework, for example, delineates three types of stigma mechanisms that can affect PLHIV- enacted, anticipated and internalised. Enacted and anticipated stigma broadly correspond to Scambler and Hopkins' (1986) definitions of enacted and felt stigma respectively, whilst internalised stigma is defined as the endorsement of negative beliefs about HIV in relation to the self (Earnshaw & Chaudoir, 2009).

Enacted, anticipated and internalised stigma overlap, coalesce and interact dynamically to inform and mediate one another (Chi, Li, Zhao, & Zhao, 2014; Turan et al., 2017). Each of these stigma mechanisms may impact on an individual in discrete ways to elicit behavioural, cognitive or affective reactions that can produce negative health outcomes. Enacted and anticipated stigma, for example, may deter individuals from seeking care, engaging with health or support services and impact on adherence to medication, thereby negatively affecting physical health outcomes (Rao et al., 2012; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007; Roberts, 2005; Sanjobo, Frich, & Fretheim, 2008; Turan et al., 2016; Turan et al., 2017). Similarly, as noted earlier, internalised stigma is a strong predictor for adverse mental health outcomes (Fekete et al., 2018; Murphy et al., 2018; Turan et al., 2016).

In sum, interest in the study of stigma and its effect on health outcomes has increased significantly since Goffman (1963). Earlier work on stigma was influenced by symbolic interactionism, leading researchers to focus on socio-cognitive approaches to understanding stigma. In relation to HIV specifically, studies tended to concentrate on the categorisation of PLHIV into distinct groups; the assignation of negative stereotypes to these; emotional responses to HIV and AIDS such as anger towards and fear of PLHIV; discomfort around PLHIV; fear of contagion; and the belief that PLHIV are responsible for and therefore deserving of their illness. These approaches have underscored the role of education in correcting erroneously held beliefs about transmission and casual contact as a means to mitigate the impact of stigma and the support it engenders for punitive laws and policies towards PLHIV (Herek, 2002, 2005).

More recently, a shift in emphasis has led researchers to integrate a structural component to the conceptualisation of stigma, to assert a dialectical relationship between stigma and social structures (Farmer et al., 2006; Miller et al., 2016; Misir, 2013). Such approaches have underscored that stigma is effected at the confluence of socio-cultural norms, relations of power and the ensuing institutional policies and practices which flow from them. This recent paradigm shift has led Scambler (2009) to observe that 'sociological studies of health-related stigma can no longer afford- Goffman like- to neglect the social structural underpinnings of cultural norms and individual choice' (p. 453). While there is a dearth of empirical studies on the relationship between structural stigma and the health

outcomes of PLHIV, this is an emerging area of research that is beginning to generate interest among scholars (Hatzenbuehler, 2016). A recent study by Miller et al. (2016), for example, provides tentative evidence for the relationship between community levels of HIV-related prejudice and the mental and physical well-being of PLHIV in the community.

Lastly, in addition to structural stigma the literature distinguishes between three discrete stigma mechanisms which occur at the micro/interpersonal and individual level-enacted, anticipated, and internalised. Each of these mechanisms can elicit distinct responses at the cognitive, behavioural and affective level from stigmatised individuals and thus result in different outcomes.

The critical cultural turn

Public health scholarship has undergone somewhat of a paradigm shift in the past 30 years to emphasise a broader critical cultural stance that acknowledges the constitutive roles of discourse, culture and socialisation in determining health outcomes (Dutta-Bergman, 2005; Dutta, 2010; Dutta & Basu, 2008; Goldin, 1994; Green & Labonte, 2008; Kleinman, Eisenberg, & Good, 1978; Lupton, 1992, 1994, 1997, 1999b). Central to this approach is challenging taken-for-granted assumptions and advocating for a praxis that seeks to shed light on the structural inequalities that impact patterns of health and illness (Dutta & Basu, 2008; Farmer, 1999; Farmer, Nizeye, Stulac, & Keshavjee, 2006; Green & Labonte, 2008). Moreover, the critical approach includes an advocacy role that actively questions existing orthodoxies that reproduce and maintain asymmetric power relations and give rise to unequal health outcomes (Lupton, 1994; Green & Labonte, 2008). As such, the critical approach ‘...is not a disinterested academic discipline, but one that engages with structures of power to challenge as well as describe them’ (Green & Labonte, 2008, p. 4).

Certainly, paternalistic top-down approaches that emphasise individualistic models of health knowledge and behaviour have been criticised for failing to acknowledge the broader socio-cultural, historical, economic and political forces that shape and influence attitudes to health and illness (Airhihenbuwa & Obregon, 2000; Dutta-Bergman, 2005; Dutta, 2010; Dutta & Basu, 2008; Lupton, 1994; Scambler & Paoli, 2008). As Lupton (1994) has observed, health and illness states are in large part ‘...products of social systems and ideological processes’ (p. 58) and, as such, the medical encounter may be viewed as a site of

struggle that reflects socially embedded inequality. Accordingly, critical public health scholars have argued for a reflexive, interdisciplinary and politically aware scholarship, arguing that ‘...the emancipatory politics of healing are embedded in the capacity of health scholarship to challenge and transform structural violence’ (Dutta, 2010, p. 538; see also Farmer, 1999).

This type of critical cultural theoretical framework has been particularly embraced by researchers and scholars working in the field of HIV prevention and education. In large part, this can be attributed both to the transnational and transcultural nature of the pandemic, and the unparalleled symbolic clout of HIV as a discursive and social construct (see Treichler, 1987). HIV as a social and cultural construct reflects on HIV as something that is conceptualised and understood through representation in the media, popular culture and, indeed, medical and scientific literature (Treichler, 1999). Refracted through these lenses, HIV has acquired multiple meanings- evident in the extremely varied and often contradictory ways in which it has been characterised over the past four decades (Black, 2013; Brown, Chapman, & Lupton, 1996; Lupton, 1992, 1993, 1999a, 1999b; Shilts, 1988; Swain, 2005; Watney, 1997; Wenham, Harris, & Sebar, 2009). Treichler (1987) has remarked on the immense capacity of HIV and AIDS to generate diverse and often conflicting meanings, while the ‘Othering’ effect of much media reporting on HIV and AIDS has been written about extensively (Garfield, 1988; Lupton, 1999a; Persson & Newman, 2008; Ren, Hust, & Zhang, 2014; Sacks, 1996; Shilts, 1988; Watney, 1997).

Print media reporting on such issues is especially relevant in this regard because of the role of print journalism in setting and framing social, political and policy agendas (McCombs & Shaw, 1972; McCombs, Shaw, & Weaver, 2014; Schnell & Callaghan, 2001). In this sense, the media is not just an observer of social and political phenomena, but rather a participant that plays a key function in shaping and constraining political and policy debates (Schnell & Callaghan, 2001). As such, the media act as gatekeepers of political discourse, choosing which topics to cover and furthermore having editorial power over how such topics are framed (Entman, 2007; Weaver, 2007). Indeed, as Schnell and Callaghan (2001) have argued, the growing commercialisation and privatisation of news organisations means that the press has more of a ‘narrative licence to...build story reports around their own interpretive themes’ (2001, p. 184). The media thus have a dual function, serving as a

conduit to disseminate actors' information, but also acting as institutional players in their own right with the power to construct and frame discourse as they see fit (Baumgarten & Grauel, 2009; Schnell & Callaghan, 2001). Consequently, the discourse that is constructed will often be contingent on who has access to the media and institutional/editorial choices about which voices to prioritise (Baumgarten & Grauel, 2009; Schnell & Callaghan, 2001; Weaver, 2007). Such discourses become impactful then in the way in which they come to create meaning, define problems and propose solutions that circulate in the wider social field.

Over the past 40 years, the media has played an increasingly more active role in disseminating information about health and illness (Clarke, Shim, Mamo, Fosket, & Fishman, 2003; Hallin, Brandt, & Briggs, 2013). Moreover, as Hallin et al. (2013) have argued, 'the production and circulation of biomedical knowledge have increasingly moved from what was construed as a private sphere of doctor/patient communication...into the public sphere, where the communicative norms of biomedicine compete and combine with those of marketing, journalism and political debate' (p. 121). Indeed, the media remains the main source of information for lay people about health matters (Gould, Drey, Millar, Wilks, & Chamney, 2009; Redmond, Baer, Clark, Lipsitz, & Hicks, 2010). How health and illness issues are framed by media sources are thus relevant in appreciating how lay knowledge of health matters and policy is constituted and reproduced (Baumgarten & Grauel, 2009; Lupton, 1999b). Many studies have examined how HIV is constructed in the media (Brown et al., 1996; Clarke, Friedman, & Hoffman-Goetz, 2005; Gao et al., 2013; Hamdan, 2011; Lupton, 1992, 1999a, 1999b; Ren et al., 2014). However, considerably fewer have examined how this might be implicated in the stigma process (Bekalu, Eggermont, Ramanadhan, & Viswanath, 2014).

Discourse, power and society

The Enlightenment era ushered in an ontological shift away from prior thinking about the social world in which God and the Sovereign, from whom all authority derived, were placed at the apex of a hierarchical order. In the place of God and the Sovereign, the rational, reasoning individual epitomised by the autonomous Cartesian subject was re-centred as the arbiter of her/his own fate (Cassirer & Gay, 2009). Subsequently, Marxist

thinking challenged this conceptualisation, arguing that forces of capital, power and ideology assumed a determinative role in the formation of the subject and the structuring of the social order. More recently, influenced in no small part by Marxist thought and Freudian psychology, poststructuralist thinkers have re-elaborated on this notion, and the question of subject formation has become a central concern of this branch of philosophy (Butler, Laclau, & Žižek, 2000).

For Louis Althusser (2008) the question of subject formation is contingent on the ideological- that is to say that ideology constructs the social self. Althusser (2008) posited the theory of interpellation, whereby an individual is 'hailed' by ideology, likened in the hypothetical scenario offered of a policeman calling out to an individual on a street, 'Hey you there!' (Althusser, 2008, p. 48). In turning to or responding to this hail, the individual becomes a subject through the recognition both that he was the one who was hailed and that the hailing was directed to him by one invested with the authority to do so. This recognition- or turning towards- Althusser says, presupposes the legitimacy of the law/ideology/power to perform this act, and the duty of the individual to submit and '...align oneself' to it (Butler, 1995, p. 6). Moreover, this is carried out largely unquestioningly, since 'the one addressed is compelled to turn towards the law prior to the possibility of asking a set of critical questions: Who is speaking? Why should I turn around? Why should I accept the terms by which I am hailed' (Butler, 1995, p. 7). It is this givenness of ideology, its indisputable right to call out and to be responded to and the tacit acceptance of this as a normal and proper part of reality that lends ideology its ideological nature. Althusser (2008) elaborates on this point:

The existence of ideology and the hailing, or interpellation, of individuals as subjects is one and the same thing. I might add: what thus seems to take place outside ideology (to be precise, on the street), in reality takes place in ideology. What really takes place in ideology seems therefore to take place outside it. That is why one of the effects of ideology is the practical denegation of the ideological character of ideology by ideology: ideology never says 'I am ideological' (2008, p. 49).

Althusser's (2008) concept of interpellation then may be understood as a largely invisible and self-sustaining process whereby individuals are continuously and automatically

positioned and re-positioned in the socio-symbolic and ideological space via what he termed 'ideological state apparatus'- namely systems of social conditioning including schools, workplaces and other social and cultural institutions. Moreover, interpellation is posited as an unconscious effect that acts on the consciousness of an individual via the discursive and social practices within those institutionalised systems of socialisation.

Interpellation has been critiqued for over emphasising the constitutive effects of ideology on subjects and for its lack of accounting for human agency and capacity for critical engagement with, subversion of, and opposition to ideological practices (Fairclough, 1992a). Nonetheless, Althusser's (2008) exposition on subject formation and the process of interpellation gained purchase among many thinkers and philosophers to form the basis of much subsequent thinking on the interrelationships between power, individuals and society. Following from Althusser, Bourdieu's (1977, 1991) concepts of Habitus and symbolic power may be interpreted as a nuanced re-articulation of how the process of interpellation unfolds. Certainly, his work expands on the idea that subject formation occurs solely via social institutions to offer a more holistic perspective that implicates complex processes of socialisation involving culture, discourse and ritualised somatic practices. Bourdieu (1977) referred to Habitus as '...history turned into nature,' which, like Althusser's characterisation of ideology, must necessarily be denied its character as the incidental inheritance of a particular set of social and power relations in order to be tacitly accepted as simply the way of things and the reality of the world (p. 78). Habitus thus acts as a roadmap, allowing the individual to navigate through the social field in which they find themselves, be it a given society, culture, social grouping or institutional body (Bourdieu, 1977). For this process to function, each established social order must produce '...the naturalization of its own arbitrariness' (Bourdieu, 2001, p. 164). Bourdieu (1977) further asserts then that a dialectical relationship exists between the subject and the objective conditions of its production- that is to say, a correspondence exists between the social structures (hierarchies, gender relations, class) in the field of power and the mental structures (dispositions such as thought patterns for example) of the individual. The homologous nature of these positions thus inscribes on the individual a sense of the possibilities and limitations of their own specific engagement within a given field of power (their position in that social world), in such a way that it appears self-evident, common sense and natural.

This effect Bourdieu (1977) refers to as doxa or 'naturalisation' (see also Fairclough, 1989) and it is achieved by 'securing the misrecognition, and hence the recognition, of the arbitrariness' on which the divisions (sex, class, age, etc.) that exist in the production and reproduction of power relations are based (1977, p. 164).

Bourdieu (1977) further outlines the importance of the symbolic order in securing, legitimating and reinforcing the distinct hierarchies and social structures that are inherent in each field. Drawing on his anthropological research, he gives the example of the practices and rituals involved in the 'social structuring of temporality' (p. 165), directing attention to the ways in which power relations are enacted symbolically across age groups. These occur not in accordance with any biological or physical signs of the passage of time on the human body, but rather through the imposition of socially devised and assigned categories that are expressed via symbolic rite of passage ceremonies. Salient examples include, for instance, the Latin American Quinceañera, Jewish Bar Mitzvah and the Catholic rite of Confirmation; or less formalised markers like clothing, make-up and jewellery that designate a coming-of-age. The importance of these rituals and other symbolic practices lies then in the maintenance and reproduction of a social order that reifies through practice the asymmetrical structuring of society across lines of age, gender and other taxonomies in such a way as to consolidate a set of hegemonic relations and the position of the dominant group.

Foucault- biopower

Where Bourdieu's (1977) insights on subject formation as a result of 'history turned into nature' (p. 78) were extrapolated from the anthropological study of Maghrebi cultures, Foucault's (1976) perspectives on the same were derived from an examination of history itself. From the study of human sexuality, governmentality and the history of medicine, the common thread running through all Foucault's work, is an investigation of the effects of power on human relations and of '...systems of subjection of and by discourse' (Foucault, 1981, p. 64). Foucault (1982) points to three ways in which subject positions are created via processes of objectification of individuals and/or groups of actors. The first he identifies as the modes of academic inquiry and intellectual discipline 'which try to give themselves the status of sciences' (p. 777), such as linguistics (the objectivising of the speaking subject),

economics (the objectivising of the productive subject) or even human biology (the objectivising of the human body). Secondly, he outlines the objectivising of the subject through what he terms 'dividing practices', whereby 'the subject is either divided inside himself or divided from others' (Foucault, 1982, p. 778). Foucault (1984) traces this process throughout history, citing the rise of psychiatry, the asylum, the prison and the pathologisation and stigmatisation of sexuality and 'sexual deviance' in Modern Europe (p. 8). The pathologisation of difference is particularly evident in discursive practices that set apart, for example, women from men, the healthy from the sick, or even within public health discourses that identify 'high risk groups' from the 'general population.' Lastly, Foucault (1984) explores the effects of subject-object formation via the 'domain of sexuality' (p. 778), asserting that 'sex is placed by power in a binary system: licit and illicit, permitted and forbidden' (1976, p. 83).

Foucault (1976) expands on the inter-relationship between discourse, power and sexuality in the 'History of Sexuality,' in which he traces the shift in Western society from a 'Symbolics of blood' to an 'Analytics of sex,' asserting that in the absence of the coercive violence that characterised the exercise of power over life and death by Sovereigns, various discursive regimes have evolved through which power operates via '...the administration of bodies and the calculated management of life' (p. 148 & 140). Sex and the strategic deployment of discursive regimes to regulate, surveil and control it administered through state apparatuses, such as schools, hospitals and asylums played an indispensable role in the exercising of bio-power. Foucault (1976) points to the nineteenth century, when sex became 'the theme of political operations, economic interventions (through incitements to or curbs on procreation), and ideological campaigns for raising standards of morality and responsibility'(p. 146).

The integrity of the social order, with its emphasis on the family as the bedrock upon which it is built; the capitalist economic order, with its dependence on a steady supply of healthy labour; and the moral order, culturally and historically endowed with Christian values were all contingent upon the policing of bodies and the ordering of sex and sexualities within carefully circumscribed boundaries of acceptable behaviour. Notable examples of how this policing of bodies and sexuality has been operationalised through medical and psychiatric discourses include the pathologising of women's sexuality via the

diagnosis of female hysteria and the designation of psychiatric illness to homosexuality- the legacies of which endure to this day (Foucault, 1976). Similarly, Stolberg (2003) notes the convergence of religious and medical discourses on masturbation throughout the seventeenth and early part of the eighteenth century that depicted the 'Crime of Onan' as a threat to the fabric of society, as well as to the moral rectitude and physical well-being of the individual. Dominant cultural views on masturbation at that time erupted into moral panic precisely because 'Onanism' was viewed as "'solitary vice" par excellence' that was deemed 'a veritable "epidemic disease"' and, as such, a threat to the foundational values of matrimony and the primacy of the family within society (Stolberg, 2003, p. 705).

The successful deployment of such discourses in relation to sex, and the effects of power through them in maintaining the social order, is wholly contingent on the contrivance of stigma. By circumscribing responsible/irresponsible social actors, right/wrong sex, moral/immoral behaviours, discourse exploits existing fault-lines, reinforces divisions and reproduces the hierarchical structure that fosters it. Stigma thus serves as a bulwark to a social order into which social inequality is an entirely immanent and essential component and upon which its own survival is dependent (Link & Phelan, 2001, 2014; Parker & Aggleton, 2003).

From the particular to the universal- discourse as a site of struggle

The different classes and class factions are engaged in a symbolic struggle properly speaking, one aimed at imposing the definition of the social world that is best suited to their interests. The field of ideological stances thus reproduces in transfigured form the field of social positions (Bourdieu, 1991, p.167).

Consistent across all three theorists is that subject formation is a largely invisible social process in which power is operationalised via discursive and institutional practices. Symbolic power is effective as a form of social control precisely because it involves the unconscious complicity and compliance of the subject based on the tacit acceptance of it as a given and taken-for-granted part of the natural order of things. 'A symbolic power', says Bourdieu, 'is a power which presupposes a recognition, that is, a misrecognition of the violence that is enacted through it' (1991, p. 209). It is this dissimulative nature of symbolic power thus that lends it its potency and effectiveness. By presenting particular/specific interests as universal interests, dominant or hegemonic discourse types exercise symbolic power as symbolic violence by legitimising certain perspectives and positions and ultimately manufacturing a consensus about what is right, moral and socially acceptable within the boundaries of a particular cultural context. The structural is essentially coterminous with the symbolic in this way. This is a point that is echoed by Laclau (in Butler et al., 2000), who asserts that:

If the hegemony of a particular social sector depends for its success on presenting its own aims as those realising the universal aims of the community, it is clear that this identification is not the simple prolongation of an institutional system of domination but that, on the contrary, all expansion of the latter presupposes the success of that articulation between universality and particularity (i.e., a hegemonic victory) (p. 50).

The existence of hegemonic or dominant discourses does not, of course, preclude the existence of other perspectives and discourses, as clearly within all cultures there are sub-cultures and countervailing points of view. The concept of hegemony in this instance rather asserts that social reality is constructed and mediated through discursive practices, some of which exert a greater or lesser degree of dominance or are privileged over others and which

therefore have a greater or lesser degree of legitimising capacity (Butler et al., 2000). Indeed, it is a feature of power that it is anything but static. Discursive, social and cultural shifts, which occur in specific points in time, can and do tilt the balance of relations of power and, as per Bourdieu (1991), alter the constitutive and generative power of discourse to maintain the extant social order. The advent of democracy and the nation state usurped the balance of power from the Sovereign hierarchies and feudal social structures, for example, whilst the horrors of World War Two and the global outrage they provoked were the catalyst to a new global order and the articulation of universal human rights. Even recent history shows this in the way in which feminist scholarship and activism, gay liberation politics and disability rights activism have, within a generation, drastically altered what is and is not acceptable in society, politics, public discourse and, indeed, in public and private behaviour (Giugni, 1998; Henry & Wetherell, 2017; Switzer, 2003).

Thus, who gets to speak and what they say have a determinative effect on social relations and impact profoundly on social actors and their potential to act. Discourse, as such, is not just the means through which power relations are produced and reproduced, but is furthermore a site of struggle where these relations are contested, mediated and negotiated- a process described by Žižek as ‘...the hegemonic struggle for which particular content will hegemonize the empty universal’ (in Butler et al, 2000, p.111). Foucault (1981) goes even further, proclaiming that ‘...as history constantly teaches us, discourse is not simply that which translates struggles or systems of domination, but it is the thing for which and by which there is struggle, discourse is the power which is to be seized’ (pp. 52-53). So while the totalising effect of dominant discourse types, which present particular interests as universal ones, can and do have a constraining effect on certain individuals or groups whilst allowing for other specific groups to thrive, their capacity to maintain that dominance is wholly contingent on its viability and sustainability over periods of time in the face of often multiple competing discourses.

Conclusion

Stigma is a multi-faceted phenomenon, polyvalent both in its manifestation and in its effects on the individual and society. At the level of the individual, stigma can constrain life opportunities, lead to social exclusion and adversely affect health and well-being. Moreover,

at the societal level stigma is a mechanism of social control that reinforces social inequality and health inequities in a process that is bound up with maintaining an asymmetrical power structure. As such, better understanding stigma entails a better understanding of the workings of power in modern society.

Insights into how power operates are offered by the work of Bourdieu and Foucault whose theories illuminate the role played by discourse in operationalising and weaponising symbolic power, bio-power and sexuality into reproducing a set of hegemonic and asymmetric relations of power. The growing influence of the work of these theorists and this particular epistemological and ontological outlook among some stigma researchers is clear, for example, having influenced the work of Parker and Aggleton (2003) and that of Link and Phelan (2014). In conjunction with the works of Butler, Zizek, Laclau (2000) and Althusser (2008) it becomes possible to elaborate a coherent framework for the workings of power and the role of stigma in cultivating the social order.

Specifically in relation to stigma formation, Bourdieu's theory of Habitus (1977) facilitates a conceptual reconfiguration that elucidates the roles of symbolic power and socialisation in the inculcation of beliefs, practices, and patterns of thinking and behaviour that govern the actions of groups of individuals within a particular social field. The effects of symbolic violence, particularly, in exerting a power that is 'misrecognised' as legitimate and natural, rather than an arbitrary and coercive force that structures reality along certain lines, lends insight into how and why stigmatised individuals tacitly collude in their own stigmatisation.

Rather than viewing illness solely as an adverse physiological/medical event, medical sociologists and other proponents of the critical cultural turn in the health sciences posit that 'illness' is a complex construct, heavily imbued with symbolic and cultural meanings that are firmly embedded in the social fabric of a society (Brandt, 1988; Brown, 1995; Sontag, 1988). In the case of HIV, the discursive legacy of AIDS- with its associated narratives of shame, guilt and fear, and ubiquitous plague imagery- provides the contextual and intertextual backdrop through which macro level cultural understandings of HIV are mediated (Fairclough, 1992b; Treichler, 1987a). This discursive legacy and the adjuvant symbolic violence it carries continue to inform and reproduce HIV-related stigma. It follows

that the print media, as a cultural and political participant and the primary source of health and illness information for lay people, may act as a conduit for symbolic violence and therefore be implicated in the stigma process (Gould et al., 2009; Hallin et al., 2013).

Furthermore, Foucauldian subjectification, and specifically the process of dividing practices, helps to further explain how symbolic violence is exercised to discursively circumscribe the 'Other' - a key component outlined in the extant literature on stigma (Black, 2013; Gilmore & Somerville, 1994; Link & Phelan, 2001,2014; Scambler, 2006, 2009; Scambler & Hopkins, 1986; Weiss et al., 2006). Policies and institutional practices that differentially affect health outcomes and the distribution of life chances are dependent on and legitimated by symbolic practices that naturalise difference along tacitly accepted but nonetheless ideological lines (Galtung, 1969, 1990; Link & Phelan, 2014; Parker & Aggleton, 2003). As a result of this mutual relationship between the symbolic and the structural, HIV remains heavily stigmatised and tends to disproportionately affect key marginalised and oppressed populations (Farmer, 1999; Farmer et al., 2006; Parker & Aggleton, 2003; UNAIDS, 2014b). It is clear therefore that no theory of stigma, nor an attempt to analyse it as a social phenomenon, would be complete without acknowledging the structural component (Scambler, 2009). Here, Galtung's (1969, 1990) theory of structural violence complements Bourdieu's (1991) concept of symbolic violence and indeed this is reflected in much of the most recent literature (Hatzenbuehler, 2016; Hatzenbuehler & Link, 2014; Miller et al., 2016; Pachankis et al., 2015).

As such, by examining the interactions, commonalities and overlaps between the symbolic, social and structural spheres, drawing on empirical data and situating analysis within a theoretically grounded conceptual framework, this thesis will show how the process of stigma formation occurs across micro-(individual), meso-(community/healthcare) and macro-(policy/national print media) level interactions in order to reproduce and reinforce the uneven distributions of power that sustain the on-going social inequality that informs the HIV epidemic.

Chapter 3- Research design and methods

Introduction

Two approaches were employed in order to address the research questions: ‘What discourses exist in relation to press coverage of HIV in Ireland today and how does the media frame people living with HIV?’, ‘How do these discourses frame understandings of HIV and the nature of the HIV epidemic in the Irish context?’ and ‘How do discourses of HIV mediate reported stigma experiences and how does HIV-related stigma shape and constrain the lives of PLHIV?’ The first examined discourses of HIV in the Irish print media in order to understand how HIV is discursively constructed and the second investigated experiences of people living with HIV to assess their experiences of stigma in a variety of circumstances and situations. This design was informed by the conceptual framework assembled as part of the review of the literature on stigma and HIV, which included an emphasis on theories of language, power and the social order. The works of Pierre Bourdieu (1977, 1991), Michel Foucault (Foucault, 1976, 1981, 1982, 1984), Judith Butler (2015; Butler et al., 2000), among others, were key texts that formed the basis of this approach. A predominantly qualitative approach to data analysis was thus undertaken. Critical Discourse Analysis (CDA), Limited Quantitative Content Analysis and Technique Triangulation were used to analyse newspaper texts and Directed Content Analysis (DCA) was used to analyse interview data. This chapter will provide details of these analytical techniques, as well the approaches to data collection and participant recruitment that were undertaken to address the aims of the research ‘to identify and analyse the dominant discourses of HIV that exist in the print media in Ireland,’ to investigate how discourses of HIV are negotiated, internalised and/or resisted by PLHIV’ and ‘to identify the specific contexts in which stigma is experienced by PLHIV.’

Study 1- The discursive construction of HIV in the media

Data collection

As was noted in the previous chapter, the print media fulfil an important function in contemporary society as a conduit for disseminating health information (Gould et al., 2009; Hallin et al., 2013; Redmond et al., 2010). Furthermore, the print media are political and cultural actors in their own right as gatekeepers to macro-level discourse with the power to set agendas and frame social and policy debates (McCombs, 2005; McCombs & Shaw, 1972;

McCombs et al., 2014). As such the print media is an important data source in social, political and health research (Baumgarten & Grauel, 2009). Print media is highly consumed in Ireland, with over 80% of the population or approximately 3.5 million people regularly reading newspapers either in print (2.9 million) or online (565,000) (NBI, 2014). By comparison, only around 25% of the population use news driven social media platforms such as Twitter (IPSOS, 2017).

Collection of data for this research involved a sampling of newspaper articles published in Irish print media over a ten year period from 2006 to 2016. This period was selected because it is contemporaneous with several key developments in HIV research and treatment that have led to a biomedical 'normalisation' of HIV and the categorisation of HIV as a treatable chronic illness. These include the release of the Swiss Statement in 2008, declaring that PLHIV are not sexually infectious when the treatment goal of undetectable viral load has been reached and studies that show that PLHIV have a comparable life-span to HIV negative individuals (Hogg et al, 2013; Vernazza et al, 2008). Additionally, this time period was contemporaneous with the publication of significant policy documents relevant to sexual health and HIV in the Irish context, including the HIV and AIDS Education and Prevention Plan 2008, the mid-term review of same in 2012, and the publication of the National Sexual Health Strategy, 2015.

The sample of newspaper articles was collected via the Lexis Nexis database.

Inclusion criteria stated that articles must:

- contain the word HIV or AIDS in the headline, so as to be reasonably assured that HIV was the main topic of the piece
- be published in a national Irish publication, so as to be of national significance and therefore part of macro- level discourse
- be no fewer than 500 words in length, so as to limit the sample size and to have pieces of sufficient length in order to perform robust analysis.

A search was conducted using the search terms "HIV and AIDS." Initially these search terms gathered in excess of 3000 articles, including many irrelevant pieces that referred to 'Aid,' as in humanitarian aid. On advice from Lexis Nexis, the search terms were adjusted to

((“HIV” and plural “AIDS”)) and this returned approximately 2000 fewer results. Refining the search further to exclude Northern Irish publications, online duplications and regional publications, a final total sample of 103 articles was retrieved. The final sample included articles from both daily publications and the Sunday papers, with pieces from the Irish Times (48), The Irish Independent (13), The Star (17), The Sunday Independent (8), The Irish Examiner (8), The Irish Daily Mail (8), The Herald (2) and the Sunday Tribune (2). A table with the full list of articles, including title, publication, article type and date of publication is included in Appendix C. The sample (103) contained pieces published in various sections of the newspapers including ‘Health,’ ‘News,’ ‘Opinion,’ and ‘Entertainment,’ and ‘Features.’ Additionally, pieces varied in style and scope, and thus the sample included pieces that were not solely or specifically health-related. Article types included news reports, opinion pieces, feature pieces, letters to the editor and entertainment pieces, among others (See figures 1 & 2). The inclusion of diverse genres facilitated the garnering of a sense of how HIV was discursively constructed across genre types. This was important as it allowed me to observe not only how HIV is framed as a public health issue, but also how it can be used as a rhetorical or narrative device to add drama and sensationalism to a piece. The majority of the sample, however, was composed of feature pieces (46).

Newspaper	Circulation Figures 2010
The Irish Times	105,742
The Irish Independent	144,896
The Irish Examiner	46,687
The Irish Star	93,729
The Irish Daily Mail	51,338
The Herald	40,933
The Sunday Independent	265,455
The Sunday Tribune	54,400

Fig 1: Newspaper circulation figures for 2010-Source: <http://newsbrandsireland.ie/data-centre/circulation/>

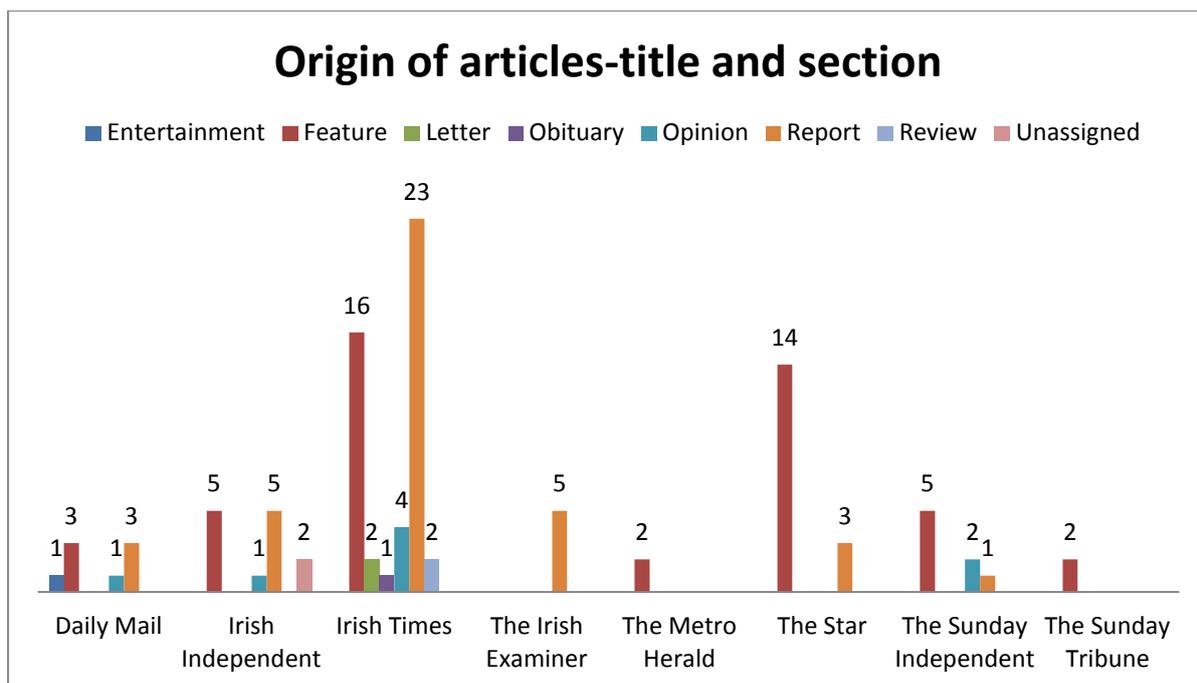


Fig 2: Chart with newspaper titles and section

Once downloaded from the database as word documents, the articles were edited back to remove any extraneous text included as part of the download. These word documents were then uploaded to Nvivo for organisation and analysis.

Data analysis

Analysis of the newspaper data occurred predominantly within a critical discourse analysis (CDA) framework (Fairclough, 1992a, 2003). Technique triangulation (Humble, 2009) was employed to attain greater validity, taking advantage of some of the features of the Nvivo software programme to perform matrix coding queries and generate charts and word-trees for data visualisation, and by performing additional limited content analysis such as word-counts (Hsieh & Shannon, 2005).

Critical discourse analysis (CDA) is concerned with examining discourse as social practice and entails a close scrutiny of the formal, contextual and intertextual properties of texts to reveal the underlying power relations (Fairclough, 1992a, 2003). The aim of CDA is to examine and reveal the often subtle ways in which language is used to reproduce, sustain and maintain structurally embedded systems of inequality, asymmetric relations of power between social groupings and hegemonic frameworks of knowledge. This method acknowledges the constitutive role that language plays in shaping social identities, subject

positions, social relationships and systems of belief and knowledge (Fairclough, 1989; Foucault, 1982). CDA also recognises the manner in which processes of symbolic violence can legitimate and facilitate the reification of norms and practices that implicitly favour the dominant group and marginalise other groups (Bourdieu, 1977, 1991; Farmer et al., 2006; Link & Phelan, 2014; Reyes, 2011).

In this sense, CDA is not a value-free method, nor does it claim to be. As a critical approach, CDA is inherently political and advocates that ‘...critical discourse analysts (should) take an explicit sociopolitical stance: they spell out their point of view, perspective, principles and aims, both within their discipline and within society at large’ (Van Dijk, 1993, p. 252). This is not discordant with the aims and objectives of public health scholarship more broadly. Indeed, as previously noted, this is an approach that has gained considerable traction, as health researchers increasingly draw attention to the social inequities that negatively impact on the ability of people to maintain good health (Dutta & Basu, 2008; Farmer, 1999; Farmer et al., 2006; Green & Labonte, 2008; Schrecker, 2016). In this way, sociologists of health, in particular, have underscored the pivotal roles played by culture, discourse and socialisation in determining health outcomes (Dutta, 2010; Dutta & Basu, 2008; Lupton, 1997). Like CDA, critical public health approaches challenge and question existing orthodoxies and advocate for structural changes that would facilitate greater social equality and better health outcomes for all (Lupton, 1994; Green & Labonte, 2008). As Schrecker (2016) has argued, what is needed more and more ‘is a political science of health inequalities...that is capable of identifying the relevant macro-micro connections’ (p. 479).

While drawing on elements both theoretically and methodologically from the Foucauldian approach to discourse analysis (Foucault, 1976, 1981, 1982; Heller, 1996)- particularly in terms of paying attention to historical context and with regard to the impact of discourse on subjectivities- the approach I largely employed in analysing newspaper texts was derived from Fairclough (1989, 1992a, 1992b, 2001, 2003, 1985).

Fairclough identifies three aspects to the constitutive effect of language, asserting that discourse:

- 1) contributes to the construction of social identities and subject positions for social subjects and types of self,

- 2) helps construct social relationships between people and,
- 3) contributes to the construction of systems of knowledge/belief

(Fairclough, 1989, 1992a, 2003).

This iteration of CDA asserts that discourse both shapes social reality and is shaped by it-it is both a 'structuring structure' and a 'structured structure' (Bourdieu, 1991, p. 165). This underscores the importance 'that the relationship between discourse and social structure should be understood dialectically if we are to avoid the pitfalls of overemphasising on the one hand the social determination of discourse, and on the other hand the construction of the social in discourse' (Fairclough, 1992, p. 65). Thus Fairclough (1992) is careful not to overstate the constitutive effects of discourse, insisting rather that '...the impact of discursive practice depends upon how it interacts with a preconstituted reality' (p. 60).

This approach is thus closely aligned to the outlook of Bourdieu (1991) in asserting that a mutually reciprocal relationship exists between the symbolic and social fields. 'Symbolic structures'- that is, language, culture, religion, discourse, for example- exercise a great deal of power in the way in which they play a constitutive role in the articulation and structuring of reality. As Bourdieu (1991) has asserted, 'Symbols are the instruments par excellence of social integration. As instruments of knowledge and communication...they make it possible for there to be a consensus on the meaning of the social world, a consensus which contributes fundamentally to the reproduction of the social order' (p. 166).

This consensus is realised by a process of naturalisation whereby certain modes of thinking, social practices and cultural norms are reified and sustained via dominant discourses through which they are lent legitimacy and authority. Bourdieu (1991) further outlines that the constitutive nature of discourse 'is defined in and through a given relation between those who exercise power and those who submit to it- that is to say, in the very structure of the field in which belief is produced and reproduced' (p. 170). In other words, just as discourse can shape and maintain the social order, this is contingent on the social conditions of its production and the state of relations that exist within the field of power.

This dialectical conceptualisation of discourse as a constitutive force thus allows for the possibility of resistance, subversion and the reification of new norms and realities.

Key discursive features

A number of discursive features of texts provide insight into how text producers construct knowledge about the world and delineate subject positions for actors represented in discourse. Key features of texts that were examined for this study were:

Dialogicality: refers to the degree to which texts include or exclude multiple 'voices' in dialogue on a subject and the way in which relations are set up between these voices. Examination of the different voices included (or excluded) in a text can provide insight into the types of opinions/perspectives/world views that are elevated and those that are suppressed. Examination of 'voice' over a corpus of texts can provide insight into the hierarchies that exist within a discourse, and which may reflect homologous hierarchies in the social world.

Intertextuality: refers to the presence of other texts within a text. This can amplify certain voices or discourses within a text. Reported speech, indirect quotation, paraphrasing and summaries (of, for example, reports, policy or research) are all forms of intertextuality.

Assumptions: refers to the inherent meaning of texts. Fairclough (1992a) identifies three types- existential, propositional and value assumptions- referring to what exists, what is the case and what is un/desirable, respectively.

Ideologies: refers to representations of the world that embody certain values, positions and perspectives, and which establish relations of power and social interaction. In identifying and analysing ideological aspects of texts Fairclough (1992) highlights the importance of incorporating analysis of assumptions and framing these within a broader analysis of social context and practice.

Social actors: analysis should examine how particular individuals or groups of individuals are framed within a text, or indeed if they are included/represented at all. Specific features to note in this regard are the adjectives used to describe them, and the degree of agency ascribed to them via passive or active descriptions.

Modality: the use of modal verbs relates to the degree of affinity a writer has with a statement and their commitment to the truth or necessity of that statement. For example, modal auxiliary verbs such as 'may,' 'might,' or 'could' hedge a statement and introduce an element of doubt or possibility.

Legitimation: this refers to the use of particular voices, specifically authority figures, institutions or individuals endowed with a degree of social or symbolic power to lend legitimacy to a text/perspective/point of view (see Fairclough 1989, 1992a, 1992b & 2003).

Analysis of texts was additionally informed by elements of Framing Theory, which is a methodology widely used in the analysis of media texts specifically (Entman, 2007; Lakoff, 2004; Weaver, 2007). Entman (2007) defines framing 'as the process of culling a few elements of perceived reality and assembling a narrative that highlights connections among them to promote a particular interpretation' (p. 164). Several techniques may be employed by writers, in the media especially, to frame events in specific ways. These include use of: metaphor; contrast (describing something in terms of what it is not); subject-specific language such as jargon; narrative story-telling; 'spin'- value judgements that help introduce inherent bias; and 'frame negation,' whereby negation of a frame evokes a frame and evoking a frame reinforces that frame (Fairhurst & Sarr, 1996; Lakoff, 2004).

Description of analytical procedures

Nvivo software was used to organise and code data. After performing several iterative readings of the texts during which notes were taken identifying key terms and vocabulary that emerged, the texts were coded thematically and for the discursive features outlined above. Initially I was sceptical of the usefulness of Nvivo for conducting CDA for two reasons. Firstly, CDA demands that texts are scrutinised for what is not said and who is not included in the discourse, as well as for what is said and by whom. Clearly coding for something that is not there is not possible, so instead I took detailed memos of my observations and initial analysis, and linked these to the individual texts under analysis.

Secondly, given the importance of context, style, grammar, use of vocabulary and over-all coherence of the texts, CDA demands that close analyses of texts be performed on individual and whole texts. As such, I struggled to see how I could synthesise my findings

across the corpus of texts in my sample. Given that my starting point was that HIV is a stigmatised condition, I was further wary of potential biases I might be bringing to the analysis and that I may have been finding what I was looking for because I was looking for it. However, as I became more accustomed to the functionality of the programme, certain features presented opportunities to introduce additional analytical techniques to explore the patterns that I saw emerging and, in the process, increase the rigour of my methods (Humble, 2009).

For example, it was clear that certain 'voices' and themes were more strongly represented than others and I wanted to explore the relationship between these. Using the matrix coding function of Nvivo, I was able to cross reference themes against discursive features to gain a deeper understanding of the patterns that were emerging across the texts and a sense of what issues were prioritised by particular voices. Running the matrix coding function allowed me to compare and contrast voice/theme as it occurred across different texts with relative ease and facilitated the creation of charts that aided with data visualisation. Additionally, this provided a means through which the results could be easily synthesised. This further solved a problem I had not yet anticipated- how to present the findings without having to explicate each article individually, an impossible proposition given the constraints of a finite word count.

Using the text query function of Nvivo it was possible to perform limited content analysis, such as searching for frequency of key terms and nomenclature identified during initial readings and coding. These queries could be saved as specific nodes within the discourse analysis folder or added to existing nodes. Using the matrix query function again, it was possible to see who was using these terms most frequently and in what context. This further strengthened the analysis by helping to confirm the discursive patterns I had identified during initial readings and preliminary rounds of coding. It was thus possible to visualise which voices employed which terms/nomenclature most frequently: Figure 4, for example, shows a visualisation of 'voice' cross referenced with use of the term 'living with HIV,' showing that this term is more likely to be used by those working within the NGO sector or by people living with HIV themselves than by people emanating from biomedical or political fields.

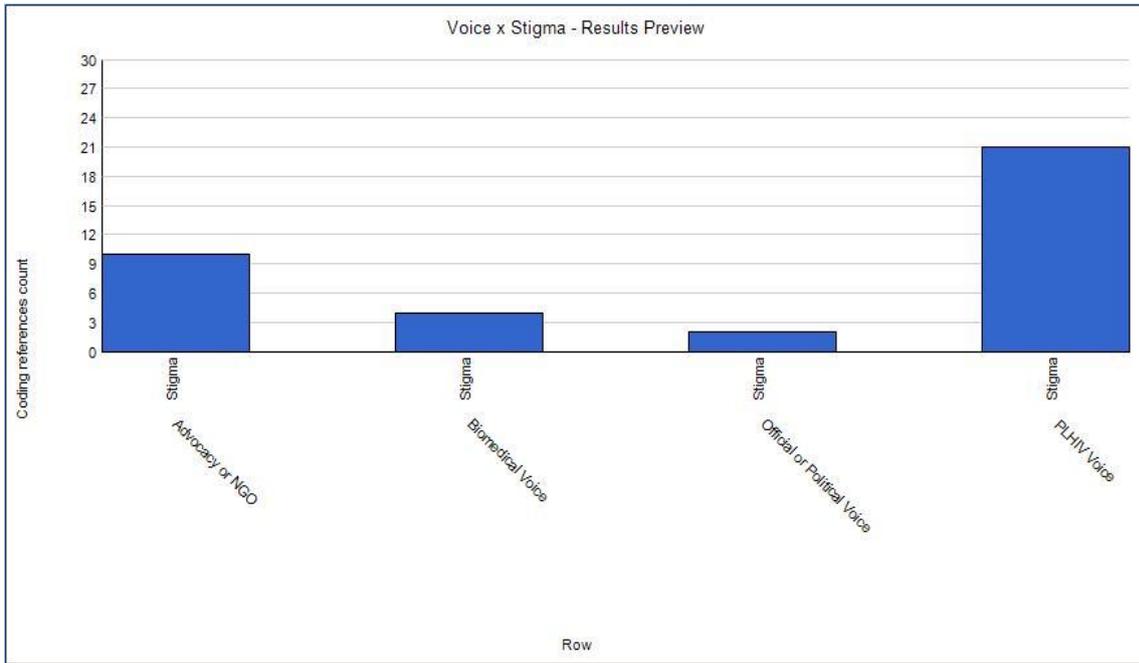


Fig 3: Data visualisation chart cross-referencing stigma with voice

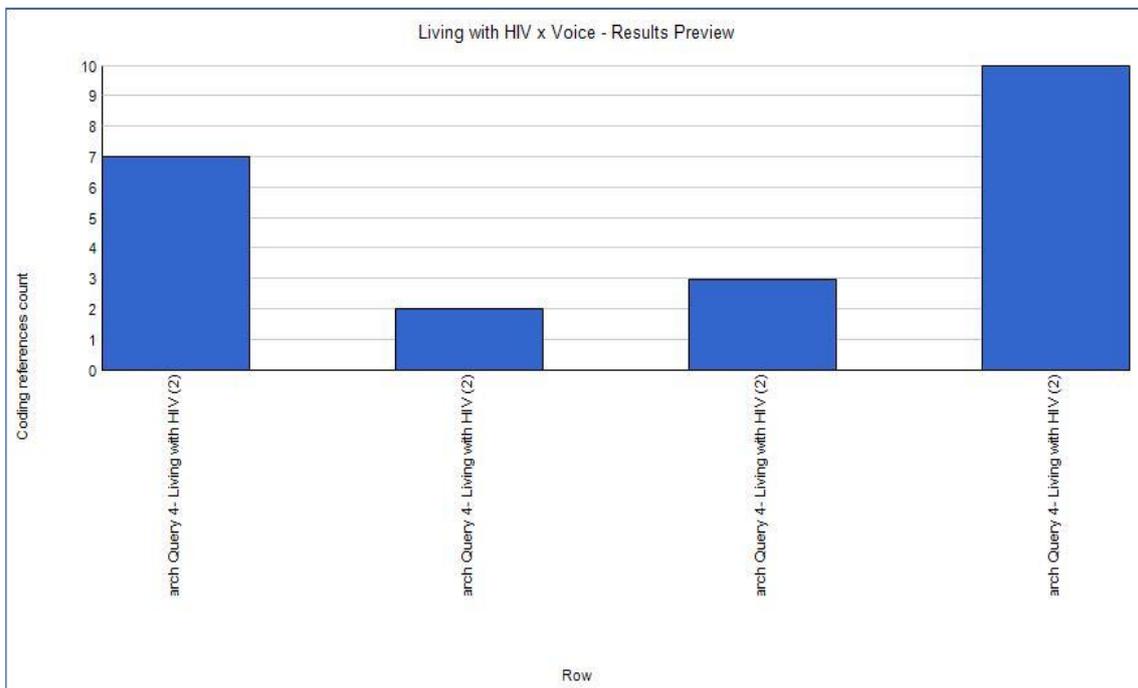


Fig 4: Term 'Living with HIV' cross referenced against 'Voice'

Study 2: Qualitative Interviews with people living with HIV

Participant Recruitment/Data collection

It was initially envisioned that participant recruitment would occur via two clinics- one in Dublin and one in Galway. Negotiating access with gatekeepers however proved unfruitful, as both clinics were in the process of conducting studies of their own at the time and had understandable concerns about 'research fatigue' among potential participants. As such, a new recruitment strategy was devised and implemented following re-submission and approval of an ethics application. Given the highly stigmatised nature of HIV in Ireland, I had anticipated that some difficulties might arise in recruiting individuals for interview, particularly absent of the support of the clinics. For this reason, it was decided to cast the net as wide as possible and several discrete strategies- outlined in detail below- were put in place to recruit participants.

Establishing relationships with alternative gatekeepers

A number of HIV support and advocacy organisations were approached to seek their support for the study. Initial contact was made with these organisations by email and I followed up with meetings to introduce myself and advocate for support for the study. AIDS West, HIV Ireland, UISCE Ireland and Cork Sexual Health Centre and Transgender Equality Network Ireland (TENI) all agreed to promote the study among their clients or on their web-based platforms. Establishing relationships with these organisations was key to data collection as the majority of participants were recruited with their support.

Online presence

In order to facilitate recruitment I created a website www.hivstigmastudy.ie. The site contained all pertinent information on the study in addition to directing people as to how they could get in touch. I also created a Twitter account (@StigmaStudy IE) specifically to promote recruitment by linking online with relevant organisations and actors. Business cards with my name, phone number, Twitter handle and the website address were printed and supplied to the supporting organisations. The website was useful also in acting as resource for potential interviewees who may not have felt comfortable carrying around paper documents with details of the study. One participant contacted me via Twitter.

Media presence

AIDS West kindly allowed me to write and publish an article about the study for their quarterly magazine/newsletter 'Happiness is Vital.' The article was subsequently picked up and reported on by the Galway Advertiser, a local regional newspaper. At least one participant was alerted to the study via the initial article.

Networking, community outreach and dissemination

In order to further build a profile for the study I engaged in a number of initiatives to establish relationships. This involved giving talks at Galway Pride Festival, a World AIDS Day (WAD) event organised for people living with HIV by AIDS West and further events for WAD in Maynooth. I also participated in and presented at community information sessions on PrEP organised by the newly formed Irish chapter of activist group ACTUP Dublin. At least one participant engaged with me as a result of these actions.

Inclusion criteria

Inclusion criteria for participation in the study stated that participants must be over the age of 18, have proficient use of English and be diagnosed a minimum of 5 years. The five year minimum period of diagnosis was imposed mainly because of concerns about the potential for post-traumatic stress disorder in newly diagnosed individuals (Martin & Kagee, 2011; Theuninck, Lake & Gibson, 2010). Although it was not anticipated that the interview process would be traumatising, it was recognised that a newly diagnosed individual may be emotionally or mentally vulnerable and the experience could have the potential to cause upset. Current data collated from the WHO World Mental Health Survey suggests that PTSD recovery trajectories can range from two to ten years, depending on severity (Rossellini et al., 2017). Taking all this into account, five years seemed like a reasonable period of time to allow for recovery from PTSD that an interviewee may potentially have experienced.

Study sample

The study was entirely open to and inclusive of people from all backgrounds, sexualities and genders, and indeed actively encouraged participation from cohorts that are

not widely represented in research on HIV. Active efforts were taken, for example, to encourage participation by transgender people via the advocacy agency Transgender Equality Network of Ireland (TENI), although ultimately none engaged with this study. Efforts to recruit sex workers through another support organisation were similarly unfruitful. Although the initial research proposal had envisioned conducting more interviews, the 'hard to reach' nature of this group proved a significant barrier, regardless of the efforts made.

Much debate exists in qualitative research regarding what the appropriate sample size should be. Green (2004) has asserted that sample size should be 'however many will be credible to the users of your research' (p. 102). Guest, Bunce and Arwen (2006) have suggested that generally little new data is generated after twelve interviews. With one pilot and fourteen interviews conducted after a year of active recruitment efforts, no new data was being generated from conversations with participants. Given this and the need to bring the project to a timely conclusion, participant recruitment was halted at fourteen and included ten men and four women. All the women identified as straight. Of the ten men, six were gay, three were straight and one declined to say. Two of the men had acquired HIV through intravenous drug use and everyone else had acquired HIV sexually. All but two of the interviewees were Irish, with one woman from Zimbabwe and one man from the United States. Although a gender balance was not achieved, this sample is roughly reflective of the gender divide in new HIV diagnoses in Ireland where the male to female ratio is 3.4:1 (HPSC, 2017b).

One pilot and fourteen in-depth, semi-structured, qualitative interviews with people living with HIV were conducted in order to examine the third research question: 'How do discourses of HIV mediate reported stigma experiences and how does stigma shape and constrain the lives of PLHIV?' This method of data collection was chosen over methods such as a survey or focus group for a number of reasons. Firstly, the literature revealed a dearth of qualitative research on the diverse stigma experiences of PLHIV in Ireland across distinct cohorts. This study sought to address this gap by conducting in-depth qualitative interviews on the subject of stigma across a mix of cohorts. Secondly, a survey on HIV-related stigma in Ireland had been conducted in 2008 and, at the time of data gathering for this study, a second similar survey was underway. Thirdly, for reasons of confidentiality and in order to

assure anonymity of participants, focus groups were ruled out as a potential data collection method. Finally, the theoretical framework demanded that rich data be generated so that the nuances of experiences, perceptions and encounters could be explored in detail.

Interviews were held in several locations, with the majority taking place in spaces provided by HIV Ireland and the Sexual Health Centre, Cork. For reasons of convenience of participants and confidentiality, the pilot and two other interviews were held in my home and one was held in the home of the interviewee. For these interviews a safety protocol was put in place. Each interview lasted approximately one hour. All interviewees were provided with detailed participant information sheets that outlined the scope of their participation and informed them of their rights (See Appendix B).

Ethical considerations

Procedural ethics

In line with university policy and best research practice, an ethics application was submitted to the NUI Galway ethics committee prior to participant recruitment. Ethical considerations revolved around the risk of emotional distress to participants and assuring confidentiality and anonymity. In the ethics application I outlined a number of strategies to address these concerns. In relation to maintaining confidentiality and anonymity of participants, all recordings and documents that contained any identifying details of interviewees were held solely on my laptop in password encrypted files. Similarly, the project file used for Nvivo was password protected. In relation to minimising or avoiding emotional distress of participants, I prepared a list of appropriate support and counselling services to whom participants could be referred in the event of becoming upset as a result of the interview process. Full ethical approval was granted.

Ethics in practice

Of key importance to me as a researcher was that the interviewees were as comfortable as possible discussing their lives with me. I left the choice of where to interview up to each individual so as to meet with them on their terms. Before each interview I engaged in a friendly and informal conversation first over a tea or coffee where possible. I then explained the outline of the interview and asked if there were any topics that they may

be unwilling or uncomfortable to discuss, such as sex, for example. I explained that they were free to withdraw from the interview at any stage.

While the participant information sheets outlined that anonymity would be assured, I furthermore verbally explained to each interviewee the steps that would be taken to protect participants' information so as to underscore the priority that this was afforded. It was important that the parameters of interviewees' engagement with me as a researcher were extremely transparent and that all aspects of this were communicated clearly. However, communicating that anonymity was of particularly high importance was, I felt, essential to setting each individual at ease in order to facilitate an open and frank discussion.

In relation to the risks to participants, I judged there to be relatively low risk of temporary emotional distress for some interviewees. This assessment was largely based on my prior experience of working with people with HIV in another setting. This experience had taught me that, generally, PLHIV are most emotionally raw and vulnerable in the immediate aftermath of diagnosis. However, it had also been my experience that people that have adjusted to living with HIV are remarkably resilient. Rather than view the interview experience as having the potential to cause distress, I viewed the interviews as an opportunity for people to tell their stories and have their voices heard in a safe, non-judgemental environment and framed them as such in initial conversations with participants.

I discovered that most interviewees were enthusiastic and engaged interlocutors. Indeed a few required minimal prompting or questioning at all and spontaneously addressed many of the subjects I had planned for in the interview schedule. In this sense, the experience seemed to elicit a catharsis for some participants, reflecting, perhaps, Zora Neale Hurston's (1942) sage observation that 'there is no agony like bearing an untold story inside you' (p. 121). In some respects, this may be unsurprising. Given the stigmatising nature of HIV, opportunities to discuss the issues and problems that one encounters can be rare- indeed, the silence surrounding HIV is perhaps the most salient aspects of living with HIV that emerged across almost all interviews.

Nevertheless, with any cathartic experience there is the potential for an outpouring of emotion. This is especially true, in my view, where the subject of conversation revolves around sensitive topics such as health, sex and relationships in the context of a traumatic diagnosis such as HIV. Another possibility during an emotionally charged interview is for participants to disclose information around other traumas that may have occurred in their lives. Indeed during two interviews for this study such disclosures occurred as the interviewees shared their experiences of physical and sexual assault.

This underscores this necessity for researchers to enter into the interview process suitably prepared and to be cognisant of their responsibility to be an ethical interlocutor. For example, an essential aspect to discussing sensitive subjects involves seeking consent to have such discussions and regularly checking with the interviewee if they are comfortable speaking about certain experiences. In developing an ethical and compassionate praxis, engaging in active listening becomes a key skill, as knowing when to drop a topic is as important as knowing when to tease out another. Another pragmatic aspect for any researcher in preparing for such encounters is to be aware of the need for their own self-care- fostering emotional resilience is important, as is being well-rested.

Despite the rather sensitive nature of the conversations that took place for this study, none of the participants became distressed or even particularly upset during the course of interviews- and I include the two who spoke about their assaults in this. Indeed most were rather sanguine about their situations and experiences. While many aspects of the interviews could be characterised as poignant, there was also a good deal of humour and an undeniable pragmatism in the outlook of all those I interviewed.

The interviews

A pilot interview was conducted in order to field-test a script of questions and in order for me to practice and refine my interviewing skills and techniques. This first experience was instructive: I realised that, for some participants, such an interview may represent a unique opportunity to discuss at length and in detail matters that ordinarily they may not have opportunities to speak about openly. The potential for generating very rich data was clear. It was also clear, however, that given the complexities of living with HIV and

how multi-faceted and expansive the issues surrounding it are, there was a chance that were the interviews not properly managed, many tangential aspects could take over the conversation and over-complicate subsequent processes of data management and analysis. As such, following the pilot, the script of questions was refined and I developed strategies, such as the inclusion of bridging or pivoting questions, in order to help guide the flow of the interview. This allowed for flexibility to explore certain subjects specific to the individual interviewee's experience, whilst staying largely on point and addressing the issues germane to answering the research questions. A sample interview schedule is located in Appendix D.

The first question provided a common starting point for all interviewees to begin telling their stories- 'Can you tell me about when you were first diagnosed and your initial reaction to this news?' This would generally lead into a question about to whom the participant first disclosed their status. This provided a segue into stories of status disclosure in other settings, including healthcare, work and the family. Specific questions were asked about participants' experiences of receiving healthcare in various settings, the challenges of living with HIV and how HIV is represented in the media, although many participants brought up these topics unprompted. Care was taken during the interviews not to pre-empt certain responses or to ask leading questions. Questions were open-ended and the structure of the interviews was flexible to allow for follow-up questions or to tease out any interesting ideas or anecdotes that arose. Prompts such as 'That's interesting- could you tell me a little more about... ' were used to elicit further information on topics of interest. Notes were taken during interviews to account for latent content such as gestures, tone of voice, sarcasm/irony, eye-rolls, laughter and other facial expressions or body language. All interviews were recorded digitally and transcribed with interviewees' permission. Transcription also included details of any latent content to provide additional context of statements.

Data Analysis

Transcripts of the interviews were analysed using directed content analysis (Assarroudi, Heshmati Nabavi, Armat, Ebadi, & Vaismoradi, 2018; Bender & Fulbright, 2013; Elo & Kyngas, 2008; Hsieh & Shannon, 2005; Humble, 2009; Jeffries et al., 2015). Elo and Kyngas (2008) describe content analysis as 'a research method for making replicable and

valid inferences from data to their context, with the purpose of providing knowledge, new insights, a representation of facts and a practical guide to action' (2008, p. 108). Directed content analysis can be either deductive, when used to support or extend existing knowledge or theory on a subject, or inductive if little research exists on a topic. Directed content analysis is also flexible enough to allow for a blend of inductive and deductive approaches (Humble, 2009). The method begins with immersive and iterative readings of transcripts or texts. If using the deductive approach, a preliminary coding scheme is developed in relation to key concepts identified from the literature review and/or the theoretical framework, and a structured analysis matrix is developed to organise and compare data. If using the inductive approach, open coding is performed and coding sheets are generated to group and categorise data (Elo & Kyngas, 2008).

For this study, the approach was largely deductive. This was because the research questions and a clearly defined theoretical framework were used to underpin and guide both the questions asked during the interview and subsequent analysis. However, given that very little prior qualitative research on the topic of HIV-related stigma in the Irish context specifically exists, some inductive analysis was also necessary and this was incorporated into the theoretical framework. For example, the spatial/environmental aspect of stigma had not been included as part of my analytical framework at the outset, and I had not come across many references to this in the review of literature on HIV-related stigma. However, the experiences of interviewees in clinic settings suggested that this was a significant element in contributing to some perceptions of how HIV-related stigma is reproduced. Such contextual factors that affect the experiences of people living with HIV in Ireland and how this impacts upon their sense of self and subjectivity could not simply be elided or ignored during analysis. Indeed it led to a much greater understanding of the complexities and multi-faceted nature of the social, symbolic and structural mechanisms involved in the reproduction of stigma. A step-by-step guide to the procedures used during analysis is laid out below.

Directed content analysis- Description of steps taken

The following steps were taken during the analysis process:

Iterative readings of the transcripts were performed to get a sense of the texts and notes and memos were taken on initial impressions, commonalities and divergences.

Based on the theoretical framework for stigma, a priori codes were created. This included, for example, codes for 'Enacted Stigma,' 'Anticipated Stigma,' and 'Internalised Stigma.' Further codes for the settings in which participants had/could potentially experience stigma were also created so that these experiences could be separated out and examined in greater detail.

Transcripts were coded one by one, with whole paragraphs, rather than singular words or sentences as the units of analysis. This was so that context could be provided upon later closer analysis of statements and utterances. The constant comparison technique was used to assure consistency of coding (Corbin & Strauss, 1990).

As new themes or topics arose, new codes were created. Some were merged into existing codes as the process continued, while others were deleted.

Guided by the research aim to 'identify the specific contexts in which people living with HIV experience stigma,' a table was created in order to categorise experiences according to context/setting and type of stigma experienced. This aided with comparison across cases, basic quantification of stigma experiences and initial synthesising of data.

Coding sheets (nodes) were exported from Nvivo to Word documents and further analysis was performed, highlighting relevant passages, similar language and over-lapping experiences. Memos were made in the margins to track interpretation and observations. Stigma experiences were further analysed to separate out micro- and meso- level interactions for examination in greater detail.

Codes were re-examined and interpreted within the context of the theoretical framework. Index cards were used to plan and story board results.

Results of the analysis were written up, drawing on exemplary passages to support and extend the theoretical framework.

Limitations

Study Sample- Interviewees

While every effort was made to recruit a diverse sample of PLHIV for the study this was a difficult task and as such, some cohorts are either under-represented or not represented at all. For example, only one sub-Saharan African was recruited. No transgender individuals or sex workers volunteered for the study. While this is an unfortunate gap, it is difficult to say how much of a problem HIV is for these cohorts in Ireland specifically given the paucity of data. Future research on HIV-related stigma in Ireland would, however, be benefitted by focussing recruitment efforts on those this study was unable to reach

The majority of the interviewees were recruited via support organisations. Indeed, several were or had been volunteers at the organisations. As a result, many had a level of community engagement and at least a basic level of social support that arguably is not available to all PLHIV in Ireland.

Finally, the relatively small cohort and the specific cultural context within which the study was conducted may limit the generalisability of the study.

Methodology

Critical Discourse Analysis is not without its critics (Breeze, 2011; Hammersley, 1997; Jones, 2007). Hammersley (1997), for one, is sceptical of the philosophical foundations of CDA, and furthermore questions the ambition of CDA in attempting to bridge theory and practice. Moreover, as Breeze (2011) has noted, 'CDA practitioners have frequently been accused of using "impressionistic" methodology for analysing text' (p. 520). Rather than invalidating the legitimacy of the methodology however, such critiques underscore the need for researchers using CDA to clearly delineate the theoretical framework that underpins their approach (Breeze, 2011). A clear and systematic approach to data analysis, using a sufficiently broad sample and applying technique triangulation can help increase rigour and minimise researcher bias.

Strengths

Discourse theory and issues of public health may not immediately appear to be comfortable bed-fellows for concurrent study and marrying them may appear somewhat ambitious, if not fool-hardy. Both, however, are rooted in the social and therefore have

more in common than at first glance. Finding an appropriate theoretical lens through which to examine the phenomena under study was key to bringing these two seemingly disparate fields together.

The harmonisation of conceptual framework and analytical method is thus one of the strengths of this research design. Both insist on recognising the importance of the symbolic and structural dimensions involved in understanding stigma and analysing discourse respectively. Indeed, the common thread that runs through the conceptual frameworks for stigma elaborated upon in Chapter Two and the particular iteration of CDA I employ is that both are anchored by a shared theoretical perspective that asserts the ways in which discourse and power shape and are shaped by the dynamics of social interaction. This harmonised, yet interdisciplinary, approach is what facilitates the exploration of the relationship between two seemingly disconnected phenomena.

While this integrated framework and methodology works well for this specific study, it would also be a suitable approach to employ for research in other contexts- with different health issues or in different cultural settings, for instance.

Conclusion

The research design was guided heavily by the literature and the theoretical framework that was generated as a result. Two approaches were employed in order to explore how discourse is involved in reproducing HIV-related stigma and how such stigma shapes and constrains the lives of PLHIV. The first approach involved examining the discursive construction of PLHIV and the framing of the HIV epidemic in the Irish print media, and the second approach involved conducting interviews with PLHIV to explore their experiences of living with HIV.

Newspaper data were collected via the Lexis Nexis database and were analysed using a combination of Critical Discourse Analysis, Limited Content Analysis and Technique triangulation (Assarroudi et al., 2018; Aulette-Root, 2010; Baumgarten & Grauel, 2009; Bender & Fulbright, 2013; Elo & Kyngas, 2008; Fairclough, 1985, 1989, 1992a, 1992b, 2003; Hsieh & Shannon, 2005; Humble, 2009). Additionally, the version of CDA that was used

drew heavily on theories of discourse and social practice by theorists such as Foucault and Bourdieu (Bourdieu, 1977, 1991; Fairclough, 1992a; Foucault, 1981, 1982; Heller, 1996; Link & Phelan, 2014).

Qualitative interviews were conducted with fourteen individuals living with HIV, recruited through diverse means. Interviews were semi-structured and lasted for approximately one hour on average. Transcripts were analysed using Directed Content Analysis, a method in which a strongly defined theoretical and conceptual framework and the research questions are used to guide and direct the analysis in order to extend or elaborate on existing theory (Assarroudi et al., 2018; Bender & Fulbright, 2013; Clarke, Friedman, & Hoffman-Goetz, 2005; Elo & Kyngas, 2008; Hsieh & Shannon, 2005; Humble, 2009).

Chapter Four: Newspaper articles- results and analysis

Introduction

The aim of the research for this part of the study was to identify and analyse the dominant discourses of HIV that exist in the print media in Ireland and, more specifically, to investigate how discourse is involved in reproducing HIV-related stigma. As such the research questions that informed the analysis were ‘What discourses exist in relation to press coverage of HIV in Ireland today and how does the media frame people living with HIV?’, and ‘How do these discourses frame understandings of HIV and the nature of the HIV epidemic in the Irish context? In this chapter I will show how analysis of the texts across all genre types revealed a tendency to frame HIV apropos of dominant biomedical and neoliberal discourses. This involved a privileging of voices from a biomedical perspective in order to provide context and expert analysis- mainly doctors, clinical researchers and other experts from the fields of biomedicine; an emphasis on concepts such as ‘risk’ and ‘personal responsibility’; a focus on epidemiological and surveillance data; and, a tendency to ‘vectorise’⁹ people living with HIV. This occurred to a general exclusion of analysis of the sociocultural, structural, or political context of the epidemic. For example, little mention was made of things such as access to and level and quality of education, access to screening and treatment, policy frameworks or legislation. This was especially the case of articles that focused on HIV in the Irish context specifically. Interestingly however, the converse was true of articles that reported on HIV or AIDS in an international context, which had an observed tendency to focus more on political and policy responses to the HIV epidemic.

Furthermore I will discuss how a discursive pattern of ‘dividing practices’ was identified in relation to the framing of PLHIV (Foucault, 1982, p. 778). I will explore how this resulted in the constitution of HIV positive subjectivities that reproduced the ‘us’ and ‘them’ dichotomy that implicitly Othered PLHIV (Link & Phelan, 2001). Examination of the vocabulary used to describe people living with HIV provided further insights into how this Othering was consistently reinforced throughout texts across diverse genres. Subject positions were drawn for social actors apropos of certain binaries- ‘health’ and ‘ill-health’,

⁹ Drawing on the OED definition of vector as ‘an organism...that transmits disease...from one animal...to another’ I use the term ‘vectorise’ to describe the way in which people living with HIV are positioned as sources of contagion and infection in such a way that de-emphasises their humanity whilst evoking an exaggerated sense of peril.

and 'high risk' and 'low risk,' for example. Consequently, PLHIV were implicitly framed as unhealthy and as a potential source of contagion. A further tendency to discursively frame people living with HIV in terms of 'redemption' as reformed or reborn characters was identified. Significant issues around the vocabulary and nomenclature used to describe HIV were also apparent. This included using HIV and AIDS interchangeably in such a way that may lead people to conflate the two and furthermore reproduce the idea of HIV as a terminal illness. Lastly, it was found that young people and especially young gay men were discursively constituted via discourses of risk and responsabilisation as dubious social and moral actors.

The key issues to emerge will be explored in greater detail below. Examples from the texts- located in appendix A- are provided in order to contextualise the analysis and explore the discursive construction of HIV via dominant hegemonic biomedical and neo-liberal frames and the positioning of people living with HIV via a discursive pattern of 'dividing practices' (Foucault, 1982, p.778).

Variations on a theme: hegemonic biomedical and neoliberal discourse

Biomedical models of health and illness have dominated the field of medicine for over a hundred years. Biomedical approaches are rooted in a positivist epistemological framework, emphasising 'cause and effect' processes that are divorced from social or cultural context, and which therefore de-socialise health and illness states (Filc, 2004). 'Health' is thus characterised as the absence of disease rather than an over-all physical, mental and social well-being. Clarke, Shim, Mamo, Fosket and Fishman (2003) coined the term biomedicalisation to describe the social transformation of health and medicine from around 1985. Among the key aspects highlighted by biomedicalisation is an emphasis on health in terms of risk and surveillance. Within this paradigm health is reproduced as a moral obligation, accompanied by attendant responsibilities for increasingly complex rituals of maintenance, self-regulation and the safe-guarding against risks (Clarke et al., 2003; Lupton, 1993). Furthermore, 'risk factors' occupy the same liminal space as signs and symptoms of disease, emerging as a salient predictor of illness, and therefore worthy of the medical gaze (Armstrong, 1995; Foucault, 1975a). Unlike signs or symptoms of illness however, 'risk factors' have 'no necessary fixed nor necessary relationship with future

illness' (Armstrong, 1995, p. 401). The space between health and illness is thus ambiguated and the normal is 'problematized' so that everyone is at risk in some way (Armstrong, 1995, p. 401). This necessarily means creating a hierarchy of risk categorisations in which individuals are designated as 'high' or 'low,' a binary that inevitably invites a logic of discernment in which high risk individuals are viewed as potentially dubious moral actors (Herek, 2003; Lupton, 1993, 1997).

The emergence of biomedicalisation, as per Clarke et al.'s (2003) conceptualisation, has been broadly contemporaneous with the rise to dominance of the neoliberal project. Definitions of neoliberalism vary and the term has been rendered vague and somewhat exhausted in a search for precise meaning, especially within the context of its use in the sociology of health (Bell & Green, 2016; Schrecker, 2016). It has been suggested that neoliberalism has simply supplanted the term capitalism with a more nebulous alternative (Garland & Harper, 2012). Elsewhere, it has been argued that the social sciences commonly interpret 'neoliberalism' in four distinct ways: as an ideology; as a set of policy prescriptions such as deregulation and privatisation; as form of governmentality characterised by the roll back of the State and the shrinking of social services; and as a set of complex relations of agency and responsibility between state and individual actors mediated by all of the former (Ward & England, 2007). Rather than dismiss neoliberalism as an imprecise and therefore limited conceptualisation, I agree with Schrecker (2016) that these various interpretations are 'best considered not as unconnected phenomena...but rather as elements of a complicated but coherent political project' (p. 478). For the purposes of this thesis, neoliberalism is understood as a dominant political project that inscribes values of individual responsibility and freedom of choice within policy frameworks that minimise the role of the State, endorse policies of 'austerity' and lionise the role of the market in fulfilling the unmet needs of citizens.

Certainly, a key feature of contemporary neoliberal discourse apropos of the Reaganite and Thatcherite iterations that came to prominence in the 1980s, is an emphasis on choice, individualism and the concept of personal responsibility. Margaret Thatcher especially promoted the idea that society is an illusion and individual responsibility was a moral exigency. In one of her most infamous quotes she asserted that 'there is no such thing as society. There is living tapestry of men and women and people and the beauty of that

tapestry and the quality of our lives will depend upon how much each of us is prepared to take responsibility for ourselves' (Thatcher, 1987).

Core elements then of both these discourses provide the scaffolding with which the HIV epidemic, in Ireland specifically, is framed in the media sample. The biomedical 'Voice' was the most prominent of the voices coded for directly in the sample (see Fig 5). This was followed by 'People Living with HIV (PLHIV), NGO/Advocacy and lastly Official/Political. When 'Voice' was cross-referenced against 'intertextuality', however, the biomedical voice was the most dominant of the 'Voice' types identified and coded (see Fig 6). Drawing on 'expert' testimony by authoritative individuals such as doctors, health professionals and other biomedical figures of expertise is a way of legitimising claims made within a piece (Fairclough, 1992b). This occurs for two reasons: firstly, the symbolic authority and elevated social status accorded to such figures lends legitimacy to their claims to speak the truth about the world 'as it really is'; and secondly, biomedicine is considered an epistemology that is a value-free pursuit which makes positivist ontological claims and thus has a greater claim to objective truth (Filc, 2004). The foregrounding of biomedical voices in journalistic reports and features on HIV present certain claims as to the truth or reality of the epidemic as seen from their perspective, so it is worth then exploring what is and what is not being said.

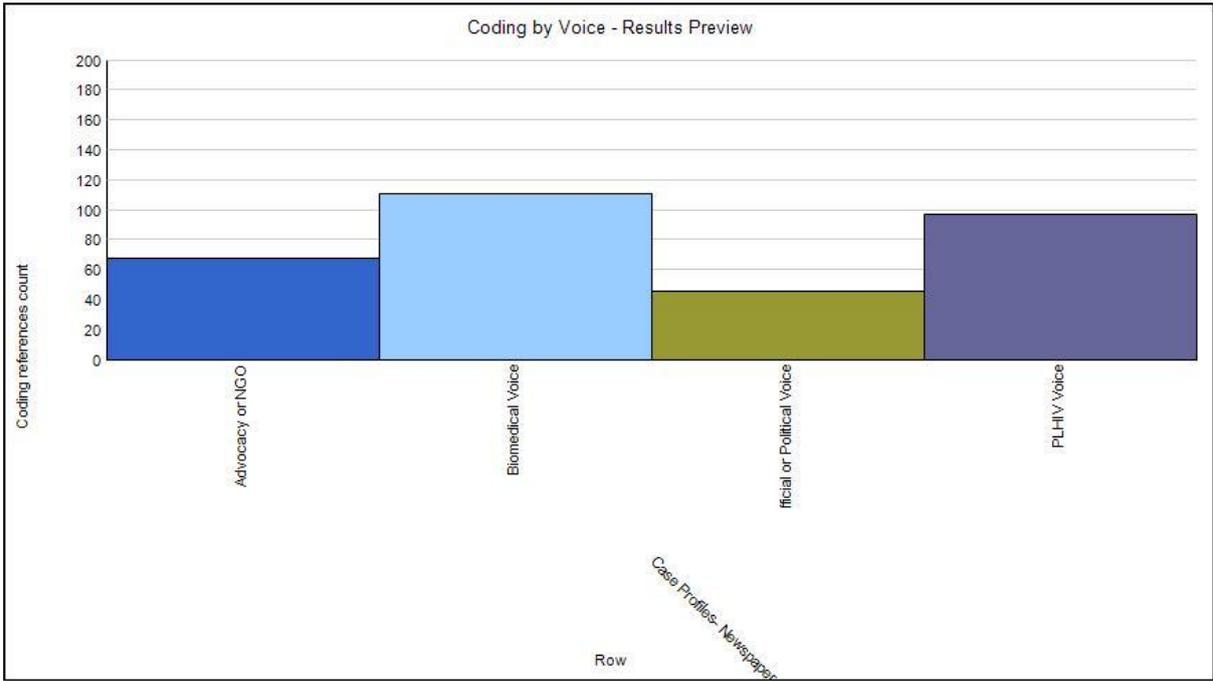


Fig 5: Coding by voice

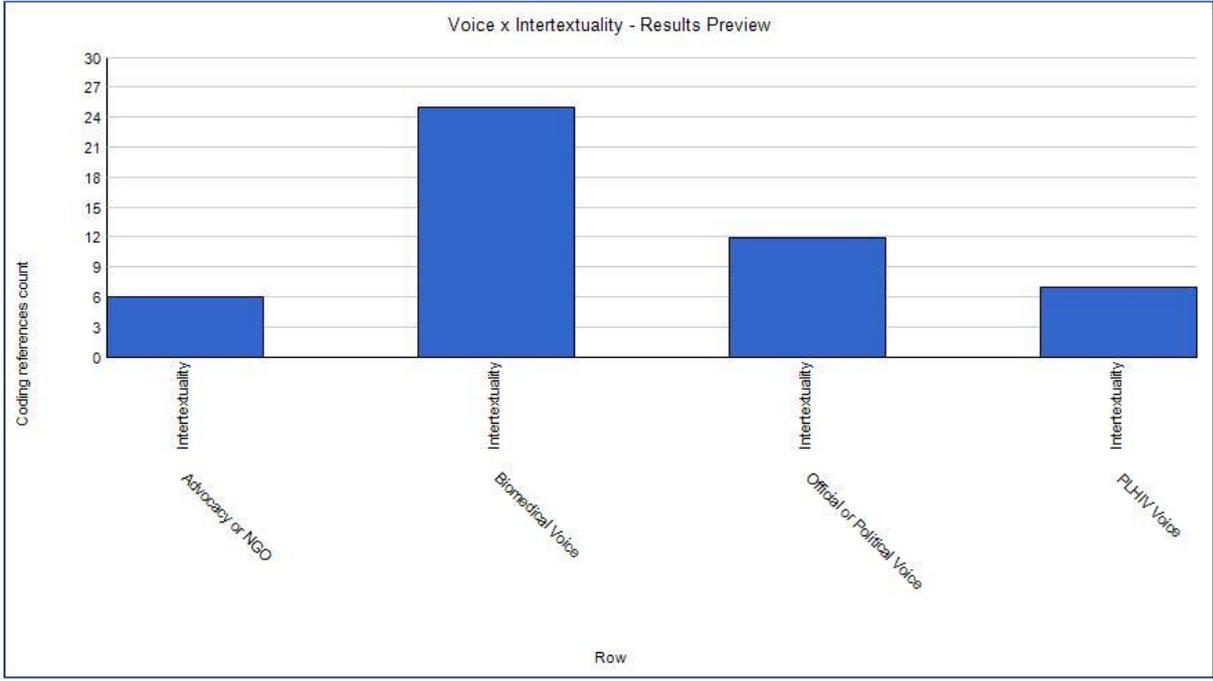


Fig 6: Coding for 'Voice' cross-referenced by Intertextuality

Discourse of risk

The theme of risk was identifiable in just under half of the articles coded (50/103), with 147 direct or indirect references to the concept of 'risk.' This rose to over half of the articles when the term 'danger' was included (52/103; 166 references). When the theme of risk was cross referenced against 'voice', this showed that this theme was overwhelmingly a feature of biomedical voices and perspectives (See Fig 7).

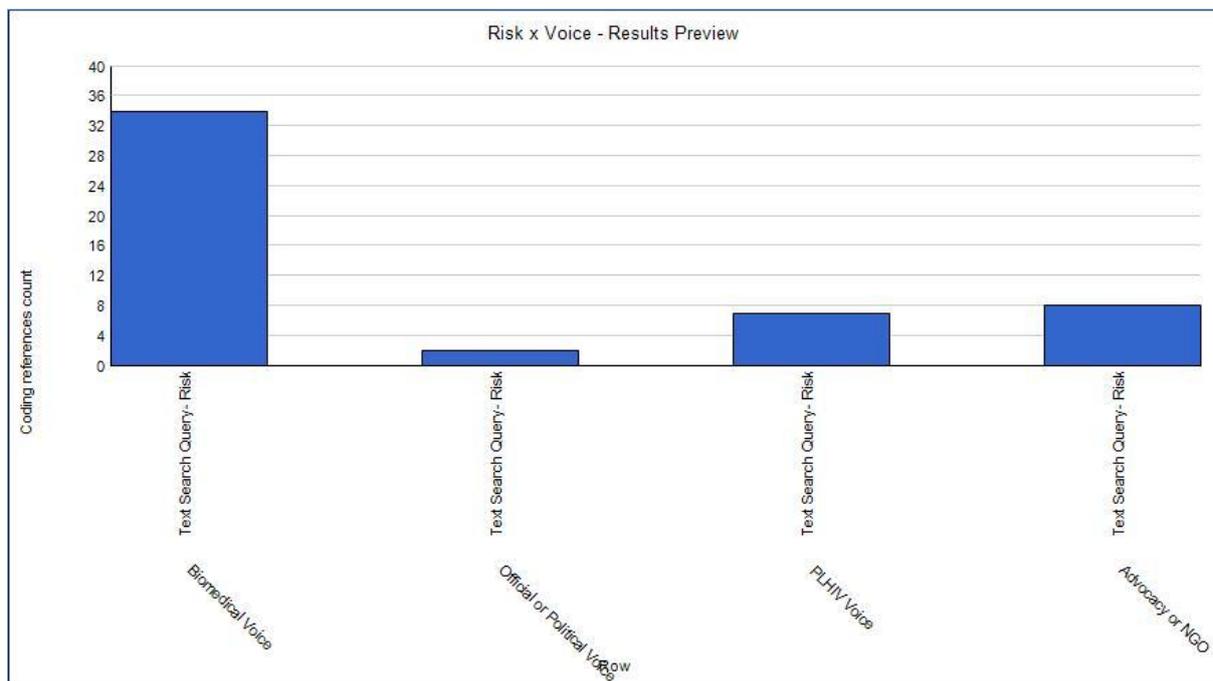


Fig 7: Risk cross-referenced by Voice

As Lupton (1993) has observed, the term 'Risk' in contemporary society is a highly loaded term and its usage cannot be considered neutral. Where once it had a meaning closer to 'probability' or 'chance', the word risk in modern parlance now carries negative connotations associated with physical and moral danger, and mortality. Lupton highlights the linguistic and moral distinction that is made between those that are 'at risk' and those that 'pose a risk', illuminating a lose-lose scenario if included in either category. She states, '...the dominant theme of lifestyle risk discourse is the responsibility of the individual to avoid health risks for the sake of his or her own health as well as the greater good of society' (1993, p. 429). Accordingly, ignoring health risks is often characterised as reckless and

immoral, putting both the individual and the wider community/society at peril and causing an unnecessary strain on public resources (Lupton, 1993).

Moral positioning, moral panic

The moral positioning of people in relation to the concept of risk was a common feature of many of the texts that engaged in the rhetoric of risk. Excerpt A is taken from an article published in 2008 in the Irish Independent. This article is typical of 'moral panic' style stories in which hyperbolised narratives are constructed around specific social issues in order to elicit a sense of concern and outrage in the readership in response to the contravention of certain social norms and the supposed breakdown of the moral and social order. Moral panic style narratives typically occur at the locus of social change and shifts in cultural normativity (Young, 2009). The subjects of 'moral panic' stories are often marginalised, disempowered or otherwise disenfranchised social groupings- in this particular piece, young people. The article describes 'Teenagers losing count' of sexual partners, drawing on the cultural trope of young people as irresponsible actors and the idea of a person having multiple sexual partners as something socially and morally transgressive. Although the words 'promiscuous' or 'licentious' are not used, this is what is implied. In the paragraphs that follow the author semantically links this social grouping and this behaviour with epidemiological information about HIV, implying responsibility for the uptick in new diagnoses:

The shocking testimony comes from the country's top expert on STIs as latest figures show that there is one new case of HIV every day in Ireland (para.3).

In the second and third paragraphs, the authoritative voice of the senior doctor, characterised as a 'top expert,' is inserted intertextually and directly to legitimise the claims made in the opening and subsequent paragraphs. The use of the adjectives 'frightening' and 'shocking' communicate that the story being told here should elicit a fearful or outraged response from the reader. Drawing on legal discourse, the writer invites the reader to hear the 'testimony' of the 'top expert' and judge for themselves those who are 'indulging in high-risk sexual behaviour.' The piece has a low degree of dialogicality- nowhere in the article does the author interview or speak to any young people. Thus the voices, and the agency, of those who are the subject of the opprobrium, are elided entirely. Also omitted

from the piece is the fact that the average age of diagnosis with HIV in the year this piece was published was 32-34, depending on cohort, with the greatest number of new diagnoses occurring in all adults between the ages of 25 and 39 (HPSC, 2009). The mean age of diagnosis the previous year was 32.5, reports of which are in the public domain and would have been available to the journalist at the time of writing.

Subjectification

In addition to the moral positioning of people affected or perceived to be affected by HIV, specific processes of discursive subjectification were observable in the majority of the pieces analysed. Such a process can be observed in Excerpt B. This piece discusses the potential introduction to Ireland of pre-exposure prophylaxis (PrEP), a highly effective preventative medication for HIV. While it would be difficult to characterise the piece as a 'moral panic' type story, the author certainly draws on some elements of this genre in constructing his narrative- asking provocative rhetorical questions and hinting at the potential for 'controversy' (para.3). Ultimately, however, the piece advocates for the introduction of PrEP. It may well be the case that the writer was ironically appropriating and subverting the genre, with subsequent editorial decisions in respect of headlines and sub-headings rendering it a more provocative piece than was intended. That proviso notwithstanding, there are several noteworthy features in the piece that highlight how difference is reproduced textually to elicit stigmatising responses.

As with the majority of feature pieces in the sample, while several voices may be observed, the biomedical is the most prominent, with quotes from an infectious disease consultant and intertextual references to clinical research studies providing the bulk of the contextualisation and rationale. After biomedical voices, the next most prominent are voices of NGO and other advocacy and support services. Finally, the voice of a single person living with HIV is provided to give some community perspective- although it is noteworthy that, like the piece illustrated in Excerpt A, there is no representation of the voices of those that are the subjects of the piece, the would-be, potential users of PrEP.

The theme of risk is fore-grounded from the outset, with the headline posing a rhetorical question- '*HIV treatment: pre-empting infection or encouraging risk?*' The fourth paragraph repeats these rhetorical concerns- '*Who should have it? Who will pay for it? And*

is there a risk that it could actually increase sexually risky behaviour? It is not until the 11th paragraph of the piece that this question is answered by the author, and the reader is assured that researchers have found no evidence of an increase in condomless sex among PrEP users and that as such claims of 'encouraging risk' are 'unfounded.' The description of potential candidates for PrEP as 'healthy, but high-risk people' provides an interesting example of the way in which texts such as this delineate distinct subject positions for two sets of social actors implicated- people living with HIV and people disproportionately affected by HIV. Firstly, the descriptor 'healthy' acts as a metonym for HIV negative people. Such a framing of HIV negative people sets up a dichotomy that necessarily draws on the reader's knowledge or assumptions that people living with HIV are 'unhealthy' (See also: Excerpt P, para.1; Excerpt N, para.24). As such, this circumscribes a subject position for people living with HIV that is synonymous with anachronistic representations of HIV that posit the bodies of people living with HIV as sites of disease and contagion. Furthermore it draws on and reinforces a hegemonic biomedical framework for understandings of health, which privilege the absence of disease as the gold standard for what it means to be healthy, rather than overall well-being.

This discursive dichotomisation of key affected populations acts as a rhetorical dividing practice that separates and labels difference in terms of binary conceptualisations of health/illness in the individual, and good/bad moral actors in the body politic. This binary additionally reflects and reinforces the suffixes 'positive' and 'negative' applied in the vernacular to describe people living with HIV and those not living with HIV respectively. The second descriptor, 'high-risk', directly precedes the word 'people' and, in the absence of the preposition 'at,' directly semantically links the concept of risk/danger to the person/social grouping, rather than indicating an increased vulnerability of that individual/group. These subject positions are then continuously repeated and reproduced throughout the text with vectorising descriptors/adjectives such as 'HIV-infected' used to describe people living with HIV and 'healthy' and 'high-risk' used to describe potential candidates for PrEP.

Excerpt P provides a further example of how the discourse of risk is utilised prolifically by journalists when writing about HIV. In this piece, the writer interviews a woman named Amanda living with HIV who is expecting her second child. Prevention of mother to child transmission (PMTCT) programmes have been among the most successful

prevention programmes. Consequently the statistical probability of vertical transmission from mother to child where the woman is taking antiretroviral medication is extremely low. In this piece however, the idea of a woman living with HIV having condomless sex and becoming pregnant is highly sensationalised.

The first paragraph discursively Others Amanda in much the same way observed in the previous two pieces, describing her as looking *'like any other healthy mother.'* Her difference is highlighted as she is described in highly loaded terms as *'a carrier of a potentially deadly virus.'* The pregnancy is framed by the author, if not the interviewee, in terms of a roll of the dice for father and baby alike via the author's choice of vocabulary and use of modal verbs: her husband *'risked having unprotected sex'* with her; the virus *'might be passed on to her unborn child'*; the condition *'could develop into full-blown AIDS.'* Amanda is repeatedly vectorised in the piece- she may *'infect her baby'* by *'exposing'* them to the virus (See also: Excerpt N, para.5). Additionally her statements and assertions in relation to motherhood are implicitly called into question, editorialised as *'controversial'* and *'bold.'* The writer automatically activates a negative framing of Amanda's life choices with the use of the term *'grotesque'* in the headline and again in the anthyphora¹⁰ in the sixth paragraph using the word *'reckless'*:

If it's another girl, then they'll probably try for a third child, they say, because they'd like to have a boy. And, no, Amanda does not think she is being remotely reckless in exposing her babies to a disease which continues to strike fear into the hearts of most adults.

The inclusion of the anthyphora itself serves to activate a negative frame by preemptively responding to an unasked question. It suggests to the reader that this is a reasonable response to the information given thus far: *'Isn't this woman being reckless?'* The use of these rhetorical devices and syntactic structures is designed to provoke an ambiguous and conflicted response in the reader- the headline invites the reader not to judge the woman, but the use of incendiary vocabulary and the negative framing set the reader up to do precisely that. The voice of the woman is included, as is mitigating information to support her point of view. Nevertheless the structuring of the piece using the

¹⁰ Anthyphora refers to a feature of rhetoric where one asks and/or answers a question.

techniques outlined above manufactures a sense of adversarial tension between the reader and the subject (Amanda) negotiated by the author.

Discourse of responsabilisation- The frame of 'complacency'

A 'common sense' assumption that seems to have gained traction in contemporary media discourses on HIV in Ireland is that the current dramatic rise in new diagnoses can be largely attributed to an attitude of 'complacency.' In the examples that follow, statements asserting the complacency factor are frequently modalised, either by posing the statements as questions or through the inclusion of modal verbs such as 'may be, 'seems to' or 'appears to be.' This is a key feature of speculative rhetoric. Beyond vague anecdotally asserted opinions however, no particular evidence is presented to support the view-point that complacency is indeed the source of the problem. Many writers proffer the opinion that the availability of antiretroviral medication is somehow a causative component in this complacency epidemic, but again, no specific evidence beyond speculative assertion is provided to support this. In addition to the lack of any tangible evidence for this position, is a lack of any meaningful interrogation or analysis of how or why such complacency, assuming its existence, arises. The availability and quality of sexual health education or programmes of health promotion, for example, are rarely mentioned.

Moreover, complacency is attributed mainly to individuals and specific cohorts, rather than structural, institutional or political complacency. Indeed, the minimal references to or critique of systemic failures in health policy implementation or practice was notable, despite this being a consistent feature of several policy documents and reports published in recent years (Barry & O'Higgins, 2008; NASC, 2010; Seery, 1999).

Two common features that emerged from analysis were:

- i) That 'complacency' was attributed mainly to young people and gay men: For example, *'HIV Rise: Being man enough to stay safe; Once considered a death sentence, HIV is now a chronic, treatable illness. But does this mean young gay men are becoming complacent about the disease, as a rise in HIV diagnoses suggests?'* (Excerpt C, Irish Times, 25/06/2015). (See also: Excerpt B, para.18; Excerpt C, para.2; Excerpt D; Excerpt E, para.8; Excerpt F, paras.1 & 3 ; Excerpt G, paras.3 & 4; Excerpt H, paras.8,9 & 10; Excerpt M, paras.61 & 62).

ii) The availability of treatment for HIV and knowledge of the treatability of HIV were routinely attributed as the underlying reasons for and/or cause of complacency. This was linked to a lack of fear of HIV and the assumption that this resulted in cavalier attitudes to sex: *'Ironically, the increased survivability of HIV made possible by the successful development of anti-retroviral drug treatments appears to have encouraged many young men to take the sort of risks which only four or five years ago their counterparts would have thought twice about.'* (Excerpt D, 'Complacency Danger on HIV', Irish Times, 02/12/2009). (See also: Excerpt C, paras.3, 4 & 5; Excerpt E, para.9; Excerpt F, para.3; Excerpt H, para.9; Excerpt M, para.62).

Taking Excerpt C: *'HIV Rise: Being man enough to stay safe'* (Irish Times, 25/06/2015) as a typical example of the discourse that is constructed around the complacency frame, both these features may be observed. This piece differs somewhat to others in the sample as a result of the higher degree of dialogicality. This is facilitated via the inclusion of several quotations from young gay men. The inclusion of these voices however, very much undermines the central thesis of the whole article. While the quotes in paragraphs 4 and 5 assert that *'people think: "I can take a pill and address it"'* and that *'young people don't view HIV as quite the horror that we did 10, 15 or 20 years ago,'* the view-points of the young gay men interviewed in paragraphs 8 through 12 refute this, revealing rather a prevalence of misinformation (*'People think it's like leprosy or something, that you can tell if people have it'- para.9*), a lack of knowledge (*'If someone told me a year ago you could get all this stuff just one time, I would never have done it. But being honest with you, I didn't even know'- para.10*), and a lack of visibility in the media (*'After getting tested I'll never do it again. But I didn't know. I'm not stupid, but no one ever told me . . . I've never seen an ad in the mainstream media about gay men and protection, I've only ever seen it in GCN [Gay Community News]'- para.11*).

Central to the premise of this discourse, is that the responsibility for one's own sexual health lies singularly with the individual. External and structural factors that may inhibit an individual's ability to do this with any ease are subordinate to this principle. This inevitably shifts responsibility away from policy-makers, health-providers and others tasked with managing matters of public health. By framing the acquisition of HIV in these ideological terms as something that is wholly in the control of the individual, then the

responsibility for acquiring HIV lies solely with the individual. Not only does this construction then facilitate the stigmatisation of PLHIV by assigning blame to those affected, it also permits the legitimisation for all the adverse outcomes that are experienced by PLHIV as a result of their serostatus. As Judith Butler (2015) has remarked, this 'notion of "responsibilization" ...designates such populations as accountable for their own precarious position, or their accelerated experience of precaritization' (p.144). Furthermore, the framing of the epidemic in this way established another binary distinction- between responsible social actors and irresponsible social actors- that is keenly reminiscent of prior media discourses that reproduced homophobic and divisive rhetoric circumscribing 'guilty' and 'innocent' victims of the AIDS crisis (Berridge, 1996; Treichler, 1999; Watney, 1997).

Complacency, homophobia and (il)legitimate sexualities

Excerpt F, *'Ignorant youth deliberately seek twisted 'gift' of HIV'* (Sunday Independent, 06/12/2015) provides an example of how the 'complacency' theme may be weaponised to reconfigure homophobic guilty/innocent dichotomies, as well as being emblematic of the type of discursive strategies that are used to distinguish between legitimate and illegitimate sexualities. Despite the hyperbolised style, this article was published not in a red-top tabloid but in Ireland's top-selling newspaper, the Sunday Independent. Ostensibly, the piece is about 'bug-chasers,' a reference to HIV-negative gay men that engage in bareback (condomless) sex and seek to deliberately acquire HIV. It was one of two articles on this subject in the sample- both from the Independent News Media (INM) group, a media conglomerate that tends towards a conservative ideological alignment.

Before sharing analysis of the piece it is necessary to provide some context. The 'bug-chasers' story appears to have come to some prominence in 2003 following publication of an article in Rolling Stones magazine (Freeman, 2003). In the Rolling Stones' piece, which interviewed both gay men alleged to take part in this practice and doctors who were aware of it, it was claimed that 25% of new HIV diagnoses among gay men in the US were a result of so-called 'bug-chasers' (Freeman, 2003). However, doctors and one of the men interviewed and quoted in the article subsequently claimed they were misrepresented, refuting the assertions that were made and attributed to them (Newsweek, 2003).

Irrespective of the veracity or accuracy of that particular Rolling Stones' article, studies have shown that this subculture does exist (Halkitis & Parsons, 2003; Halkitis, Parsons, & Wilton, 2003). There is, however, little evidence to suggest that this is in any way a common or wide-spread practice (Halkitis & Parsons, 2003; Halkitis et al., 2003; Moskowitz & Roloff, 2007). While it is clear that the phenomena is more apocryphal tale than common practice, the 'bug-chasing' story had many elements to it that make for sensationalist 'click-bait' type media fodder and as such was reported on more extensively than clearly was warranted. Consequently, the 'bug-chasing' phenomenon has become somewhat of an urban legend in some contemporary news reporting on HIV that has nonetheless endured and continues to be sporadically reproduced (Blum, 2016; Channing, 2016).

In the article (see Excerpt F), the practice is described in the headline as a '*trend*', suggesting that it is commonplace and/or popular among young gay men. In loaded language more commonly found in tabloid publications than broadsheets, the men who are supposed to have engaged in this practice are described as '*warped*', '*ignorant*', '*arrogant*' and '*giving two fingers*' to those who have died of AIDS (para.19). This characterisation of gay men as lacking in empathy and heedless of the context or consequences of their actions hints at psychopathy, drawing on historical discourses that pathologised gay men and positioned them as aberrant and predatory (Helmets, 2016). Although this description is directed specifically at 'bug-chasers,' the assertion that this is an increasingly popular practice clearly implicates all gay men as a potential threat.

In the fourth paragraph, this potential threat is aligned with 'drug users'- another regularly maligned group- and an explicit moral distinction is drawn between these groups and the '*common upstanding citizen*.' In the same paragraph this threat is juxtaposed against the erroneous claim that HIV had '*risen by over 400%*' among heterosexuals, thereby implicitly semantically linking the threat posed by these two groups with such a staggering increase.

By contrast to the discursive construction of gay men and drug users, the author recounts a strangely dislocated anecdote about 'Martin,' a young straight man. He is described in the piece in superlative terms- he is '*educated*,' '*quiet*,' '*middle class*,' with a '*good job*,' and from a '*respectable*' family. The portrait of 'Martin' draws on the discourse

of hegemonic masculinity; his behaviour is not described in sinister language, rather he is *'adventurous'* and his sexual encounters are characterised as *'conquests.'* This is further exemplified by the reference to *'GAA jerseys'* and young men engaging in sex tourism in *'shady corners'* of presumably exotic and developing countries. Consequently, a blunt dichotomy is drawn between the behaviour and practices of young straight men and young gay men (See also: Excerpt H). For the former this is a socially acceptable and even expected type of behaviour, whilst for the latter such practices are aberrant, irresponsible and ultimately immoral. Thus it keenly recalls Foucault's assertion that 'sex is placed by power in a binary system: licit and illicit, permitted and forbidden' (Foucault, 1976, p. 83).

Other features of note during analysis were the overwhelming number of references to death and dying- twelve direct or oblique in total, in comparison with two mentions of HIV treatments (for example: *...the worst type of slow and agonising death possible* (para.12); *...what would any of the 39 million people who've died slow, agonising Aids-related deaths say?* (para.19); *...all those before them that succumbed to this terrible disease* (para.19). The use of the term *'pre-corpse club'* to refer to AIDS patients in paragraph 11 is a particularly callous epithet and one which is rather difficult to imagine being applied acceptably to people with other terminal illnesses.

The author's use of HIV and AIDS interchangeably in paragraph 8 suggests they are the same thing. This is compounded by his assertions in paragraphs 10 and 11 where he describes in vivid terms Martin's 'lucky' escape in testing negative for HIV. Such a proliferation of references to death and the characterisation of Martin's negative test result revive and reinforce anachronistic notions of AIDS that are incongruent with the contemporaneous experience of living with HIV in the era of antiretrovirals. There is also an inherent contradiction between the assertion made in paragraph 3 about people being complacent because of knowledge about treatment and the claim made in paragraph 10 that *'people remember the horrors'* of the early days of the AIDS crisis.

Lastly, dialogicality in the piece is near non-existent. For example, nowhere in the piece are 'bug-chasers' or any gay men interviewed. Given that 'Martin's' story is absent of

direct quotation, there is reason to believe that this too may be an apocryphal tale and that the only real voice contained in the piece is that of the author.¹¹

HIV as terminal illness

A feature of many of the articles in the sample was a tendency to produce conflicting or ambiguous messages about HIV. Many pieces sought to provide a comprehensive overview of the condition dealing with such things as the epidemic as specific to the Irish context, its history and its current status as a treatable condition. Yet in doing so would fall back on using hackneyed narratives that reproduced obsolete portrayals of HIV as a terminal condition and implicitly conflated HIV with AIDS. The legacy of AIDS looms large in the media and recent cultural history, so perhaps it is unsurprising that even when trying to tell another story, writers veer into more familiar territory, drawing on prior discourses of AIDS that to a large extent are no longer relevant in contemporary context. Whatever the reason, the history of the AIDS epidemic and representations of it clearly still exert a significant influence in the imaginations of many writers as they seek to write about current realities.

One of the more common ways in which this occurred was to describe 'HIV' in terms of what it is not. Phrases that were used quite frequently in this context were the collocations '*death sentence*' or '*fatal condition*' (See Excerpt C, sub-heading & para.3; Excerpt M, paras.3 & 59; Excerpt F, para.3). The 'death sentence' metaphor in particular is rather loaded for its connotations with crime and punishment. Additionally there is the implicit suggestion that if HIV is 'no longer a death sentence' then it must be a life sentence. Indeed, in one of the texts this exact phrase was used. Another way in which this occurred was via often graphic descriptions of symptoms former AIDS patients had experienced and expositions on 'agonising deaths' that were suffered in the past (See Excerpt F, para.12; Excerpt G, para.1). Certainly, descriptions of HIV as a condition that people can live very well with were rare by comparison and were often hedged elsewhere. Absent of other frames of reference to describe the contemporary reality of life for the majority of people with HIV

¹¹ This viewpoint was compounded by my experience of contacting the author of the piece. Despite initially agreeing to answer some questions about the article, the author failed to respond to subsequent follow-up emails requesting information about the erroneous figures cited and where he obtained information about the phenomenon of 'bug-chasing.' Shortly after my contact with him, the article, which had been archived online at the Sunday Independent website, was removed.

and, given the tendency to position people living with HIV as 'unhealthy,' this created a sense of doubt and ambiguity as to the potential to live well with the virus. This was furthermore compounded by a tendency towards conflicting and contradictory messages, observable for example in Excerpt M. In this piece the writer states in the third paragraph that HIV is '*no longer a death sentence,*' yet ends the piece with a quote that asserts '*People think, "Ah, I'll do it just the once," but taking that one chance could be your last.*' Similarly in Excerpt F, the author of the piece talks about condomless sex as '*Russian roulette*' (para.12).

The concept of AIDS as punishment was further compounded by the constitution of HIV positive identities as reformed subjects (Excerpt O, para.1). Under this discourse a HIV diagnosis was frequently posited as acting as a 'turning point' in the lives of people affected, a catalyst for embarking on a different path (Excerpt M, para.60). Many of the people living with HIV who were featured or interviewed as part of stories on HIV were often volunteering or otherwise working to support other people living with HIV and to educate others about HIV prevention- practices which facilitated the creation of a certain narrative about their lives. A further iteration of this was the human-interest genre of news story that ostensibly sought to reduce stigma by framing a '*public face of HIV*' (Excerpt O, para.3). The resilience of the people featured in these pieces and the altruism of their actions is not being questioned here, rather it is the framing of their stories in such a way as to imply a certain redeeming quality to their actions and practices that is problematic, suggesting yet another dichotomy-sinner or saint. Certainly, this reinforces the concept of HIV as a moral failing, particularly given the discursive legacy of AIDS as 'gay plague' and the contemporary tendency to circumscribe HIV within discursive frameworks of risk and responsibility. Ironically, one of the clearest articulations of this 'redemption' discourse in the sample was found in a piece on actor Charlie Sheen, specifically positioning him diametrically to it:

Not that he intends to become a reformed character. No, in fact, if anything was clear from his TV interview it's that Charlie Sheen doesn't believe that HIV has the power to make him a better person. Nor does he seem to want it to. And he knows that this flies in the face of the modern belief that bad luck and disease and disability and tragedy are given to us in order that we do some good with them. Charlie Sheen isn't having that (Excerpt L, para.7).

HIV, AIDS and nomenclature

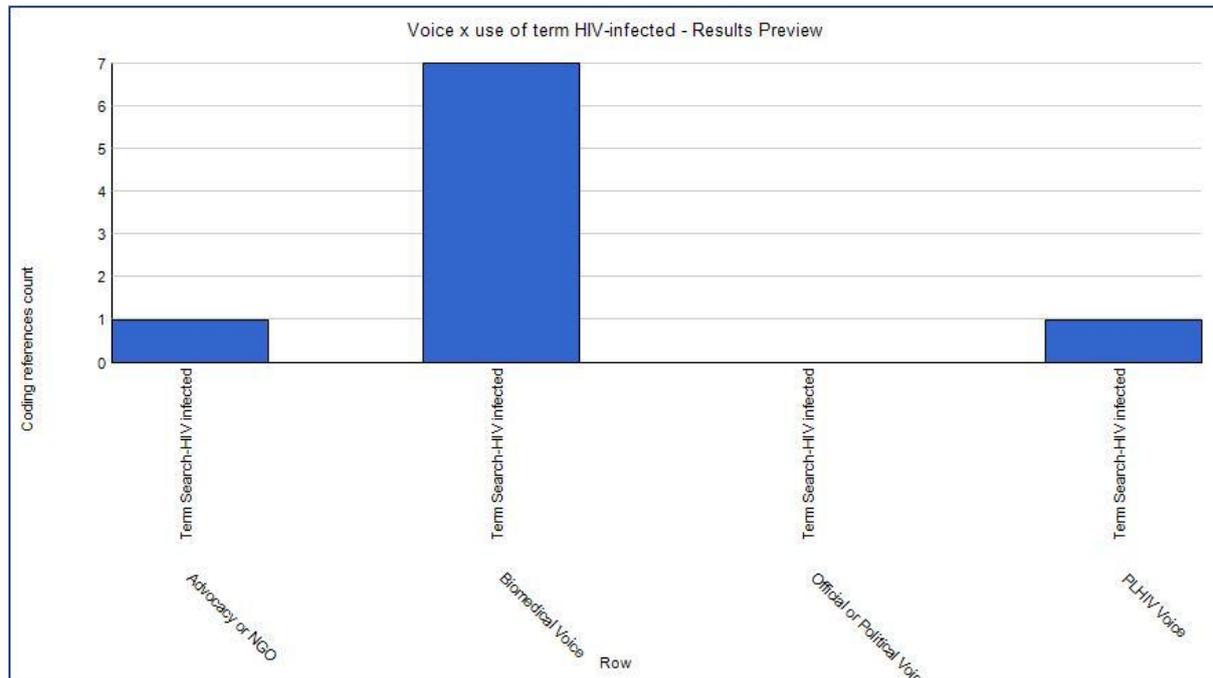


Fig 8: Voice and use of term 'HIV infected'

Interview participants in this study voiced strong opinions about the language used around HIV. One of the things that interviewees found particularly frustrating was the tendency of many people to conflate HIV and AIDS and the ignorance of the difference between the two. Analysing the newspaper texts in the sample it was clear that consistency and application/usage of correct nomenclature was a problem across all publications included in the sample. Almost no articles drew clear distinctions between HIV and AIDS and indeed more often than not grouped the two together as 'HIV/AIDS,' 'HIV and AIDS,' 'HIV-AIDS' and 'HIV or AIDS.' Such references numbered 129 in total across 48 articles.

However, many publications did use the preferred moniker 'people living with HIV' with 56 references across 30 articles, suggesting a gradual shift towards more non-stigmatising use of language. The term 'HIV positive' was by far the most common moniker with 189 references across 72 articles. Analysis further showed, however, that the term 'HIV-infected' and its derivatives-for example, 'infected with'- are still used frequently with 147 references across 40 articles. When cross-referenced against voice it was apparent that this phraseology was most commonly used in the dominant biomedical discourse (See Fig 8). 'HIV-infected' is a particularly loaded term and various patients' rights groups, advocates

for people living with HIV and even UNAIDS strongly discourage its use for its stigmatising impact (Dilmitis et al., 2012; UNAIDS, 2015).

Differences in reporting domestically and internationally

Significant differences in reporting on HIV domestically and internationally were apparent within the sample. Of the total, 73 articles dealt with HIV in a domestic context (Ireland or the UK), and 30 had an international focus, with 14 articles on HIV in Africa and an additional 13 on Russia, China, Thailand, the US, among others. Among the topics that were covered were the international research agenda, for example reporting on vaccine trials, medical breakthroughs, and reports from international conferences and meetings of the WHO and UNAIDS. The articles that had a country or continent specific focus however placed a much greater emphasis on political and policy issues than on individual behaviours or risk groups. This was in stark contrast to feature pieces that examined the HIV epidemic in the Irish context, where politics and policy were referenced minimally, if at all.

Topics that were covered in the international pieces included funding for prevention programmes, access to treatment and prevention, legal and policy frameworks for addressing the HIV epidemic, the impact and effects of inequality, stigma reduction measures, harm reduction measures and the roles of the government, the media and aid agencies (See excerpts I, J, K and N). Interestingly, the complacency frame that was such a prominent feature of Irish reporting on HIV was almost entirely absent from the African/International articles, with the exception of one piece where it received one line (Excerpt I, para.19). The formulation of this frame is a little different however, with the writer claiming that 'complacency' has arisen not because of the availability of treatment but the opposite, because of an habituation to seeing people get sick and die. As such, while 'complacency' was posited as the primary cause of the rise in new diagnoses in the Irish context, lack of political commitment and a coherent policy framework were frequently attributed as the drivers of epidemics in Africa, Russia and elsewhere (Excerpt J, para.2).

At the same time, within both domestic and non-domestic articles, there was a tendency towards Othering of various subjects, including people living with HIV. For example, Excerpt I examines the role of the media in reporting HIV in Zambia. In the opening paragraph the writer describes the difficulties of engaging readers on the topic of HIV in

Africa, stating *'the subject and location seem so distant from us in every sense'* (my emphasis). In the following paragraph she questions what HIV looks like in *'the place where it is a daily reality?'* This raises questions: who are the collective indicated in the pronoun 'us'? Is the subject matter really that irrelevant to an Irish audience or just some members of an Irish audience? Who then is included and who is excluded from this 'us'? Is Ireland not a place where HIV is a *'daily reality'* also? With her statements the writer is making both propositional and existential assumptions about her readership, about who is and who is not affected by HIV, about how and where HIV occurs and about who counts in the collective 'we' or 'us.' People living with HIV in the West are entirely elided from the 'us,' implicitly Othered and made alien as the writer emphasises their distinctness *'in every sense.'*

Moreover, a distinction is made in this piece on the different roles played by media in the West and in Africa in regard to the HIV epidemic, asserting that the media in Africa, *'unlike media in the West'*, serves a social function by promoting public health messages and helping to reduce stigma (para.7). The writer does not make it immediately apparent what the function of the media in the West is, however, in the final paragraph it becomes clear as the discussion turns to the value of sensationalist stories that *'will sell papers.'*

Excerpt N provides a similar example of journalistic tendencies to position HIV-positive identities in relation to the 'Other.' In this piece such subject positions are circumscribed for a variety of social actors- women, Africans and people living with and/or affected by HIV, whilst the writer himself is positioned as the innocent party. The writer's African girlfriend is vectorised as he states it is she who *'has infected'* him (para.5). Acquiring HIV is associated with shame and he describes how he feels he has let his family down (para.6). He jokes with his pal that he is 'no Mick Jagger,' a joke that draws on assumptions about male sexuality and the stereotype that HIV is acquired via prolific sexual behaviour (para.7). When he finally receives the news that he is in fact HIV negative, he is elated at being 'healthy,' 'normal' and 'free,' necessarily assuming/implying that to be otherwise is unhealthy, abnormal and imprisoned.

Conclusion

Analysis of texts showed that biomedical and neoliberal inflected frameworks of understanding of health and illness dominated newspaper coverage of HIV in Irish media, with concepts of 'risk' and 'responsibility' informing how the HIV epidemic in the Irish context was discursively constituted. Individual risk-taking behaviours and attitudes of specific cohorts of people, particularly young people and young gay men and the theme of 'complacency' were identified as key components to a discourse of responsabilisation. Texts with a focus on HIV in the Irish context were notable for the lack of emphasis on social, cultural, and political factors; however, the opposite was true of news articles with an international and, particularly, an African focus. Subject positions for social actors, including people living with HIV, were constituted via discursive 'dividing practices'. Considerable vectorisation of people living with HIV was identified via the prolific use of loaded terms such as 'HIV-infected.' Analysis of texts further showed the potential for readers to conflate HIV and AIDS due to inconsistent use of nomenclature and writers' use of these terms interchangeably.

Chapter Five: Findings from Qualitative Interviews

Introduction

The findings of the media data analysis showed a discursive pattern of Othering of PLHIV within biomedical and neoliberal frames that emphasised risk and responsibility. Discursive ‘dividing practices’ were identified that circumscribed HIV positive subjectivities as lacking in health and furthermore vectorised individuals as potential sources of physical and moral contagion. This was particularly reproduced by use of biomedically inflected terminology through use of nomenclature such as ‘HIV-infected.’ This was reinforced by its prolific use by authoritative and dominant biomedical ‘Voices.’ HIV and AIDS were regularly conflated and many texts reproduced anachronistic discourses of AIDS that re-invoked ideas of plague and death.

The findings outlined in this chapter will show how some of these discourses mediate the stigma experiences of the PLHIV interviewed. Quotes from individual interviewees are embedded throughout as a representation of collective experiences and overall findings. The first part of this chapter explores context specific experiences of HIV-related stigma in healthcare settings, in the family, in work and employment and in relationships and dating. Distinct experiences of enacted stigma are identified within healthcare settings, mediated largely by fear of PLHIV as sources of infection. Containment of the ‘risk’ of infection from PLHIV becomes a salient factor in the differential treatment of PLHIV within such settings. Anticipated stigma is further identified as a barrier to engagement of PLHIV with healthcare services, while internalised stigma emerges as a barrier to adherence.

Interviewees further outline how experiences of enacted and perceived stigma in micro-level interactions in the family, work and within dating and relationships are frequently mediated by assumptions about infectiousness and myths and misconceptions about HIV and its transmission. The picture to emerge is one in which PLHIV have to navigate such interactions with a degree of caution and where decisions to disclose status are fraught with tension relative to the potential consequences

The second part of the chapter explores in more detail the interactions between the symbolic sphere and the social field. Utilising Bourdieu’s (1977) concept of habitus,

interviewee experiences with stigma are explored by situating them within this framework and specifically examining instances of symbolic and structural violence that shape and constrain the actions, interactions and behaviour of PLHIV. A culture of silence and secrecy emerges within which PLHIV are induced to keep their status hidden through various inducements to silence at different levels of interaction within the social field. A homology of positions between the symbolic and the social field is revealed as the findings show how the macro- level discursive construction of HIV outlined in Chapter Four coalesce and overlap with the micro- and meso- level experiences of stigma of PLHIV. Furthermore it is shown how the subjectification of PLHIV produce specific affective and cognitive effects that elicit a sense of 'Other,' and the ways in which this can mediate interactions of PLHIV in the social field is explored.

Lastly, the third part of this chapter briefly explores some of the strategies through which interviewees resisted stigma, looking specifically at social solidarity, humour as a coping mechanism, activism and the desire for meaningful engagement of PLHIV in decision-making practices.

Part One: Context specific experiences of stigma

Healthcare settings

While there was a general sense of satisfaction with care received by medical personnel in the HIV clinics attended by interviewees, issues of stigma and discrimination arose for most participants in healthcare settings outside of this context, with all but two participants reported having experienced some form of stigma. These ranged in severity and mechanism from non-disclosure or avoidance of particular services as a result of anticipated stigma, to enacted stigma in the form of denial of service or altered or conditional terms of service by medical personnel.

Dentists

Experiences of stigma within the context of dental care varied, with both anticipated and enacted stigma reported. A number of participants reported anticipated stigma, with one interviewee- Jamie- asserting that he avoided attending a dentist's for sixteen years. Initially he said that this was due to a fear of dentists generally. This fear was, however, compounded by his positive HIV diagnosis, after which he decided he would 'go nowhere

near it.' Jamie's anxieties about attending a dentist were further exacerbated by anecdotal knowledge of discrimination towards HIV positive people by dentists. Specifically, his long term partner- also living with HIV- had attended a dentist who would only provide service to the man on the condition that he attended the final appointment of the day. This type of conditional service was also reported by another interviewee who, upon disclosure of status, was initially told by a dentist that he did not 'deal with that,' before ultimately offering the compromise of attending to the individual at the end of the day, a compromise that was declined.

Further to the experience of altered or conditional terms of service were encounters with dentists who employed excessive risk management strategies to 'deal' with HIV positive clients, with two participants reporting that dentists donned extra pairs of gloves to perform dental work on them. Such actions were commonly described as 'demeaning.' Similar to this, Aoife, spoke of her shock at the response of one dentist to her status:

And in one of the particular dentists they charged me a €100 more for their own protection, for wearing I don't know what or doing what exactly. I was so taken aback by it that I never really looked in to it. I just said I'm never going there again.

In Bernie's case it was not an extra fee but complete denial of service that followed disclosure:

I said to him, 'Look I need to tell you, you know I found out I was HIV positive, but I'm ok. You know, my bloods are good. I'm undetectable and everything.' And he kind of started laughing and he goes, 'Oh right, I'll just put extra gloves on.' And he spent about two minutes cleaning my teeth and said, 'That's grand. You're done.' And I was like, 'I thought it was going to take half an hour?' 'Oh no they're fine, they're fine,' he said. And then every time I rang for an appointment they said they couldn't take me- that they were booked out for the next six months.

A desire to avoid the kind of scenarios outlined above was cited as a primary motivator for non-disclosure to dentists, illustrating how anticipated stigma may mediate engagement with health services:

I've taken an approach, in consultation with my doctor, knowing that I'm undetectable and on treatment, that dental work- that they are trying to take universal precautions, and that there's no risk to them. And so I don't disclose just to avoid any unnecessary uncomfortableness (sic) on anybody's part. So that's been my approach- is not to disclose (Charles).

Issues around confidentiality, potential forced disclosure and insensitivity to concerns of patients around this were further raised by interviewees. One such encounter involved an experience in hospital for a surgical dental procedure. The encounter revolved around the lack of consent sought for the inclusion of several medical students- potential peers of the interviewee- during a post-surgical consult and occurred not long after he had been diagnosed with HIV at the age of 21:

And he came back in with 10 students...they were all young people around my age. And I nearly died because they were all like looking at my charts. And I was like...I don't know what it said, it mightn't have said HIV. But at that time and in that mind-frame when I wasn't that comfortable with HIV myself. And these are all like people who could potentially know me or know of me, because Dublin is quite small. Ireland's quite small. So that was terrifying. You know? That fear (Danny).

GPs

By and large, interviewees' experiences were mostly positive with regards to GP care, with only two reporting any significant experiences of Enacted Stigma. Of these, one recounted a denial of service which occurred in 1998. Declan described how this occurred in the context of him switching GPs upon the retirement of his old GP. Of concern also in this account of his experience with the GP service was the apparent breach of confidentiality via forced disclosure of status to non-clinical staff in the GPs office:

I applied to one GP and I mentioned the HIV on the form or whatever when I sent it in and when I went back to get the decision- I didn't speak to the doctor but the receptionist kind of took me aside and said that the doctors wouldn't take me on because they felt they wouldn't have the specialist knowledge and I was kind of annoyed at that for, I suppose mostly because they didn't tell me themselves like.

That they left it to the receptionist to talk to me. And I sort of could maybe see their point of view. That the GP is general. But it still betrayed kind of a lack of knowledge about ... which was then, well, not common, but it wasn't a new disease, you know (Declan).

Another participant, Terry, outlined what he perceived to be a negative response to disclosure of status to his family GP, described by him as 'old fashioned' and backward.' Terry recounted that the doctor responded to the news of his status by grunting in a manner interpreted by Terry as an expression of disgust. He furthermore said that he believed the GP to be 'relieved' when he requested to switch to another doctor. It was, in Terry's words, his 'first encounter with, that whole area of stigma kind of thing like.' Terry was satisfied with the reception he received at his subsequent GP, but noted that the physician admitted that 'he knew very little about it, but that we'd work together between me, him and the clinic.'

This lack of knowledge about HIV in relation to GP care was a point echoed by Jamie who outlined how his first visit to a HIV support service related to his frustration in searching for a GP with knowledge about HIV. He indicated that this was not an uncommon problem among peers he had discussed this with. He further outlined the problems faced by PLHIV living in small, rural or tight-knit communities- indicating the depth of anticipated stigma that was experienced, specifically in relation to potential forced or accidental disclosure. Fears in this respect often prompted people living with HIV to travel extensive distances to other towns or cities for GP care:

The first time I ever came here (Support Service) was I wanted a GP where I wouldn't have to explain what HIV was. Some people just wouldn't tell their doctor. Some people tell their doctor and it turns out that they know more than their doctor. And some are from such small communities. One person was saying his sister and his aunt worked in the local health centre so he can't- so he has to travel from somewhere godforsaken, like Galway (Jamie).

Non-disclosure to primary care physicians was furthermore reported by Anna as a response to fears that confidentiality would be breached by non-clinical staff at the GPs she attended.

This was largely motivated by anxiety over the perceived risk that news of her status would be relayed to other parents at her children's school:

I never told my doctor either because I thought I can't tell the doctor in England down the road because I didn't trust the receptionist. So I never told the doctor. And when I went with the shingles, they didn't give me the treatment. If they knew I was HIV positive, they'd- I'd have got the treatment straight away, but I deliberately didn't tell the doctor, which I think is mad now because, you know, what if the receptionist said it to one of the mothers in the school or something? (Anna).

Lastly Danny reported an interaction with his GP who questioned him about how he had acquired HIV during his first visit with him shortly after Danny was diagnosed. This was a question he felt to be inappropriate and particularly insensitive given the proximity to the time of his diagnosis. Although he was annoyed and disappointed by it, Danny indicated he felt too emotionally vulnerable and 'lifeless' at the time to self-advocate or challenge it.

Other Medical Settings

While many interviewees reported positive interactions or had no negative interactions to report in medical settings outside of the HIV clinic context, experiences of enacted stigma were reported by several interviewees in a number of different settings and across a sliding scale of severity. Most of these encounters revolved around the differential treatment motivated by an apparent fear or concern on the part of clinical staff about HIV transmission. Charles, for example, noted that he was segregated from other patients during hospitalisation when, he felt, it was not necessary. He also had the impression that staff were avoiding engaging with him. Aidan recounted how, in the early Nineties, he was obliged to wait until the end of the day for a procedure to be performed, echoing the experiences of several other interviewees in the context of receiving dental care. Declan reported how he perceived that the doctor 'seemed a bit surprised or kind of not quite sure of himself somehow' when he became aware of Declan's status and furthermore noted that he mentioned 'something about taking the extra precautions.'

This theme of taking excessive or extra precautions arose for a number of interviewees. Bernie and Jamie also reported having encountered enacted stigma by

medical staff, both in the context of having scoping procedures. Jamie had to undergo a bronchoscopy at a hospital in Belfast in 2010, only to find that the room in which the diagnostic test was being carried out was all covered in plastic. Jamie, a qualified nurse, believed that this was a precaution to safeguard against transmission far in excess of standard universal precaution protocols and interpreted this as a discriminatory action. Like Danny with his GP, Jamie felt too vulnerable at the time to challenge the medics involved.

For Bernie, an encounter with a doctor in a Dublin hospital in 2009 resulted in her scheduled appointment for an endoscopy being postponed when the doctor who was due to perform it refused to tend to her. She described an interaction with the doctor just prior to the procedure:

They had me already prepped. The needle thing and all in me. And he went through my chart and he sat there and he just went, 'Oh, you're HIV positive, I didn't know that.' And I said, 'Well what difference does it make?' I said 'Eh, sure I'm sure you clean everything after each person.' 'Oh I can't do you,' he says straight out. 'I wouldn't be able to deal with you. Maybe they'll do you at James' today. And he walked out of the room and I never saw him again (Bernie).

Bernie outlined how, upon asking to speak to someone in charge, she was met with a woman who told her they had to 'be careful.' Bernie told the woman that it was not good enough and that she was not leaving the hospital until she received the procedure. She explained that she had taken two days off work in order to have the procedure done and could not possibly request any more time off to return another day. She was then obliged to wait until the end of the day until another doctor became available to perform the endoscopy. In an illustration of further difficulties involved in self-advocacy, Bernie recounted how she looked into complaining formally through the equality tribunal but was advised that in order to do so, she would run the risk of her name and complaint being made public. This was something she felt unable to do because she did not want her status known at work. Bernie further reported having to attend for a second scoping procedure two years later at a different hospital in Dublin. This time she said the doctor had a similar surprised reaction when he realised her status saying, 'Oh! You're HIV positive...I have to check this.' On this occasion, however, she said a nurse who was present apologised to her

straight away, had a word with the doctor outside the room and the procedure went as planned after that.

Questions by medical staff about how their patients' acquired HIV were deemed inappropriate, not just because of the apparent or perceived medical irrelevance to any treatment or procedure, but because it was felt that there was an implicit moral judgement involved in asking the question. For example, although Terry had no particular experience of differential treatment as a result of his status, he remarked how a question from a consultant about how he had acquired HIV 'threw' him. Though he said nothing in the moment, he later brought up the issue with her colleague and challenged him on the response he received:

Because when he said he was finished I said, 'Look...' - he was going to talk to her about my results and then get back to me. And I said, 'Ok. While you're in with her,' I said, 'Could you ask her a question? I want to know why she asked me how did I contract HIV. 'Because,' I said, 'I don't see the relevance of that question.' 'Actually,' I said, 'I was a bit insulted, to tell you the truth like.' So he came back and he said she said it was to do with that if I had gotten it through drugs, the treatment could be different. The way the bowels are affected or something. I said, 'Sorry, that doesn't pan out at all.' I said, 'I'd still be getting the colonoscopy, I'd still be doing it. I have HIV. It really is irrelevant how I got it' (Terry).

In Terry's case, his frustration about this issue was quite apparent during the interview. Indeed this issue of moral judgement and the assignation of responsibility for one's status was raised more than once. It was something he felt happens frequently in medical, and other, contexts in relation to HIV. This sentiment was echoed by Bernie in discussing interactions she had had with medical staff outside of the context of the HIV clinic:

The doctor would be like, 'Oh, you're HIV positive... Oh, how did you get that like?' And I'd just say, 'Does it matter how I got it?' That's always my answer.

Nursing

Experiences with nursing staff were mixed. Notably, all the women had positive experiences of nursing staff. Bernie, for example, had high praise for nurses, saying she finds

they are always 'lovely', as did Joy whose experience of nursing and midwifery staff during her pregnancy was completely positive. Anna commented on the intuitiveness of a nurse who was looking after her- how he picked up on something she said about feeling 'dirty' and immediately linked her in with a counsellor on site. Several other interviewees, however, reported problematic encounters with nursing staff. One interviewee-Charles- felt nursing staff in particular avoided him during a stint in hospital for treatment for meningitis. Jamie noted that nursing staff with whom he had worked previously, and who were unaware of his status, had discriminatory views on patients with HIV and often 'would tend to refuse' to attend to patients with HIV or Hepatitis. Two of the interviewees who were/are injecting drug users, singled out nursing staff in particular as having treated them in a discriminatory, even hostile, manner. Aidan, for example, noted that the attitude of staff towards him during several hospital visits was one of distrust and scepticism. He related an incident regarding an occasion of hospitalisation for E-coli infection during which he had an unpleasant encounter with a nurse. The nurse shouted at him to get back in bed one night when he got up one night to walk about when his legs cramped up in bed and he was in pain:

I really believe that her attitude wasn't towards asking, like, what's the reason why I'm awake or you know. Because at the time I was in when I had that E-coli, you know, I was really sick and it was really painful. I woke up one morning and I couldn't get out of bed and I had to roll out of bed because I couldn't physically lift my back off the bed. The pain in the lower back was really killing me. Like, they had a look up into my kidneys and all. So it was really bad, you know. And I felt I wasn't being listened to or believed. That I was just a guy that had issues around drugs who was just looking for pain medication, you know. Which wasn't the case. The case was I was in really bad pain (Aidan).

Aidan further recounted a subsequent incident with a different nurse at the same hospital after reacting to the medication he was prescribed for the E-coli. As with his previous complaint, the issue stemmed from not being listened to or believed:

I went to the A&E and your one says to me in A&E, the staff nurse or something, she says, 'There's more people here that has more issues than you, you've only got an

infection of the- urine infection', she says it was. And I was actually in agony and pain at the time. And I walked out of the hospital. And I went to the (name of clinic) and I lost me (sic) head with (name of HIV consultant) and he took me in straight, straight away, because he knew I wasn't messing. You know what I mean? That happened and it's horrible- people don't believe you, you know (Aidan).

Both Aidan and Paul, former and current injecting drug users respectively, reported having encountered this type of behaviour from nurses, and both men speculated that the stigma they experienced was due to a combination of their HIV status and their drug addiction. Paul, in particular, outlined forcefully how the stigma he had experienced had largely occurred in healthcare settings and was significantly compounded by his status as an injecting drug user:

Once they hear drug addict...they look at you like you've ten heads. They treat you differently, you know? You're like told to wait, you know what I mean. If you ask for something or whatever, they're like, 'Wait your turn. We'll get you when we're ready.' You know? Half of the time it's the people that are looking after you that are fucking stigmatising you. The people that are looking after you that are making you feel fucking, you know, two inches tall (Paul).

Jamie also recounted an incident in which he indicated he felt demeaned because of his status. This occurred in the hospital in which he received the bronchoscopy referred to earlier. He outlined what he perceived to be a hostile manner in which the theatre nurse communicated his status to another nurse and the differential treatment of him as a person living with HIV that this seemed to imply. Similar to his prior experience, he felt unable in the moment to challenge the nurse on her behaviour:

Oh yeah, same thing- she just came up and (*gestures with hands*), 'HIV on the floor in the waiting area.' And I was just like... (Jamie).

Lastly, Eamonn recounted an incident that occurred in an A&E, requiring stitches to a severe laceration after being attacked on the street with a glass bottle. Eamonn said he disclosed his status immediately to the emergency services and the police that brought him in to A&E. He related how the nurse became very upset and refused to go near him. He outlined how

he tried to explain that 'there was no harm' but he believed she was 'scared' of him and would not treat him:

In a way I can understand it in a way like- if I was HIV negative, if I didn't have HIV, I would be a bit cautious as well. But I think people are- if they are trained to do that job, they shouldn't worry about that (Eamonn).

Stigma Experiences in Medical Settings-Summary

In exploring interviewees' experiences of stigma in healthcare settings, it becomes clear that this is a significant and on-going issue for people living with HIV in Ireland across all cohorts, and is manifest in a variety of ways across different services and personnel. Distinct experiences of enacted stigma were identified by participants. These included: inappropriate or insensitive questioning; altered conditions of service, including being required to wait until the end of the day for treatment and illegally being charged extra for the same service; breaches of confidentiality and forced disclosure to clinical and non-clinical staff in the absence of consent; being ignored or not being listened to; and denial of service or effective denial of service by withholding appointments.

Anticipated stigma was further observed and was implicated in avoidance of services and non-disclosure to clinical personnel as a self-protection measure by several participants. Ability to self-advocate varied across interviewees, with some choosing to challenge stigma behaviours and others feeling disinclined to do so based on a desire to avoid confrontation or for a self-reported lack of confidence in the moment. Others were tacitly accepting of differential treatment-indicating a degree of internalised stigma- attributing such behaviours to a 'fear' or 'ignorance' of HIV on the part of staff. 'Lack of knowledge' about HIV and inadequate or incomplete training among healthcare staff were identified as significant factors implicated in stigma behaviours and as an issue generally for many clinical personnel including primary care physicians.

Family

The theme of family arose in all interviews to at least some extent. Very often discussion centred on disclosure to family members and the level of acceptance that was felt. A small number of people expressed that their HIV status negatively affected

relationships. For others, however, the experience of being supported led to a stronger bond. Experiences of enacted stigma were rare. Anticipated stigma was a fairly common theme that emerged however. In many cases this significantly affected relationships, with many interviewees choosing to forego or postpone disclosure for fear of a negative reaction.

While many interviewees said family members were 'shocked' by the news of their loved one's HIV diagnosis, for most disclosure had been a positive thing and resulted in the person receiving much needed love and support during what was a difficult time. Many framed this as being a lucky happenstance- highlighting the perceived unexpected or rare nature of this support. Aidan, for instance, commented on how lucky he felt to have been supported by his wife, who accompanied him the day he received his diagnosis:

I have to say- she was stronger than me, you know what I mean. And only for that I'm here today, you know. Because she has been the one that has really stuck by me through thick and thin. She never had the virus. She has never used drugs. And she has stuck by me through all of it, through all these years, you know. So I find that I'm very lucky in that way you know (Aidan).

Danny, similarly recalled the importance of support he received from his mother and also framed this in terms of his good fortune in having a solid relationship with his mother. He remarked that although she was upset for him, her reaction was more one of concern for his health:

You know, so I knew I was very fortunate that I could bring her in from that moment. So she came in. I don't know how she came in but it felt like two seconds and she was there, but sure look, all Mams are super heroes! (*laughs*). So she'd come in and first thing she wanted to know was about my health. And then I looked at her and I was like 'Mam, I can't go to Australia anymore.' And she just saw the hurt in my eyes, between the sobs and she was devastated for me, but as a mother she just really cared about my health at that time (Danny).

Later in the interview, in an anecdote that is illustrative of the practical, as well as emotional, support he received, Danny recounted a story about his mother insisting he go to

the clinic to speak with the doctors when he began experiencing bad side-effects from his medication. He indicated that he might otherwise have just stopped taking the medication without consulting the clinic.

Disclosure postponed

While Aidan and Danny both immediately disclosed to their wife and mother respectively, for other interviewees disclosing to family members was a difficult process and took more time. Declan, for example, described how it took him about five years before he began to accept his diagnosis and felt ready to disclose to his family. Likewise 'Charles' took a few years to himself to adjust to his diagnosis and learn about his new health condition before he felt ready to disclose:

I just dealt with it. I mean the first few years it was understanding it- first couple of years- understanding it and then the whole coming out. To, at least, loved ones, family. And that was difficult. It was like, I had come out- I had been openly gay for years- and it was like a whole coming out again, and maybe even harder in some ways. Because there was such a stigma. So I worked through coming out of the HIV closet to-really just family and a few closest friends.

Non-Disclosure

Anticipated stigma played a significant role in the decision to forgo disclosure to family members. Fear of rejection was so thoroughly engrained that disclosing one's status was a momentous and anxiety inducing event. For some participants, this was avoided by electing not to disclose to certain family members. Terry for instance chose not to tell his brothers- 'four Irish lads'- believing it a bridge too far for their relationship. Joy decided not to tell her parents for fear of rejection, but also out of a wish to prevent them from worrying about her:

I don't want them to look me in a different way. Even though I know it's not my fault. I don't want to worry them, you know. Because when you are coming from Africa and you see the way people are dying, there's no medication, there's nothing (Joy).

Anticipated stigma was also acutely experienced by the participants who are parents, many of whom had yet to disclose their status to their children or who delayed doing so for

several years. Joy, Aoife, and Anna, all referred to their fear of rejection by their children. For Anna, whose children are now grown up, it would take four years before she felt ready to tell them. She described buying a cake beforehand, so as to soften the blow for her two boys after the conversation. Joy articulated her fears that the knowledge of her status would somehow affect her relationship with her daughter:

Because it's just been the two of us. So I think it's just me. I know she would never, never. I know that for a fact she would never- but I don't want her to look at me in a different way. I think that's my fear. Not for her, but for me. That's all (Joy).

This was a point that was echoed by Aoife, who delayed telling her daughter about her condition at the request of her ex-partner. Aoife further outlined how despite her fears around disclosing to her daughter, she hoped for acceptance. Furthermore she articulated that disclosure to her daughter potentially represented an opportunity to have a frank and honest discussion about sexuality and sexual health:

My only fear is that she will do the same as her Dad did. Which is be really ok with it in the beginning. And turn it around to hurt me or to leave me or to, whatever. So that- that's my worst possible scenario. I just want to be accepted for me by my own daughter. And oh! With any grace, possibly supported as we go forward. But, but it is about her as well. And I'd love to use it in a way that is helpful for her in terms of thinking about her own sense of sexuality and you know, how precious that really is.

Aoife's fear was compounded by negative experiences of disclosure within her own family where she described a 'lack of trust' and having 'had huge distance occur, within family relationships' as well as having 'that experience of just not feeling safe...and feeling more for the other person and how they've received it.'

Enacted Stigma

Like Aoife, David's relationship with his family suffered as a result of his disclosure of his status. He described how his relationship with his mother-seemingly tumultuous to begin with- deteriorated when he decided to 'come out' and be open about his status in their community. Ultimately he felt that his mother's negativity towards him was bound up

with a disapproval of his homosexuality and that ultimately she was 'embarrassed that the neighbours knew' of his HIV status.

Like David and Charles, several of the interviewees who are gay men framed the process of disclosure to family and loved ones as a second 'coming out.' For some, such as Terry, having lived through much of his life as a closeted gay man, life in a newly imposed 'closet' represented an unacceptable prospect and was very much part of the impetus to disclose to close family and friends:

Because I'm 59. And growing up in the fifties in Ireland, like, being gay was like in the closet, hiding everything like. And then I ran off to be a priest to try deal with that and I'll be cured basically like (*laughs*) and I'll save the world then. (*Sighs*) I make it sound very light but it wasn't. And I just thought, 'Jesus, this is another closet that I'm gonna (*sic*) face now like, you know. And I thought, 'No, no I'm not. I'm not going into a closet' (Terry).

Finally, although enacted stigma was rare, it was manifest among some families of interviewees. Usually this occurred when fears related to transmission were explicitly expressed and occasionally resulted in differential treatment. That acknowledged, such occurrences were on the lower end of the scale of severity and largely stemmed from a lack of knowledge rather than antipathy. For Declan, for example, this meant having to reassure his sister-in-law that he posed no threat to her children:

One of my sister-in-laws was very concerned about the kids, her kids. That there'd be any risk to them. Even though I kind was explaining all the sort of ways in which it is transmitted and the ways in which it isn't, you know. She was very freaked out and, yeah, I think that was my biggest sort of worry as well, that my family would be kind of looking at me or kind of nervous of me, especially with their kids (Declan).

Misconceptions about how HIV is and is not transmitted led to a situation in Kevin's family where 'ground rules' were set for him around the house. These mainly revolved around his use of the bathroom:

I just think they were- didn't know about it. And they didn't want me to- like if I went to the toilet, to wipe the seat and to make sure I didn't leave anything in there, in case it splashed up or anything, you know (Kevin).

Family-Summary

Experiences of stigma that were identified within families predominantly involved anticipated stigma. This was evident in the fear of rejection expressed by a majority of the participants who were interviewed. For many interviewees this led to either delaying or forgoing disclosure to close family members, including parents and children. Concern for the family member(s) and a desire to prevent them from worrying was another reason expressed by some participants for forgoing disclosure. Knowledge of an individual's status led, in a small number of cases, to the breakdown of trust and a deterioration in the relationship with some family members. A small number of participants additionally noted that they were treated somewhat differently by family members post-disclosure. There were, however, no overt cases of exclusion or ostracism reported.

Work, Employment & Education

Of the fourteen people interviewed for this study, six were in full-time employment or education, one was a stay-at-home Dad and the remainder were unemployed and/or engaged in voluntary work at the time of interviewing. Of those that were in employment, one had disclosed her status to her employer, one had selectively disclosed and one had not disclosed. Of those that were in full-time education, one was publicly open about his status, while the other two had selectively disclosed to certain teachers, professors and/or fellow students. None of those who had disclosed their status reported stigma experiences at their schools or colleges and, on the contrary, agreed that they felt supported by those they had disclosed to. The names of the companies and organisations involved have been omitted to protect the anonymity of the study participants.

Perspectives and experiences on disclosure or non-disclosure of status in work environments varied among participants. For Aoife, the process of disclosing to her employer took time. She was supported however and was happy with her decision:

I'm in my job 12 years and I- It took me years to decide to disclose and since the day I disclosed I've always been really glad I did. And I feel really accepted in my own right. But- and I've had to take so few days off. I mean, this experience for me is very predictable and there isn't an issue (Aoife).

For Bernie, on the other hand, disclosing her status to her employer was, in her view, absolutely out of the question. This perspective was based on two factors- fear of a negative reaction (anticipated stigma) and a first-hand knowledge of colleagues stigmatising views on HIV and PLHIV (perceived stigma). Working as a technician in a pharmacy, she described frequently hearing derogatory comments related to the assumed HIV status of 'methadone patients' from pharmacists and other colleagues. She also discussed how erroneous beliefs about casual transmission were common among staff where she worked. She described being warned by a pharmacist not to touch a cup used by customer who the pharmacist assumed to 'probably have AIDS and Hep C.' This was an attitude she said she had come across 'with an awful lot of pharmacists.' She further described an incident in the shop when she cut her hand and was bleeding:

Like I remember I cut myself badly one day in the chemists (sic) and the blood was just gushing out like, so I grabbed everything and just ran into the office and one of the girls was there like, 'I'll help you.' And I said, 'No, I'm grand' I said. 'I'll do it myself,' I said. 'You should have gloves on you anyway,' I said. Because I do the first aid. I did the training with the girls, so I was like everyone should wear gloves no matter who the customer is. You always put gloves on no matter what you're doing. And then she was like, 'It's not like you have AIDS!', she says to me. I was standing there going, 'Oh God...!' (*laughs*) And I said, 'Well even if I haven't, you should have your glove on you, the blood is dead when it comes out,' I was saying. 'Oh God...'
And there's a few comments I've heard in work like that (Bernie).

Illustrating how perceived stigma can induce PLHIV to stay silence about their status, experiences such as this were a key motivating factor in preventing Bernie from disclosing her status. She further described the burden involved in keeping her status secret, noting in particular the difficulties this caused her in relation to getting time off to attend clinic appointments. In fact, for Bernie, this was one of the most problematic issues for her in

terms of living with HIV, as when asked what she believed was the greatest challenge for people living with HIV, she responded:

I think the hard thing is when you're working- trying to work and keeping yourself healthy. Like, I know when I went on the medication in 2002 I got shingles very bad. I was out of work for 8 weeks. Lucky enough I was in (name of retailer) and I got full pay. I just told them it was from the shingles, but I'd started the medication and I was so sick from the meds that I couldn't do anything. I was just sick all the time. Eventually they changed me then to another one. But like that, if I have appointments in work like- I had a mole at one stage on my back, so then I used that in my last job to say, 'Oh I've to go and get that checked.' I find that a lot of pressure when you're working. My clinic is only on a Thursday. And Monday for blood tests, that's it. And you go in and you could be waiting four hours (Bernie).

Like Bernie, Charles felt that stereotypes and myths about HIV were quite prevalent and this was something that had so far inhibited him from being completely open about his status at work with his colleagues and employer. He had, however, disclosed to some close work friends, the occupational nurse and the company doctor at the large multinational firm where he was a senior manager:

Well, so, I've been with the same company for 25 years. Um, but, um, so I've only disclosed almost to friends at work more than it has been to my employer. Although we've- my company has an occupational health nurse. And generally I would disclose in that scenario because it's a non-disclosure, if you understand, sort of scenario. And so just very limited to people otherwise, just a rather very close circle. And sometimes I feel like, I always, I always felt positive- no pun intended (*laughs*)- about being somewhat of a gay- being comfortable with my gayness and so I was somewhat of a role model I felt, or poster child if you will, to be the gay brother, the gay son, the gay co-worker. Um, the gay boss and whatever. And so I was always just open in that way and I felt a little bit like I could do something in that regard to be somewhat the positive HIV positive role model to a certain extent, but it's still something I haven't really come a long ways with. Um, there's just a lot of

misconceptions, you know, out there, preconceived notions or whatever. And so I haven't been as open as I have with, say, my being gay (Charles).

Perceived and anticipated stigma of the sort outlined above by Bernie and Charles were identified as being a common motivating factor for non-disclosure in the work-place for many of the interviewees. Like Charles, Terry felt that being out as a gay man in his former job had been a big step for him, but that being open about his HIV status might cause him difficulties. This was a point of view that was further echoed by Jamie, who stated he had never disclosed his status in an interview situation and felt that doing so could potentially put him at a disadvantage. Additionally he felt that his status had prevented him from pursuing potential job opportunities:

Obviously I would love to go back into healthcare. But I don't know how comfortable I would be disclosing my status. It depends on whether I would need to first of all. But I would love to go back to working with kids. But whilst it doesn't bother me, being HIV with children- and I'll come back to that. And any employer shouldn't discriminate, however, they probably might not want the flak (Jamie).

Anticipated stigma was further identified as having an inhibitory effect in terms of pursuing or continuing in certain jobs in the way in which some interviewees felt about themselves in their jobs. Jamie above, for example, mentioned how he had considered applying for a job as a teaching assistant, but that fears about what the parents of children he might work with would think of him prevented him from doing so, asserting that the 'negativity would kill' him and that 'it does stop me from taking that job.' Similarly, Anna mentioned how when she worked as a massage and aroma therapist, she felt 'like a fraud' and she worried about what clients might think of her if they knew. As a result of this she stopped working in that field.

Three instances of enacted stigma were described by two interviewees as having impacted on their working lives and job opportunities. These included two instances of forced disclosure, where the individuals' statuses were revealed to co-workers and supervisors absent of consent, and one instance of the employer altering the conditions of a worker's employment as a result of his status.

For instance, Eamonn described a situation that occurred while he was taking part in a training course with a large government-funded national non-profit organisation that provides training, education and job-support for unemployed people and people with illnesses and disabilities. Eamonn had disclosed his status to the organisation after having been accepted to a programme that involved a combination of class-based learning modules and work experience placements. He said that his status was contained in a risk assessment form that was made out for him by the organisation. This risk assessment sheet was subsequently distributed to his teachers and employers, without the organisation explaining to him that this would happen and without seeking his consent to disclose his status to these third parties:

P: But the thing was that everyone was told about my health status, like the manager was told, the coordinator was told, the first-aiders were told...And I was- when I went on work experience in the (name of employer), the staff- the people were told, my supervisor was told. And I found- I felt very isolated.

R: And did you give them permission to talk about your status?

P: No. That was their rules. See the complicated thing was, they don't, they- the (name of organisation) is for people with disabilities and HIV is now classified as a chronic illness. However they have no- no one has any. Like even my GP hasn't any experience with people with HIV and knows nothing about it. And especially the staff in the (name of organisation) didn't know nothing about it. And I think they saw it upon themselves as their duty to inform people that I was a hazard (Eamonn).

Eamonn additionally outlined that in another of his work experience placements, staff there had also been informed of his status without his consent and he remarked that a member of staff 'freaked out' one day when he got a paper cut. He further commented that he believed his status may have been a factor in his failing to secure work after the programme had ended. Eamonn was despondent at his future employment prospects in his community, saying 'I don't see myself ever getting a job because everyone knows I've HIV now' (Eamonn).

David's experience working at a cosmetics factory mirrors that of Eamonn's, highlighting the lack of training around data protection and enforcement of confidentiality protocols within some workplaces. Similar to Eamonn, David had disclosed his status to senior management. Subsequently he became aware that the manager had shared this information to other staff members without obtaining David's consent to do so:

The first aider was told, discreetly, not by name, that someone had HIV. And they had no protocols to deal with that because I was the only person in the factory with it. And they deliberately went around and my boss at the time couldn't keep her mouth shut and told half the staff before I was ready to say anything (David).

Lastly, an instance of enacted stigma in the workplace reported by another interviewee- Terry- resulted in him being informed that he would have to cease performing his duties. This occurred in 2012 after Terry had been treated for a type of cancer that is closely associated with HIV infection. Although Terry had not disclosed his HIV status to his employer, the type of cancer he had was known by his employers and this seemed to have aroused suspicions. Terry, an openly gay man, subsequently disclosed his status in confidence to the doctor at his workplace and recounted a conversation he had with her in the cancer ward as they were discussing his return to work:

And my doctor in the (organisation) came to see me just before I was being discharged and she said, 'I need to tell you that the director, the (organisation) director (*sniffs/clears throat*) is wanting to find out about your diagnosis.' He's was a little bit suspicious when he heard Burkitts lymphoma. Because it's such a-

And I said, 'What does he want to find out? Or what does he want to do like?'

She says, 'Well you know, if it's HIV...!' (Terry).

A meeting with the director after his recovery from cancer confirmed the new conditions of his employment, namely that he would no longer be permitted to return to his work as a chef and would be moved to an office position. The question of his status was not directly or explicitly raised with him. However, when Terry asked for an explanation for why the terms of his employment were being changed, the director responded, 'Well you know the health and safety and everything.'

Lastly, three interviewees- Aoife, Danny and Charles- noted that their HIV positive status had prevented them from pursuing job opportunities abroad or engaging in work-related travel. For Aoife and Danny, opportunities to work in the United States and Australia had to be turned down due to the travel and work restrictions on people living with HIV in those countries at the time. Charles similarly was unable to take up a position in Singapore for his job.

Stigma experiences in employment and education- Summary

In examining the stigma experiences of interviewees in the workplace, it is clear that anticipated and perceived stigma can have a significant impact on an employee's engagement in their workplace and heavily influences decisions around disclosure and non-disclosure of status to employers. Although protections exist for people living with HIV under the Employment Equality Act (1998) and disclosure of status would, in theory, make it easier for employees to get time off in order to attend appointments, the potential perceived risks of disclosing status, both socially and professionally, appeared to outweigh any benefits for interviewees. Furthermore, anticipated stigma was observed to have inhibited some interviewees from pursuing potential job opportunities they were qualified for and furthermore affected their confidence in performing roles they were adequately trained for. Of the three interviewees who had disclosed their status to their employers/training organisation, two had experienced enacted stigma via forced disclosure of their status in breach of data protection policies and legislation. Enacted stigma was further observed in the case of a fourth interviewee when the employer removed the individual from his post, apparently due to unfounded fears around casual transmission of HIV.

Stigma experiences in relationships & dating

Both anticipated and enacted stigma were identified in interviewees' accounts of dating and in relationships. Many acknowledged that their HIV status was a factor in either not pursuing or avoiding serious relationships. Anticipated stigma was generally articulated as a strongly felt fear of rejection for the majority of participants. Joy, for example, reported she had not been in a relationship for eleven years, saying the idea of pursuing a relationship again scared her:

But the fact that it's the fear of the unknown that if you have a relationship and then you love somebody and then you go to that stage and then by telling him or her that you are like this- the rejection. It's hard. It's hard. That's my fear (Joy).

Interviewees furthermore discussed the anxieties that existed for them around disclosure to potential new partners, highlighting the Catch-22 that occurs in beginning a new relationship, where the issue of the right to privacy of the individual must be weighed up against any possible future ramifications of non-disclosure and the problems that that implied in terms of potentially creating distrust within the relationship. For some, such as Charles and Anna, it was easier therefore to not pursue serious relationships:

And I've been essentially alone for 16 years now. Um, and but I don't know, I only had a few brief relationships before that, so it's not drastically different to how I was. Um, but it definitely has. Um, you, you, just sort of let that- just don't think about it, you don't think about the relationship. Don't think about openly dating. Or, if you start to meet somebody, you have that fear of, 'Ok, I'm going to have to disclose here, and that's going to be the end of it.' Because, they've entered this relationship not knowing that and because you didn't disclose beforehand, now you have to wait for that moment of- and so, I just keep the relationships at arm's length. And so, to be honest, I'm sure it has inhibited me some (Charles).

I was living in England. I was very much on my own and if I had partners I'd use condoms. But I wouldn't tell anyone. I'd deliberately pick people that there- it was going to go nowhere, the relationship, so I didn't have to tell anyone (Anna).

Of the participants that were currently married or in long-term relationships, none reported having experienced any stigma behaviours, although one noted that his wife did have on-going anxieties around transmission. Most interviewees that were part of a couple did use condoms as part of safer sex practice. Two of the women discussed how this was less of concern for their male partners who were quite happy to forgo using condoms. The reasons given for this related to their partners' undetectable status in one case and in the other, her partner feeling 'immune.' It was clear, however, that the prospect of condomless sex was rather anxiety inducing for both women.

Two interviewees became particularly uncomfortable when the topic of condomless sex was brought up. One expressed doubt about the veracity of the claim that PLHIV were non-infectious on treatment, saying that as the WHO had not yet endorsed this position then it must not be accurate and thus he 'would still be more in favour of the safe sex option. Regardless' (Kevin). The other interviewee became quite agitated and rejected emphatically the prospect of ever having condomless sex: 'No. No. No. No. I wouldn't like that. I wouldn't enjoy the experience. It's- No' (David). Only two female interviewees said that they had practiced condomless sex on occasion with their partners. Nevertheless, the fear of transmission often became an insurmountable problem. For a number of interviewees this ultimately led to the breakdown of their relationships as they were made to feel 'like a second class citizen' (Danny). For others, while the fear of transmission was less pronounced for the HIV negative partners it still elicited a 'niggling anxiety' (Declan). One way of dealing with this was to avoid discussion of the issue, just 'use condoms and that's kind of it really' (Anna). Within other relationships, HIV negative partners were very 'relaxed' (Bernie) and often preferred to forego condom use. However, this led to problems in some relationships as PLHIV felt 'forced to take responsibility for the two of us,' adding that 'that was a stress in itself' (Aoife).

Several participants talked about how their status had impacted on their relationships after disclosure, noting how at first their partners were accepting of their status but that 'it ended up being the elephant in the bedroom' (Aoife). This was a point that was echoed by Danny, who relayed how his first relationship post-diagnosis, became less and less a partnership of equals as his boyfriend's fears about transmission impacted on the relationship:

And I told him and we were together for around 11 months. It went well. However, that whole relationship was awful. He was like, at that time it was only the 96% if you are undetectable- of not passing it on- so there was that 4%. And I was always made felt like the vector and everything that went wrong was my fault (Danny).

Interviewees further noted that bad experiences or 'being made to feel disgusting' (Aoife) had subsequently had a chilling effect on them in terms of pursuing other relationships. Such experiences often resulted in an internalisation of the fears and anxieties that arose

around transmission. Such difficulties underscored how perceived and anticipated stigma can lead many people living with HIV to self-exclude themselves from social life as a means of self-preservation. For some this meant accepting leading a solitary life:

I am told constantly by people, by my own family, there's people out there that don't matter, or who don't mind. And I'm sure there's people who do find those people, but I haven't found them yet. And I have spent a lot of time on my own and I've become very solitary now (Eamonn).

The sexual exclusion of HIV positive men in the gay community was something that consistently arose amongst that cohort. Several of the study participants who are gay men spoke about the use of dating and hook-up apps such as Grindr, Gaydar and Plenty-of-Fish and noted that anti-HIV discrimination and stigmatising discourse was extremely common among users of these platforms. A common complaint among interviewees was frequently being asked by other users if they were 'clean' or 'dirty':

I've recently become single again after 8 years, so- and it's all changed. Dating apps- just awful. Awful. They're there to serve a purpose- people can be so nasty on them. And if somebody asks me, 'Are you clean?' one more time (Jamie).

For this reason most interviewees did not publicly disclose their status on their profiles and those who did had had mixed responses. David, who is open about his status, had received both positive and negative messages from other users, as had Charles. Charles, however, also noted how a personal ad he had placed on a hook-up site had been removed as a result of platform users' complaints. He expressed disappointment at the realisation that this would happen among the community from which he thought he could expect solidarity and support:

I can talk about relationships in a bit, but just as far as personal ads are something where I try to disclose. I've actually used Craigslist and I've been, I've been, what's the word on Craigslist, where they ban your ad or whatever? Or they take down your ad. Craigslist just lets users mark ads as to be taken down and if enough users mark it then it goes down basically. So it's not like Craigslist itself manage that but that's how it works. So people will find an ad offensive and if enough people find it

offensive and mark it then it gets taken down. And so I was really dismayed that that must have been gay people taking me down (Charles).

Stigma experiences in dating and relationships- Summary

Anticipated and perceived stigma were observed as having a significant impact on decisions to pursue or avoid sexual and/or romantic relationships. Complexities about initiating relationships were laid bare as many discussed the issues that arose in relation to disclosure- disclosing straight away meant facing potential rejection and the possibility of confidentiality being breached, a risk that was, for many interviewees, too great to be contemplated. Delayed disclosure was furthermore identified as having the potential to cause a future rift with partners. A number of interviewees discussed that this problem was dealt with by self-imposed social and sexual exclusion, while others preferred to engage in casual condom-protected sex with partners to whom they did not disclose their status. Enacted stigma was experienced by a number of participants who had been involved in serodiscordant relationships, with HIV positive partners within the relationship reporting having felt or being made to feel like 'vectors.' Enacted stigma was further identified as a common problem for gay men living with HIV who were habitual users of dating and hook-up apps, with interviewees reporting the tendency for people living with HIV to be characterised as 'dirty.'

Part Two: Symbolic and structural violence-Construction of a stigma habitus

In this part of the chapter I situate the findings of the data analysis within the conceptual framework of a 'stigma habitus' (see Fig 9). Within this framework, I draw on two key concepts from Bourdieuan theory that were explicated in Chapter Two- habitus and symbolic violence.

If Bourdieu's concept of habitus is understood in simple terms as a type of social roadmap through which and by which individuals are aware of the limits and possibilities of their engagement within a given social field, the stigma habitus accounts for the way in which stigmatised individuals are similarly shaped by their experiences of navigating a social field with a stigmatising condition. Key to this process is symbolic and structural violence,

through which one's stigmatised status is continuously reproduced and reinforced. In this section I specifically examine instances of symbolic and structural violence as experienced by interviewees in order to explore how these are involved in positioning PLHIV as stigmatised identities.

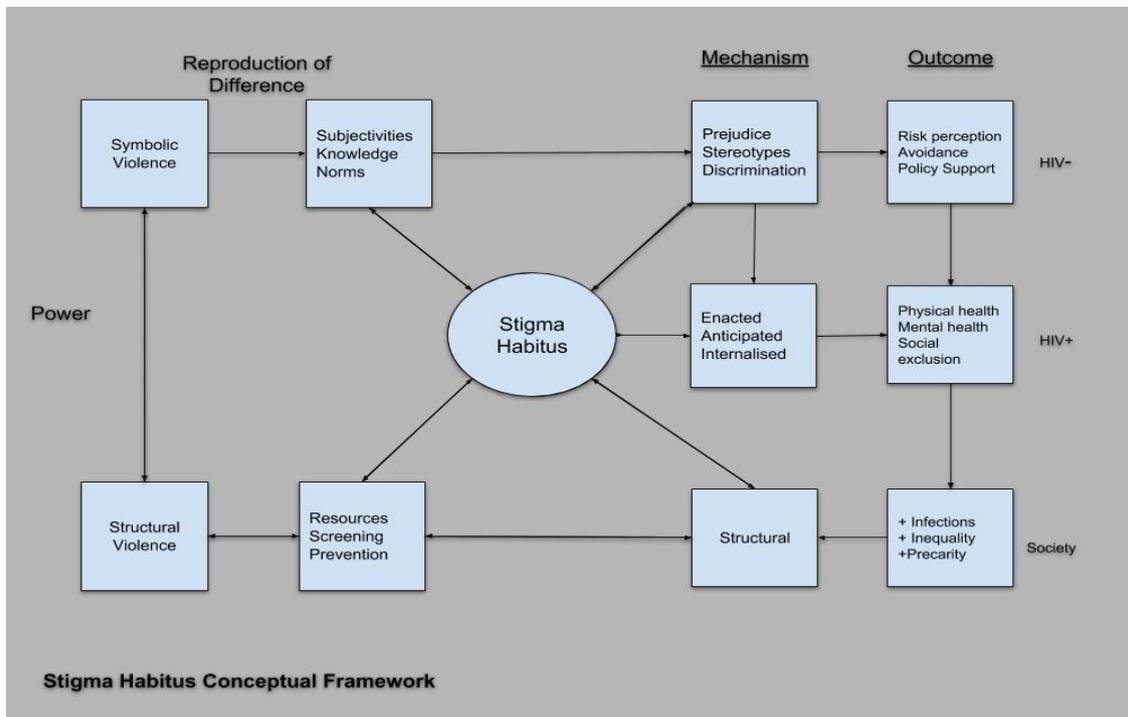


Fig 9: Stigma habitus conceptual framework

Symbolic violence i) A culture of silence and the elision of PLHIV from public and private spheres

When asked what the greatest challenge for people living with HIV in Ireland was today, the majority of participants identified stigma, but further affirmed that the aspect of this they found most difficult was the culture of silence and secrecy within which HIV was shrouded. All but two study participants were mostly private about their status to all but their closest family and friends, and irrespective of being public or not, all interviewees had a perspective on the HIV 'closet' and what that meant. What was striking was the myriad of ways- both subtle and unsubtle- in which people living with HIV were consistently signalled or encouraged to remain silent and keep their heads down and how this contributed significantly to the elision of people living with HIV from both public and private spheres.

Interviewees consistently described how they were encouraged to either keep quiet or to lie about their status, even in the context of confidential medical encounters. For example, Charles described how he was advised by his company's in-house physician not to disclose his status on an official form during his annual health check. Likewise, his consultant encouraged him not to disclose to dentists, arguing that he was undetectable and that it would help him avoid any awkward situations. Declan, had a similar experience when he sought advice from his clinic on where to access dental care in his hometown:

Somebody in (name of clinic) rang the dentist to kind of suss them out, saying, oh I've a patient here who is moving from Dublin, and just kind of made up a little story. So the receptionist of the dentist here in (*name of town*) told the doctor to 'Tell your patient not to tick it on the card but to tell the dentist' (Declan).

Well-intentioned as such advice may be, it highlights the extant pressures that are exerted on people living with HIV to maintain secrecy- the implicit message being that nothing good will come of speaking about this openly. It is keenly reflective of the impact of Stigma Power in 'keeping people down, in or away' (Link & Phelan, 2014, p. 24). On one level it could be argued that this is a reasonable/realistic pre-emptive action to avoid anticipated stigma or enacted stigma. It also, however, reinforces the notion of the person with HIV as a *persona non grata*, especially when the message is emanating from authoritative institutional figures such as healthcare professionals and HIV consultants.

Outside of the institutional and community level of hospital clinics, dentist offices and workplaces, this was a practice that was also reflected in micro-level social interactions with family and friends. As previously mentioned, David, for example, remarked that his mother was displeased that the neighbours would know of his status. Similarly, Anna observed how her partner did not want his family to know about her HIV. This was further echoed by Aoife who spoke about her sister's outrage at the idea of her going public with her condition:

And there was a moment when I thought- why not? Why not? And I could do that too. But really, when it came down to it, I didn't have the bottle. I just didn't have the bottle. And I think when I was processing that I also said this to another sister and she nearly freaked out in front of me. And I was a kind of bemused by that. And

she said, 'And what would Mammy say?' It became about everybody else then. And I just thought, 'Oh my god. Nobody wants to own this' (Aoife).

Charles too had a similar experience as he was informed- by a 'trusted' Irish friend, 'that Ireland's ok with you being gay, but you may not want to come out of that HIV closet.' Again, while the advice was no doubt well intended, the illocutionary force of the statement veers towards something akin to a threat, alluding to severe unforeseen consequences as a result of being open.

In addition to impacting the individual living with HIV, some participants raised the point that this culture of secrecy and silence affected family members and friends who were also unable to talk about their loved one's condition. Bernie, for example, mentioned this in the context of fears that neighbours or friends may make assumptions about their family member based on stereotypes about people living with HIV. This is emblematic of the vicious cycle that exists with HIV-related stigma- fears of being judged inhibit one about being open about one's status, yet maintaining secrecy about one's status does little to dispel damaging stereotypes. It is illustrative of the reproductive capacity of Symbolic Violence in sustaining and maintaining the Stigma Habitus:

Yeah, it's like my mother would say to me, she'd have friends of ours that'd have cancer and she can't say, 'Well my daughter has HIV,' do you know? And the same thing, she's heard them talking about people. I mean it's like they label everyone HIV positive, 'Oh you're a junkie,' or you know (Bernie).

Besides explicit exhortations and well-intentioned advice to remain anonymous, a number of interviewees' accounts of their experiences in HIV clinics suggested a certain spatial and environmental element to the inducement to silence and anonymity. One interviewee, for example, observed that the clinic he attended was tucked away at the back of the hospital, a location that he felt reflected HIV as a 'hidden illness.' He further noted that the place 'gets a lick of paint every now and then but it is very dirty, not very welcoming' (Kevin).

Terry described at great length an experience he had in the context of his clinic. Having become aware of a free HIV support service in his city that he and other members in his gay men's group had not been informed about, the group obtained business cards advertising

the HSE-funded service. They requested that staff at the clinic hand them out to patients attending for their appointments so that other people who were potentially uninformed about the resource could be made aware of it. They suggested to staff that this could be done either during private consultations or by placing them into the bags in which patients received their medication. Initially the staff agreed, however, at his own consultation a number of months later, while he was in with the nurse specialist, he noticed all the cards still in their boxes in a cupboard in her office. When he asked the nurse why they were not being given out, he was told, "They're not too happy about it in the hospital." Something to do with the ethos- the Catholic ethos of the hospital.' He further elaborated that the clinic had also refused to put up any posters advertising support services or other health promotional material with reference to HIV on them:

Because we also wanted to put up posters, because it's a mixed clinic. They don't have their own clinic and even the room where the clinic is, there's, like, the kidney- posters for kidneys, treatment posters for this- Even last week I just noticed, because I was up there for my appointment, which- I had to laugh- there's a poster, 'If you're living with gout' (*laughs*). I was like, looking around and saying, 'Jesus! Not one!' They wouldn't put up the poster (Terry).

Interviewees often remarked that the sense of secrecy that they felt must be maintained around HIV impacted profoundly on how they interacted with other people and on the ability to form relationships at all levels in society- family, the community and sexual or romantic relationships. This was often articulated in terms of a sense of distrust and scepticism of others and as an inability to be open and transparent. This resulted quite often in a sense of social isolation and self-imposed social exclusion:

I think- what HIV does to you as an individual it makes you close in on yourself: you're not that open with people, you're not that sincere with people, you're always suspicious of people. And- it's not that you're suspicious- you're not open and honest as much as you should be and things like that, you know. It's like you're hiding this horrible, horrible thing you know (Aidan).

Symbolic violence- ii) stereotypes, myths and misconceptions

The implicit inducement to secrecy and silence is further reinforced by other forms of symbolic violence towards PLHIV that permeate through Irish society. One of the ways in which this is exerted is through the enduring existence of negative stereotypes, myths and misconceptions about people living with and affected by HIV. Exposure to these socially embedded and largely erroneous ideas was raised by almost every participant in the study. Some of the stereotypes, myths and misconceptions interviewees had encountered included:

HIV as a terminal illness: Many interviewees reported having experienced the stereotype of HIV as a 'death sentence.' One interviewee reported that he had received mass cards from family members when they were told of his diagnosis, a gesture he interpreted as kindly, if misguided. While he found that all rather amusing, for others, having to counter this myth was frustrating-

You know? It just does me head in. 'Cos they're like, they're going on as if you're, you know, you're terminal in bed dying like, you know (Paul).

PLHIV must be sickly: Many interviewees discussed how people often assumed that to be living with HIV necessarily entailed a great deal of sickness and ill-health. One participant even noted that a friend to whom she disclosed refused to believe she had HIV because of how healthy she was-

Even up to now, he won't accept it because he says I look great (Joy).

Casual transmission: Myths and misconceptions about how HIV is and is not transmitted were very commonly reported by interviewees. Examples included reports of interviewees being asked 'if you could get it through kissing,' (David), while Charles recounted the following-

I was staying with them and their young daughter had picked up my tooth brush and the mother was very concerned that- whether the young daughter had put it in her mouth or whether she had contracted HIV from my toothbrush (Charles).

'Types' of people affected by HIV: the perception that HIV only affects certain groups of people was a common stereotype encountered by participants. Characterisations of HIV as a 'gay illness,' a condition that signalled 'promiscuity', an illness associated with drug use and 'junkies', or HIV as an 'African' illness were frequently reported-

Most people they will think it's for LGBT people, but they wouldn't really associate it with heterosexuals so they'll say, 'Oh yeah, they deserve that because they are being promiscuous' (Joy).

Yeah, my mother-in-law, brought it up kind of- not recently but about a year ago- that her process and me telling her that I was HIV and that that's what was in her mind, that I kind of must have been gay or must be using IV drugs (Declan).

But it's still the gay plague, you know. ... Well maybe not plague but illness. Definitely a gay illness. Definitely, definitely, definitely... Yes! Yes, they do, they do- a gay illness and an African illness. Definitely (Jamie).

PLHIV as 'dirty' and as a source of contagion: This was a particularly common complaint among men who used dating apps. The degree to which this could be internalised by people with HIV, however, was also apparent-

But I do find- when I was in (name of clinic) and I went and the nurse was taking my blood and I said something to him about, I don't know, maybe feeling dirty- I had this thing about my hands you know (Anna).

PLHIV as deserving of or to blame for their condition: this was a stereotype raised by quite a number of participants, with one interviewee describing how it had been explicitly said to him on occasion and another tacitly endorsing this perspective in reference to himself-

I remember when I went in, the guy who was running it at the time, but he was still working in the other place, he just said, 'Well like, ah, it's your own fault, you took it up the arse (Terry).

You play with fire, you get burned (Kevin).

A measure of how deeply engrained these ideas are is how they continued to impact on interviewees' perspectives on themselves as potential vectors or sources of contagion in the days, weeks, and even years after diagnosis. Terry for example, recounted meeting up with a friend after finding out about his diagnosis. Terry was heavily involved in gay men's health in his community and even helped run a support group for men living with HIV prior to his diagnosis, so his knowledge around HIV was very good. Nonetheless, his reaction immediately after diagnosis brought up irrational fears about casual transmission:

So I rang a friend and she said to come over that evening and I went over and I was telling her all my worries about what am I going to do about home- I live with my sister, she shares a house with me- and I said, 'Like, what am I going to do? I'll have to get my own towels. I'll have to get everything.' And we were both drinking coffee and she took my coffee and gave me hers (laughs) and drank it and said, 'What are you on about? You know better!' But I think it's- You can have all the knowledge, but the shock (Terry).

This dissonance between what a person knows empirically about HIV, HIV transmission, as well as existing treatments and prognosis, and their affective reaction to the news of their diagnosis was not uncommon, and speaks to the extent to which these ideas were deeply embedded. Aoife, for instance, outlined her reaction to her diagnosis:

And there was certainly a sense of dread and fatal- fatality that was associated even though, for some reason, I was aware of some kind of medication and improvements, for want of a better word, or people living longer with particular treatments (Aoife).

This continued to be a life-long issue for many interviewees, long after diagnosis. Anna, for example, talked about this in the context of the birth of her grandchildren. This new life-event resurrected irrational and unfounded fears for her around holding or touching her grand-children. Despite empirically knowing she was not a risk, she nonetheless felt anxiety around the situation and felt the need to reassure her daughter-in-law that she was not a danger to them:

It did take me by surprise. It was a huge thing actually and it didn't make sense. And I remember I keep looking at my hands and- And I knew that the child would be fine

but I was worried that they might think, 'Oh, I'm not letting your mother near my child (Anna).

Jamie similarly held such fears about being around children in particular, describing how it mediated his interaction with his nephew, many years after his diagnosis:

I didn't go near children, like hugging them or anything, like until I knew, until about two years ago. And it wasn't until- and I've got a nephew who's four, who I adore and who adores me. I got out of changing his nappy- but I'd just say, 'Oh, that's fucking disgusting, I'm not touching that.' But I was too scared to. I just had that mental block because, HIV, I shouldn't be changing him...It's just, it's insane- it just made my stomach churn, the fear, the thought. Case in- we were walking up the street and his dummy dropped on the floor. Normally, give it to Mummy. So he picked it up and gave it to me. And I was like, 'Oh my god! What do I do? What are you expecting me to do? I, I can't!' And then I went and told (Name of sister) and she was like, 'Yeah? And?' That's mental, isn't it? And that was my own, my own. I blocked myself at first from quite a lot of people. I isolated myself and I never quite got over that (Jamie).

Symbolic violence iii) Media and cultural representations of PLHIV

Although a question about media representations of PLHIV was included in the general set of questions/interview script, more often than not this was a topic that was raised independently by research participants un-prompted. There was a fairly strong consensus that there was an overall lack of coverage of HIV as a health issue in Irish media. Indeed, most noted that 'you don't see much about it in the newspapers or the media. It's not really highlighted like, you know' (Paul). Several remarked that the only real coverage of HIV occurred mainly around key dates in the calendar: 'We get good views twice a year. World AIDS Day and Irish AIDS Day. We get a bit of coverage for about five minutes on RTE and probably a couple of lines in the newspapers' (Kevin). Reasons ascribed to this lack of coverage differed among participants, with some asserting that because HIV was now a treatable condition, it was no longer a subject that piqued journalists' interest as a good news story. Others noted that, as a health issue, HIV was not a priority public health

problem 'in the hierarchy of things or whatever. I'm sure probably suicides are killing more people than HIV is in this country' (Charles).

Of the coverage that did exist, a common complaint among interviewees was that the media covered mainly 'negative aspects of HIV' (David). These included anachronistic portrayals of people living with HIV as dying patients and the tendency to present HIV as a health issue that only affected certain risk groups such as people who use drugs, migrants and gay men. A number also brought up problematic and sensationalised reporting about HIV that presented PLHIV as knowingly or deliberately passing on the virus to others, and how this may affect how people perceived others living with HIV:

I think there was some Eur.../football thing that happened in Poland anyways, because I was working in (news outlet) at the time and I looked at a newspaper and it was like 'HIV positive woman knowingly slept....' Eh, 'prostitute', sorry, that's the word, prostitute... 'HIV positive Polish prostitute slept with 50 men'. And in my head I'm like, did those 50 men not wear a condom with this woman themselves? But this woman was demonised. And at that time that felt wrong to me and I was negative at the time, well, I wasn't negative but I wasn't aware of my status at that time. And that resonated with me. Of people's perceptions of that, you know (Danny).

Others brought up the lack of visibility of 'normal' people living well with HIV in widely consumed cultural output such as TV shows and films, with one interviewee noting that storylines with HIV-positive characters always died. Another remarked that more realistic portrayals of PLHIV in such programmes would do a lot to make the condition more socially acceptable:

I think- Yeah, for instance I think, say for instance, on television, say like on soap operas. People watch soaps- HIV should be brought into the media more. Not so much as what- like there's normal HIV people living their lives kind of thing (Eamonn).

The point about the power of the media and cultural representations of HIV to influence and shape people's perceptions of it and those affected by it was remarked upon by several participants. It was regularly commented that the media tends to conflate HIV and AIDS,

with observations that this was confusing and could lead to people assuming they were the same thing. Others commented on how their own perceptions of HIV prior to diagnosis had been completely informed by what they knew from or had seen in the media. Finally, one interviewee noted that prior stigmatising representations of HIV during the 1980s continued to exert a powerful force on how HIV was viewed:

So the minute you say you're HIV, they'll say, 'Oh you've got AIDS?' You know? Because, the things that they've seen on the telly, in the newspaper, or what they've seen in Africa, you know? So they'll just assume, 'Oh! So this person is gonna be just like this.' So it's hard (Joy).

So then I cried for around ten minutes. And the next thing I asked is 'Am I going to survive?' (*laughs*) Genuinely! Because I didn't know the difference between HIV and AIDS! But I've always seen the AIDS person in the media, let's say. And that's the dying person. And I was like, is that going to be me? (Danny).

But it's still the gay plague, you know. That's the hangover from 'The Sun' and the things they...aghhhh! (*exclamation of frustration*) (Jamie).

Symbolic violence iv) Language and nomenclature

Numerous participants raised the issue of language use around HIV. For most people, a common complaint was the confusion around the difference between HIV and AIDS- that the two terms were often used interchangeably by those in the media and others more generally. The sense from interviewees was that the use of the word AIDS as a metonym for HIV tended to muddy the waters for people in conceptualising or understanding what living with HIV means, especially given the legacy of the AIDS epidemic in the 1980s and the baggage that the term carries. The association of the term AIDS with death and dying is not something that reflects current reality of living with HIV in a developed nation and was very much considered by interviewees as an improper term to use when referring to people living with HIV or talking about HIV in a modern context:

See people remember it as, you know Freddie Mercury and things like that when they talk about AIDS (Aidan).

Like I've never had any kind of stigmatising things said to me directly but people may say to my friends, 'Oh your friends with "Danny" who has AIDS'. Do you know? And it's just that difference that shows you like the whole ignorance around it all (Danny).

If you ask someone to explain the three letters, not many people do. They all think that HIV is AIDS and I explain to them, 'No, it's not.' AIDS is Acquired Immune Deficiency Syndrome (David).

Terry pointedly brought up the issue of nomenclature in relation to the description of people living with HIV as 'being' HIV positive, and how he perceived this to set HIV apart from other health conditions and illnesses. The use of the verb 'to be' in this way had the effect of creating a specific subject position for an individual that was centred around the condition itself, so that the illness was placed first and centre, dominating the identity of the individual and overshadowing other aspects of their sense of self and social identity. Furthermore, this phraseology was rejected for acting as a signifier for the sorts of moral and social transgressions that 'being' HIV positive imposes/confers on an individual's identity via the socially embedded processes of symbolic violence:

Like I mean I don't ever say I'm HIV positive. I mean obviously I have HIV because- Well I never said, 'I am cancer.' Like I had cancer, I have cancer. I have a flu or something. But this label of 'I'm HIV positive', it makes me one- feel part of my identity and then other people label you it, 'Oh yeah, you're HIV positive' (Terry).

Another observation was related to the use of the word 'infectious,' with one participant vociferously objecting to the use of this word in the title of the clinic he attends for his HIV care. As with the issue of the use of the word AIDS, it was suggested that in the era of ART and undetectable viral loads the continued use of this word in relation to HIV care may be more damaging for the weight it carries. Specifically, the idea of HIV infectiousness was understood to perpetuate stigmatisation of PLHIV as sources of contagion:

And it's shocking. And I have to go to the infectious diseases clinic. It's called the infectious diseases clinic. If I was newly diagnosed, how would that make me feel?...Because I'm not infectious...I'm undetectable, so I'm not infectious, and yes I

have a disease, but I'm not diseased. It's a small, tiny compartment of my life which I manage very well (Jamie).

The rejection of an HIV positive identity to which others attached subjective meanings based on stereotyped assumptions or moral judgements about a person was a point further echoed by others who specifically talked about the link between language and stigma on several occasions:

And I just think about the language around PrEP kind of symbolises how people think about HIV. As in why should we give a drug for people who don't want to use condoms? Do you know what I mean? For sluts or whatever. And if people have that idea about PrEP, what do you think they think about people living with HIV? You know. And we have to stop telling them that they are less or they're dirty, they're unclean, they're second class citizens. We need to change the language around it (Danny).

Symbolic violence v) Subjectification and the 'Othering' of the self

Many interviewees articulated in distinct ways that their experience of living with HIV encompassed a feeling of 'Otherness.' This was often expressed, not in terms of being different from others *per se*, but of something having been lost or altered about themselves post-diagnosis. Some articulated this as a 'change' that occurred in how they thought or felt about themselves. Joy put this in terms of having an abrupt sense of one's vulnerability: 'So you would think you are safe and everything is fine. Then all of a sudden your world is changed.' Another interviewee commented that his diagnosis had somehow disrupted or altered his life trajectory and how the trauma of this affected his ability to relate to other people:

And I think it has impacted on my life, it put my life- it has put me in a direction- A different type of life which has conditioned my mind differently. That's why I don't relate to people a lot. I don't know what people are talking about when they- I'm not very good at conversations (Eamonn).

One of the more common frames for this sense of dislocation from self and 'Otherness' was having a feeling that something was 'missing' or 'lacking.' Aoife put this quite eloquently,

semantically linking this to 'deficiency' in HIV (Human Immunodeficiency Virus). For her this was the 'big piece' that circumscribed how she felt and thought about herself as a social being, greatly impacting on the way in which she interacted with others and giving rise to the feeling of being constrained in some way:

I have this kind of paranoia, for want of a better word. I'm wondering are people picking up on my level of energy or what are they reading and what do they see in my face and do they see what I see sometimes, which is a look of- There's, there's just a look. It's to do with- I can't just get the word, but, it's a lacking. And I think- Even, even in the deficiency piece. H-I-V... Human- Immuno- *Deficiency*- that. There's something in that sense of deficiency and lacking (Aoife).

The idea that something or some part of the self was lacking, lost or missing somehow, was echoed by several other interviewees:

No, I'd say that the worst psychological thing for me with the HIV, I suppose. Not quite- ashamed is the wrong word to say but, I can't think of a milder form... A sense of not being whole, I suppose (Declan).

Because it's one of the most hurtful things, thinking that you're less or that you'll never be what you were or that something was taken away from you that you'll never get back. But I missed kind of, like, the old confident me. The ambitious, goal orientated...social me that I feel that I've lost (Danny).

The feeling of 'Otherness' was not one that necessarily waned with time as one adjusted to a diagnosis, but was rather something that was carried all through life, constantly reinforced by on-going experiences of stigmatisation and the feeling of being separate and apart from everyone else. This was powerfully outlined by Aidan:

It's like as if- I feel, and I've felt it before- that you're being like an alien or something. You're not one of them you know. They're the sort of feelings you get as a person with it, you know. And them (sic) feelings come from reality because you're living it, you know? You see the people staring, you see the smirks and you see- so it does happen, you know. I'm a long time diagnosed. I was diagnosed when I was

diseased and it was more or less gonna kill you. Like it's not now. So I'm not new to it you know (Aidan).

Such feelings were often intensely internalised, as individuals negotiated living with a stigmatised identity. The extent to which this could impact on health and well-being in terms of impacting on adherence to medication was outlined explicitly by Paul:

I like to forget I have it. Do you know what I mean? Like I even stopped taking my therapy for a while. You know. Because I wanted to put it in the back of me mind. And forget that it was there. Forget that I had it. That's it. I even put off getting tested, you know? Because I was afraid of the result (Paul).

Structural violence

Structural violence may be defined as the imposition of policies, practices and systems of governance that facilitate the differential distribution of resources, services and opportunities, which disproportionately affect the ability of an actor or actors to achieve their full potential (Galtung, 1969). In the context of HIV care and prevention structural violence via organisational/institutional structure, inadequate or improper policies and practices and resourcing and environmental or infrastructural issues can present barriers to accessing testing and care, and ultimately affect health and well-being outcomes (Galtung, 1969; Galtung & Tord, 1971).

Interviewees gave an insight into the ways and the degree to which structural violence results in institutional barriers that affect the health outcomes and well-being of people living with or affected by HIV. This was evident, for example, from discussions that arose from experiences of accessing healthcare services, and from interviewee perspectives on things such as availability and quality of sex and sexuality education, awareness campaigns and health promotion efforts related to HIV and STIs.

HIV Clinics

In discussing experiences of attending HIV clinics, a number of interviewees identified issues around access and waiting times that could impact on health outcomes. One interviewee talked about access to testing, revealing that he had been turned away from a clinic the first two times he went to try to access screening:

I tried, I tried twice previously, but I was number 31 out of the 30 allowed in. So, I wasn't seen to (Danny).

Clinic environments were described by some participants as 'not a nice place to go' (Adrian), 'awful and a 'conveyor belt' (Jamie). Many interviewees reported long wait times on the days on which they had their quarterly or biannual appointments. For instance, Bernie described waiting times of up to four hours, which necessarily required her to take an entire day off work. She outlined how this was the primary factor in her decision to forego changing treatments, despite suffering from severe diarrhoea as a side-effect of her current regimen:

If you change your meds you've to go in two weeks, four weeks, six weeks. So you're going in for a few weeks in a row. So they actually wanted me to change again last year and I just said that I can't because of my job. I could not change (Bernie).

Another interviewee described having to wait over an hour before he was seen on the day he went to have his diagnosis confirmed after initially testing positive in his GPs. He described the clinic as 'intimidating' and 'unwelcoming':

That's what I'm saying- there was no interaction. You registered at the counter and you were told to take a seat and wait. You were given an appointment- I know now that the appointments don't matter a damn on any date or any clinics. You were given an appointment for two o'clock I got there for a quarter to. I wasn't seen until nearly three (Kevin).

Quite a common problem that was raised consistently was the perceived lack of continuity of care in the clinics. Many interviewees reported seeing a different doctor each time they had a clinic appointment and rarely had contact time with their named consultant. While not everyone considered this to be a problem- taking it as a sign they were doing well- for others this implicitly signalled that they were not a priority and that the doctors were not engaged or interested. Many also expressed that not having a relationship with their doctor was frustrating. This became an issue particularly at times when they perhaps needed extra support, in the context of changing medication for example, or if going through a rough patch emotionally:

The pharmacist is lovely. The nurses are great. I'm on my fourth consultant- that annoys me a bit. There's no continuity (Anna).

And I said, 'Excuse me doctor, what was your name? I've been living with my condition for ten years. I know my medication. I'm very, very good at taking it. I'm merely letting you know in case there's a blip so you'll be able to account for it. Don't lecture me' (Jamie).

Another problem raised was the lack of integration of services- specifically in relation to ongoing mental health, emotional and social care needs. Numerous interviewees remarked that they had never been offered any form of counselling or support, nor had they been linked in with ancillary support services in or outside of the clinic setting. One interviewee described how when he was initially diagnosed he would try to 'drag out' the time spent with his HIV doctor in order to have someone to talk to. Another mentioned how he had been offered no advice on how to discuss his HIV status with his children, despite feeling that this was support he and his family would benefit from. Anna noted how in seven years she was never asked about or offered counselling support: 'And maybe I don't need it now, but there were times. I mean I've been here seven or eight years now, but they haven't (Anna).' According to Terry, the lack of mental health support was so acute that he feared for the well-being of some PLHIV:

And honestly, I find the mental side of this illness, is not dealt with at all. At all, at all like. If you have people lonely, depressed about it, you can talk about any other illness anywhere. There are people who bottle up. I actually- I'm scared for them really. Because like, what do they do? (Terry).

Lack of effective communication by clinical staff was an issue that was further raised by several interviewees. Several recounted how treatment regimens they had been placed on provoked or exacerbated mental health difficulties or resulted in unpleasant side effects. Interviewees recalled how they had endured these side effects for a long period of time because they were either too scared to initiate a conversation or they had not been informed that it was possible to change treatments if problems arose. Danny, for example, described how he was prepared to stop treatment all together until his mother intervened:

I was lifeless. So my Mam, being my Mam, dragged me into the clinic that day and she was like, 'I'm not having that talk in my house.' And I'm happy she did because when I went in, they gave out to me. You know there are so many different drugs out there, medications, that we could have just changed you if they were that severe. But I didn't know that. No one told me (Danny).

Sex education and prevention

Nearly every interviewee brought up the topic of sex education and sexual health promotion, usually in the context of having been asked what could be done to improve perspectives on HIV or what was needed to change things for the better in terms of sexual health and awareness of HIV and STIs. Lack of sex education, particularly for young people in schools, was the dominant theme in this regard and most interviewees had strong opinions on the need for this to be improved. Several brought up the point that the type of sex education offered in schools was at the discretion of individual schools and that this was problematic given the dominant Catholic ethos. The lack of information specifically for LGBT students was a salient point that was raised by Danny:

Well our relationship and sexual health education is terrible in schools...I can't even remember being given sexual health talks. I think first year in SPHE. I was given it by my PE teacher. And we all just laughed through the whole thing. Because it was boyish. It was an all boys' school, do you know, it wasn't taken seriously whatsoever. Let alone- and they can't say anal in school, they can't say anything to do with LGBT especially when I was there. So do I feel, as a 21 year old gay man who didn't know that HIV even existed in Ireland- I keep referring back to that because it's important. I think that's a failing also of the school. And maybe people say well you didn't go out and search for it yourself, but when you're that young you think you're impervious to all these things for one. And you don't go out looking for these things, you know (Danny).

Aidan also talked about the importance of sex education in schools, claiming his children had not received any. While he was proactive in raising the matter with his own kids, he felt strongly that the school had a duty to provide programmes of sex education to young people:

And I don't know what approaches schools have, you know but I think they should be taught about their bodies anyway you know. As a thing not to be laughed upon or sniggered at and all. But it needs to be taught and taught properly, you know (Aidan).

Joy highlighted how the deficits in people's knowledge about sex, STIs and safe sex practices extended well beyond school-aged children and remained a problem for many adults she had come into contact with throughout her time in university. She speculated that dominant cultural Catholicism and the embarrassment of parents may have been significant factors that prevented people from engaging with the issue within the family:

They don't know. *Anything* (Speaker's emphasis). They don't know anything about HIV. Even about STIs. They don't know nothing. I was surprised last- no I was in my second year or third year. I had my presentation on sexual health in college. Because I had done the training here (HIV organisation) for sexual health and I had to do that in college. We were 17 in my class. They don't know anything about STI. They don't know anything about HIV. Nothing. I was like, 'How do you not know?' (*laughs*) 'Honestly? How- my daughter she is only 11 but she knew when she was five. Because I taught her. I guess because of the way here being a Catholic, probably they don't talk to their children. Which is sad. Because you meet forty year old who doesn't know how to put on a condom. He doesn't know what STI- what STIs are. They don't know anything. And HIV they don't know how you can contract it, whether you can pass it on or whether if you have a baby, if you have a partner, whether the people will have it or not- they don't know nothing (Joy).

Health promotion campaigns for sexual health, STIs and HIV were often discussed in the context of interviewees responding to questions about why they believed there was so much ignorance and stigma around HIV. Many drew comparisons with the Eighties, observing that although there were fewer people being newly diagnosed than in Ireland, there were far more information campaigns and advertisements about HIV. A couple of interviewees made the point that the majority of safe sex messaging seemed to be in relation to avoiding crisis pregnancy and tended not to emphasise STIs as much:

I think they've stopped educating people about it. But like it was all in the Eighties and now all of a sudden there's nothing. You see an odd article about it... you know like I'd be interested- if I'd see anything, I'd always have a read. But you never see anything now, there's no education there I don't think. And I see now there's an ad on the telly for condoms so you don't get pregnant (Bernie).

Whatever about- I find that when you're talking to them, both men and women, the only thing they seem to get in sex education is pregnancy prevention (Terry).

There was a perception among many interviewees that STIs, HIV and HIV-related stigma were not particularly prioritised as a public health issue, when compared to other health conditions. Comparisons were drawn, for example, with health promotion efforts in relation to mental health, and the strides that have been made as a result in the de-stigmatisation of that as a problem in Irish society:

It's being able to be open about it really or to feel comfortable to be open about it for me I think that is the biggest challenge. It still seems to be a kind of taboo-ish matter or thing to be living with. The mental health probably seems to be getting more press which is a great thing, or, kind of, more encouragement of the resources and for it to change the society mindset of 'It's ok to talk about' and its sort of not a hush-hush kind of shameful thing that nobody mentions, it seems to be. But HIV doesn't seem to have achieved that yet (Declan).

The view was that for HIV, 'there just doesn't seem to be anything' (Bernie). One interviewee wryly observed that resources that are put in to advertising the flu vaccination each year, while another discussed her disappointment at what she perceived to be a short-lived and tokenistic attempt to address HIV-related stigma:

I do think that there should be more education around it and more information for people and there has to be a programme of education or advertisement about it you know. I mean they advertise every year for the flu jab, you know (Aidan).

I remember a number of ads with the like of Eamonn Dunphy and I don't know who else on TV there a few years ago- maybe three years ago or so. There was a little bit of a campaign saying, you know, this can affect anyone, and let's talk about this. But

I was thinking this is great! This is the beginning of something. And then it just came to nothing. Then after a few months there was just nothing. So I just felt that was the beginning of a lie...it didn't go anywhere, so what a great start to nothing. Really. I genuinely felt a bit let down about that (Aoife).

Another participant, who is involved in HIV activism and campaigning, discussed a recent anti-discrimination campaign he had been involved in and the disappointment he felt with how PLHIV were represented in it. In the lengthy quote that follows, he recounted a conversation with a person with responsibility for the campaign in the HSE whose comments strongly echoed those of Charles' friend apropos of Ireland 'not being ready' to accept HIV:

I'll go into the anti-discriminatory campaign that's on at the moment and it really hurts me. And I remember talking to (name of individual) of (name of organisation). And I said to X, I was like, 'X, the anti-discriminatory campaign directly affects people living with HIV and people who I talk to every day. In 2016 we still bring out campaigns where people cannot show their faces or have to have hands over their faces. You cannot show them directly. In 2016. The messages are do not discriminate. This is reminiscent of the 1980s/1990s governmental leaflets.' And they gave the excuse that 'The modelling agencies don't let us use that.' And I was like, 'That's the most lazy excuse in the world. Get students to take selfies saying 'I'm not going to discriminate' because that's what LGBT societies are set up for. That's what students want to do. And everyone loves taking a selfie. And it wouldn't cost you an absolute penny. Make it go viral and it's a lot better than that.' I'm like- because that's perpetuating the stigma and the shame we have around it. And it's silencing people. And I just think it's completely wrong and barbaric that we are doing that in 2016. If you look at like the governmental things of the 80s and 90s, they were the exact same. And X was like, 'Well Danny, last year we only came out with the 'Yes equality' marriage referendum like. We're not even at that point yet' (Danny).

Part Three: Stigma resistance

In this sub-section, I look briefly at some of the strategies employed by interviewees to resist and subvert a stigmatised identity- via volunteering, peer support, humour and activism.

Social solidarity

Like Danny, several of the interviewees were engaged in voluntary activities aimed at reducing the stigma and the burden of living with HIV for themselves and others. Numerous interviewees were either currently volunteering or had volunteered in the past with support organisations. Joy, for example, was actively involved with one organisation in Dublin and had taken part in the Stamp Out Stigma campaign a few years previously. Engaging in these activities gave a sense of empowerment and the feeling of contributing something to the community. Such experiences further underscored the importance of peer support as a tool not just for social support and empowerment, but also just a chance to be at ease in a safe environment:

It's nice to be with people. I know you get people- it's good to meet people from other cultures too. That's interesting as well. You can feel completely relaxed with people who have the same problem you know (Eamonn).

This was not an outlet that was widely available, however, especially outside of urban centres. Charles, for example, commented that, 'There's not a lot of just HIV positive...social grouping, coffee clutches or whatever.' Several interviewees also remarked that the structure of support groups was not well suited to everybody. Jamie, for instance, indicated that if he had met a peer group 'that possibly wasn't sitting around in a circle,' he might not have isolated himself as much.

Cultural differences were another obstacle that was identified to engaging with support services. Anna remarked that she had disengaged from a support group as she felt overwhelmed and found it difficult to identify with the experiences of African women and gay men who tended to dominate the groups she first attended. Her sense of isolation at that early stage of her diagnosis had, however, motivated her later to become a peer support worker who supported newly diagnosed women on a one-to-one basis:

I always said I would have loved to have met someone like me. That's why I do this now. It's no big deal. We- the women talk about it like, but it's just another HIV positive person that's doing well, you know (Anna).

Many interviewees were engaged with volunteering in other capacities also, particularly with sexual health outreach in schools and universities, and expressed how they felt this was an important contribution to prevention efforts. Jamie further explained how his role as a peer rapid testing volunteer in a sexual health clinic allowed him to covertly educate others in informal settings about HIV. For instance, he outlined how this provided him with an excuse to bring up things such as UVL-related non-infectiousness in conversation:

I mention the partner study a lot...if it comes up. And it is good because when I start talking about it, which obviously- 'I'm a volunteer at the health centre- a right Joan of Arc- I do rapid HIV testing, you know darling. Did you know?' And that's the way to get it in, to get in there (Jamie).

'When life gives you AIDS...'

Humour was an important coping mechanism for quite a number of participants. Certainly there was no shortage of puns on having a 'positive' outlook during interviews. For David, this was an important way to embrace his status, reclaim his identity and resist stigma:

Well, I have learned that you don't let the disease own you, you own it...I've gotten two tattoos as a result, to reinforce myself in what I feel is necessary to do. So I have a tattoo here with three symbols- one of them being a positive symbol, so people can see that I'm not hiding it...and I also have, as a cheeky gesture, the biohazard symbol here (David).

Likewise, after a low point in his life, some AIDS-related gallows humour served as a catalyst for Jamie to re-frame his status and motivated him to volunteer at a local support centre:

There was a photograph at an exhibition and it was, 'When life gives you AIDS, make lemonAID'. And...I saw it and I thought yes! So I contacted the HIV support centre and I got so much from that (Jamie).

Activism, empowerment and a seat at the table

While the majority of interviewees were remarkably socially engaged- and this may be particular to this group given that the majority were recruited via support organisations- a small number of interviewees were further involved in HIV activism. These individuals were mostly open about their status. Some had done media appearances and spoke regularly about their experiences of living with HIV in other settings. Danny described his motives for becoming politically engaged with HIV as stemming from the desire to turn HIV 'into an opportunity' to become empowered. He outlined that this work emerged out of a sense of altruism and the recognition that PLHIV had a great deal of unmet needs:

I knew I wanted to get involved with HIV and activism because I had all these amazing supports and I really wanted to help other people who may not have these supports. I wanted to provide resources that weren't there when I was diagnosed (Danny).

Jamie echoed this desire to do something to help others in a similar situation and counter the fear and stigma around HIV, but noted the challenges involved in going public about his status:

And I would love to be able to have the strength to be able to stand up and be counted and say 'Look at me, I'm doing alright. I've had it ten years and I'm still laughing and joking and not morbid and not...' Because I've done it all. I've dealt with it. Being HIV is just a tiny little part of me now (Jamie).

A further challenge to being actively involved in work that would help ameliorate the situation of PLHIV was emphatically outlined by Terry who felt strongly that there was no meaningful involvement of people living with HIV in decision-making processes that affected him. He expressed his disillusionment with power structures after participating in a policy steering group a few years previously and his desire to see things change:

And you always felt that you were just the token HIV person...Because you're sitting at the meeting and they're discussing this and they're talking about that and it's like, these people don't have HIV. These people haven't experienced the thing and they

don't know and yet you're always the last voice in everything that's said like. And now I want to be the voice, I want to speak for myself (Terry).

Conclusion

This chapter examined the reported stigma experiences of interviewees looking firstly at the context specific experiences of interviewees in healthcare settings, the family, work and employment and in relationships and dating. The second part explored how symbolic and structural violence contribute to the construction of a stigma habitus by situating the findings within this framework. Lastly, the third section looked in brief at some of the strategies employed by interviewees to resist or subvert stigma via social solidarity with other PLHIV, volunteering, humour and activism. The chapter to follow will explore in greater detail the stigma habitus concept and integrates the findings of both the media data analysis and the qualitative interviews

Chapter Six: Discussion

“Words wreak havoc,” says Sartre, “when they find a name for what had up to then been lived namelessly.” Because any language that can command attention is an ‘authorized language,’ invested with the authority of a group, the things it designates are not simply expressed but also authorized and legitimated (Bourdieu, 1977, p. 170).

Introduction

As a polyvalent social process that is generated at distinct levels of society, is manifest in discrete interactions in the social field, and elicits a multitude of outcomes, stigma has evaded simple definitions or singular conceptualisations. Nonetheless, scholarship on stigma broadly and HIV-related stigma specifically has been moving towards a conceptualisation that affirms the generative functions of culture and discourse in embedding stigma into the social superstructure, reproducing and reinforcing social inequalities (Farmer, 1999; Farmer et al., 2006; Hatzenbuehler et al., 2014; Hatzenbuehler & Link, 2014; Link & Phelan, 2014; Lukachko et al., 2014; Parker & Aggleton, 2003). Symbolic violence is thus a key component in facilitating the structural violence that supports and propagates the on-going existence of stigma via institutional practices and policies that implicitly disadvantage stigmatised individuals. This can lead to social and economic precarity, adverse health outcomes for affected cohorts and the maintenance of asymmetric relations of power (Hatzenbuehler & Link, 2014; Link & Phelan, 2001, 2014; Parker & Aggleton, 2003). Consequently, any framework for conceptualising stigma must acknowledge, and seek to elucidate, the mechanisms of symbolic and structural violence through both empirical investigation and a theoretically grounded analysis of the conditions of stigma production. As such, by integrating poststructuralist theories of language, subjectivity and power with existing conceptual frameworks for stigma, and situating analysis of the cultural and structural conditions of the stigma process within this framework, this study adds to the scholarship on stigma by showing the dialectical relationship that exists between the symbolic and social fields. Furthermore, it draws attention to the way in which institutional practices, informed by structural stigma can elicit adverse health outcomes and negatively affect prevention efforts.

I utilise the concept of Habitus from Bourdieu (1977, 1991) to articulate a reconceptualisation of the social process of stigma formation. This reconceptualisation embeds the forces of symbolic and structural violence into the stigma framework and emphasises the concomitance and reciprocity of the social and symbolic spheres within a field of power. That is to say that a homology of positions exists between the structural and the symbolic- those who experience symbolic violence are also subject to structural violence in ways that can adversely affect their life outcomes. Additionally, a dialectical relationship exists between the social field and the symbolic-structural spheres. As such, the symbolic and the structural both define and constitute the social order and are themselves defined and constituted by it. By accounting for the inter-relationships between the symbolic-structural spheres and the social field in defining sets of relations within the social order, the concept of a Stigma Habitus helps to more fully explain the multifarious nature of the phenomenon of stigma.

This chapter will discuss the results of this study in order to extend existing frameworks for stigma by articulating the stigma habitus concept. The chapter is divided into two main sections. The first section will discuss the reproduction of difference to give an integrated overview of the findings of both the media data analysis and the interview analysis. It will detail the ways in which the reproduction of difference was constructed by media texts and explore how such constructions were reflected in the reported stigma experiences of interviewees and link these to discrete stigma mechanisms and outcomes. The second section will explore how the framing of the HIV epidemic in Ireland via a discourse of 'responsibilisation' fits into a broader neoliberal rationality. Discussion will centre on the effects of this discourse in invoking norms of shame and blame that stigmatise individuals and at the same time hold them accountable for experiencing the precarity that stigma induces and sustains. This discourse will be challenged, to argue that structural violence and institutional apathy, rather than individual complacency, has played a more crucial role in deepening the sexual health crisis. The chapter concludes with some final observations and implications for health promotion policy and practice.

Symbolic violence and the reproduction of difference

Language matters a great deal in the way in which it creates meaning, constructs social reality, constitutes subjectivities (or types of social actors) and facilitates understandings of complex issues (Fairclough, 1989, 1992a). In modern society, the media plays a crucial role in this process- curating the relationship between the symbolic and the social and thus shaping ideas about the social world. Media accounts of HIV therefore play a key constitutive role in constructing identities of people living with or affected by HIV and in generating understandings of the epidemic which both reflect and reproduce the cultural milieu in which it is situated (Lupton, 1999a; Sontag, 1988; Treichler, 1999). When media accounts of HIV reproduce and reinforce difference they contribute to the stigma process by generating subjectivities and social identities for PLHIV. This 'othering' process occurs when particular discursive strategies are used to subjectify PLHIV and the HIV epidemic in specific subtle and nuanced ways that implicitly set PLHIV apart from the rest of society. One of the ways this occurs is by linking the social identities of people living with or affected by HIV to undesirable social and moral characteristics and transgressive sexualities. These subject positions then inform cultural tropes, foster prejudicial notions and propagate negative stereotypes about PLHIV (Foucault, 1982; Parker & Aggleton, 2003).

As transfigured forms of symbolic violence, these tropes, prejudicial notions and stereotypes circulate in the wider symbolic and social field as forms of knowledge and have a bearing on the behaviour and actions of individuals and institutions within a given culture or society. Specifically, symbolic violence provides legitimation for discriminatory acts/behaviours and underpins the structural violence- in the form of policies and practices and socially embedded systems- that negatively affect the groups disproportionately affected by HIV and PLHIV. This occurs by enshrining the notion of difference between social groupings into the cultural fabric of a society so that it appears natural and taken-for-granted. As Butler (2015) has observed, 'many exclusions are made without knowledge that they are being made, since exclusion is often naturalized, taken to be the "state of things"' (Butler, 2015, pp. 4-5). Hence the reproduction of difference and the tethering of that difference to a specific social grouping is an essential component to the process of stigma formation (Link et al., 1989; Link & Phelan, 2001; Parker & Aggleton, 2003).

When examined through a critical discursive lens, analysis of the media data draws attention to how these exclusions and differences are constructed textually in such a way that implicitly 'others' PLHIV by invoking notions of contagion, immorality, guilt and sexual deviance. Certainly patterns emerge in the accounts of stigma experiences where embodied and enacted experiences of stigma in the social sphere coalesced with these embedded discourses. Stigma thus occurs at the confluence of the symbolic, structural and social spheres, each mutually informing and reinforcing one another. Inasmuch as the stigmatised HIV subjectivity is circumscribed two-dimensionally through discourse, this provides a blueprint for the three-dimensional reality inhabited by PLHIV: the discursive vectorisation of PLHIV translates to the actual vectorisation of PLHIV in the social world, for example. Hence it is only by unpacking the discourses through which understandings and conceptualisations of HIV as a symbolic and a material reality are constituted and exploring how these mediate the lived stigma experiences of PLHIV within the wider social field does it become possible to articulate how this process functions.

The vectorised subjectivity

...by applying the binary branding and exile of the leper to quite different objects; the existence of a whole set of techniques and institutions for measuring, supervising and correcting the abnormal brings into play the disciplinary mechanisms to which the fear of the plague gave rise (Foucault, 1975b, p. 199).

Analysis of media data revealed how difference was reproduced in media texts by demonstrating the way in which HIV positive subjectivities were textually constructed via a discursive pattern of 'dividing practices' (Foucault, 1982). The assignment of positive or negative serostatus is one obvious binary employed in biomedical and lay parlance to distinguish between those living with HIV and those not. Such a biomedical distinction is clearly necessary in the context of an epidemic, given the exigencies involved in containing and preventing onward transmission of a pathogen. The constant reinforcing of this binary, however, via discursive practices that link the 'other' to negative characteristics is where this becomes problematic. The use of the term 'healthy individuals,' for example, as a metonym for 'HIV negative individuals,' necessarily positions PLHIV inversely as an embodiment of ill-health, thereby setting up a dichotomy between the groups (Persson,

Newman, & Ellard, 2017). Such a positioning of HIV positive subjectivities in the symbolic order apropos of binaries of health/illness thus simultaneously invoked vestigial representations of AIDS, whilst furthermore reinforcing hegemonic biomedical notions of health as the absence of illness.

Two key propositions about HIV are presupposed by this specific binary construction of PLHIV. The first assumes, clearly, that HIV positive individuals are sick or unhealthy (Lawless, Kippax, & Crawford, 1996). In the context of an infectious disease, the corollary proposition is that if PLHIV are sick and unhealthy, then they have the potential to make other people sick and unhealthy. This notion is constantly reinforced by the prolific use of the biomedically accurate but nonetheless loaded term 'HIV-infected' and its derivatives, since the designation 'infected *means* ill,' (Sontag, 1988, p. 118). Accordingly, the signifier 'infected' acts less as term to name a material serological status than it does to symbolically vectorise individuals, 'revive the antiscientific logic of defilement, and make infected but healthy a contradiction in terms' (Sontag, 1988, p. 118). As such, the binary construction of HIV positive and HIV negative individuals implicitly 'others' PLHIV by reinforcing notions of contagion and alluding to an embodied threat.

In the era of ART and UVL-related non-infectiousness, PLHIV thus live with the dual contradiction of being 'infected but healthy' and a non-vectorial vector all at once (Rodger et al., 2014; Rodger et al., 2016). Among interviewees this contradiction manifested as a form of cognitive/affective dissonance in which knowledge of non-infectiousness paradoxically existed in tandem with self-embodied feelings of contagiousness. All study participants were on stable treatment and were knowledgeable about the ways in which HIV is and is not transmitted. Nevertheless, anxieties and fears about transmission, including casual transmission, were common. These fears and the knowledge of a devalued status were experienced most acutely in the traumatic immediate after-math of diagnosis. For some the trauma was intense to the point of invoking suicidal ideation:

When you come out of the clinic here, there's a bridge that you can walk over and it goes over the motorway. And I swear, for about maybe a minute, I was looking, 'Yeah, maybe it'd be better if I just threw myself down there like, you know, it'll be quicker' (Terry).

This cognitive/affective dissonance was an enduring aspect of the experience of living with HIV and appeared to linger long after the initial shock of a diagnosis. This suggests a strong affective reaction to knowledge of one's status and the subjectification of PLHIV as sources of contagion (Chambers et al., 2015; Lawless et al., 1996). HIV positive subjectification as non-vectorial vectors/infected-but-healthy thus confers a paradoxical state of being and sense of self that has to be continuously internally deliberated and mediated. That this mediation was on-going for several interviewees who are living with HIV for upwards of twenty years attests to the depth of this affective reaction. Furthermore it suggests that for some this dissonance is never really fully resolved as the 'inscription of the HIV body as abjectly contagious' remains an on-going process, 'blunted yet incomplete.' (Persson, 2013, p. 1070). In light of the negative connotations that surrounded and continue to surround HIV this may be unsurprising. Nonetheless this speaks to the need of many PLHIV to be able to access on-going psychosocial support throughout their life-time and therefore it is concerning that the majority of participants expressed difficulties around accessing such services.

The vectorised subjectivity became particularly problematic in the context of the sexual lives of PLHIV. All participants had undetectable viral loads (UVL) and the majority were aware of and endorsed the belief that UVL effectively eliminated the risk of sexual transmission (Rodger et al., 2014; Rodger et al., 2016; Vernazza, 2008). Irrespective of this, with rare exceptions, most participants were unwilling to forego condom use within their own sexual practice and indeed expressed deep unease at the idea of engaging in condomless sex. In spite of a growing biomedical discourse of HIV 'normalisation' the experiences described indicate that for PLHIV and their partners, sexual intimacy and sexual practices continue to be mediated by deep-rooted fears of contagiousness (Persson, 2013). Although interviewees largely agreed with the concept of treatment as prevention (TasP), paradoxically, such endorsement did not translate to changes in sexual practice and this was rarely viewed as a viable option for them in their own lives. While interviewees distanced themselves from vectorising discourses by positioning themselves as moral sexual actors who always engaged in 'safer sex,' this construction was almost universally and singularly delineated as sex with a condom and rarely included TasP as a legitimate preventative strategy. Even interviewees who had engaged in acts of condomless sex were careful to

emphasise that this was in the context of engaging in non-penetrative and thus 'lower risk' acts.

This vectorised subjectivity was so firmly inscribed on the identity of interviewees that it appeared to entirely resist any reconceptualisation in light of emergent biomedical discourses that assert 'normalisation' of the condition. Certainly, at the very least, it resisted a re-assessment or reconsideration of what constituted safe sex practices within their lives. This is in line with the findings of Persson (2013) who observed that 'embodied traces of an excessively infectious subjectivity often emerged like an involuntary spectre alongside the participants' 'better knowledge' of transmission risks' (p. 1071). Sexual practice thus became an act of self-regulation bound up with an ethics of the self-as-vectorised-subject within a domain where fear of transmission and the knowledge of non-infectiousness are paradoxically coterminous. Despite optimism about the potential for new biomedical realities to collapse infectious/non-infectious binaries, this highlights how 'normalisation' of HIV remains problematic 'because of the many resistant aspects of HIV that cannot be rendered normal' (Persson et al., 2017; Squire, 2010, p. 409).

The culturally entrenched idea of PLHIV as a source of contagion mediated many of the reported enacted stigma experiences. Commonly reported instances in healthcare settings included actions or behaviours that appeared to be motivated out of a fear of HIV transmission. These included denial of service, being charged extra for services, having to wait until the end of the day to be seen, segregation and isolation and the application of precautionary measures in excess of standard universal protocols. Rather than being motivated by personal or moral hostility however, most participants agreed that ignorance, lack of knowledge and insufficient training were responsible for HCPs behaving in this way: 'Like even my GP hasn't any experience with people with HIV and knows nothing about it' (Eamonn). Moreover, as these experiences were in the context of healthcare outside of GUM and ID clinics, this confirms the findings of other studies which have found that accurate knowledge of HIV transmission among non-HIV specialist HCWs is low, resulting in a higher perceived risk of occupational HIV acquisition and increased stigma experiences for PLHIV (Bishop, Oh, & Swee, 2000; Hsiang-Chun, Nai-Ying, Chung-Ching, & Ming-Chu, 2014; Jovic-Vranes, Jankovic, Vukovic, Vranes, & Miljus, 2006; Vorasane et al., 2017).

These experiences can have a strong impact on PLHIV's engagement with healthcare services and may adversely affect health outcomes (Bogart et al., 2013; Johnson et al., 2015; Kinsler et al., 2007). This points to how structural deficiencies related to the training and education about HIV for HCPs specifically are a significant contributing factor in the on-going vectorisation and stigmatisation of PLHIV (Marshall, Brewington, Allison, Haynes, & Zaller, 2017; Davtyan, Olshansky, Brown, & Lakon, 2017). Certainly, training of HCPs in relation to HIV has been shown to reduce stigmatisation and improve patient experience (Andrewin & Chien, 2008; Li, Comulada, Wu, Ding, & Zhu, 2013; Pulerwitz, Oanh, Akinwolemiwa, Ashburn, & Nyblade, 2015). As such, the findings here underscore the need for healthcare providers and policy-makers to prioritise addressing the gaps in knowledge and experience of non-HIV specialist HCPs in order to reduce stigma as part of wider structural responses to the HIV epidemic (Li et al., 2013; Pulerwitz et al., 2015).

Healthcare was just one area where the vectorising aspect of HIV-related stigma presented problems for interviewees. As was previously noted, only six of the fourteen people interviewed were in full-time employment or education. Experiences of stigma in the context of employment and work-place environments were frequently mediated by assumptions about PLHIV as vectors. Misinformed views around casual transmission were common in many workplaces, while others reported breaches of medical confidentiality that were rationalised by employers as a normal part of standard 'health and safety' protocols. Certainly, Eamonn attributed his lack of employment to the common knowledge of his status, while several others outlined how their employment prospects had been constrained by their statuses. For example, some had to turn down promotions or job offers in countries where their status would have precluded them from emigrating, while others highlighted concerns around anticipated stigma, particularly if working with children.

If this demonstrates how stigma is mediated by erroneously held beliefs about how HIV is transmitted, it also integrates with stigma frameworks that draw attention to how stigma unfolds in a power dynamic, constraining the opportunities of stigmatised individuals and affecting life outcomes (Hatzenbuehler, 2016; Herek & Capitano, 1998; Link & Phelan, 2001, 2014; Parker & Aggleton, 2003). This helps to account for how HIV-related stigma can expose PLHIV to increased precarity by reducing access to employment and curtailing career

advancement (Annequin et al., 2016; Annequin et al., 2015; Barrington et al., 2017; Liu et al., 2012).

Interestingly, it also shows how discrete stigma mechanisms affected outcomes differently (Earnshaw & Chaudoir, 2009). For example, enacted stigma led to the diminished chance of securing work when an individual's HIV status was known (Corrigan et al., 2010; Rao et al., 2008). Separately, anticipated stigma led individuals to not seek certain employment opportunities they were well qualified and able for (Link et al., 1989; Link & Phelan, 2014). Finally, perceived stigma was implicated in non-disclosure of status to employers, leading to difficulties in seeking time off work to attend clinic appointments, thereby having a negative effect on health outcomes (Hatzenbuehler, 2016; Phelan et al., 2014). Overall, this highlights the complex and diverse ways in which the stigma of HIV, mediated by erroneous beliefs rather than the condition itself, can reduce life chances, lead to financial insecurity and affect the quality of life of affected individuals (Degroote et al., 2014; Gaudine, Gien, Thuan, & Dung, 2007; Holzemer et al., 2009).

The sexual subject and the construction of (il)legitimate sexualities

While the invocation of the HIV positive subject as embodying a state of ill-health reproduces the HIV positive body as a source of potential infection, this further implied a dual contagion, ideologically circumscribing PLHIV as a source of moral decay. In this way, PLHIV are positioned as a dual threat both to the physical and moral health of the body politic (Lawless et al., 1996; Lupton, 1993). The continual insertion of the HIV positive body into binaries such as dirty/clean; guilty/innocent; deserving/undeserving; high risk/low risk constantly reaffirms and reinforces the othering of PLHIV, whilst additionally asserting the dominance of specific but arbitrary perspectives on the right and wrong kinds of sex and (il)legitimate sexual identities (Foucault, 1976; Persson & Newman, 2008). One of the ontological implications of this binary representation is that it effaces the possibility of a space-in-between, elides the complexities of human sexuality and identity, and allows only for 'an incomplete perception of social reality' (Persson et al., 2017, p. 706). By universalising, and thus hegemonising, an incidental set of social and sexual relations, a discursive space exists in which it becomes possible to diminish and delegitimise other sets of relations (Butler et al., 2000). Consequently, the constitution of a binary symbolic

framework in which sexual relationships and identities are categorised creates the possibility to discriminate on the basis of an arbitrarily inherited taxonomy of sexuality via socially constructed norms of sexual propriety and deviance (Foucault, 1976; Scambler, 2009).

Within print media discourse the right type of sex- or at least the only one that can be publically acknowledged in the pages of a national newspaper- is almost universally constructed as heteronormative (and, increasingly, homonormative)¹², monogamous and generally reserved for those of child-bearing age (Foucault, 1976, 1984). Such a construction precludes the possibility for other types of legitimate sexualities/sexual expression, casting them instead through a narrow moral lens and framing them as transgressive and worthy of scrutiny. For example, The Irish Independent's moral panic style story in which the inchoate, hormone fuelled sexualities of teenagers and the sexuality of single older men in particular are specifically singled out for opprobrium (See Appendix A; Excerpt A; paras.2 & 3). Arguably, attending for a sexual health check could be framed as an act of sensible sexual citizenship. In this piece, however, this practice is rather offered up as evidence of morally dubious and reckless behaviour. Indeed, the fact that they are having sex in the first place is what is constructed as deviant in some way, indicative of disorder within the social body. The semantic linking of this aberrant sexual behaviour to rising rates of HIV discursively positions the HIV positive body within the symbolic order as the consequence for and literal embodiment of sexual and moral transgression, while furthermore serving as a warning to the readership of what may happen when such social mores are defied. This demonstrates how the framing of sex and HIV in the media intertwines notions of sexual impropriety or misbehaviour with PLHIV and thus constructs a particular cultural stereotype of the sexual deviant that is implicated in the stigma process (Lean, 2007).

A further feature of this preoccupation with the right and the wrong type of sex is the notable tendency of media discourse on HIV to identify the mode of transmission by

¹² The term homonormativity has been employed to describe the de-radicalisation and increased mainstreaming of gay politics over the past three decades. Duggan (2002) emphasises that access to the free-market and to normative patriarchal institutions such as marriage have become the main-stays of the agenda for equality, whilst notions of social justice that acknowledge relations of class and power within an asymmetric economic order have been relegated to a back seat position.

which people have acquired the virus. This allows for a form of moral serosorting¹³ to occur in which a value judgement is invited and the reader is directed to where PLHIV should be placed in the moral social order. For example, in an interesting syncretism of religiously inflected discourse with the sterile, clinical language of bio-medicine/physiology The Irish Times points out that the subject of an obituary published in 2007 not only acquired the virus sexually, but that she acquired it through ‘extra-marital heterosexual intercourse’ (Appendix A, excerpt O, para.3). The inclusion of this unnecessary detail of the type and character of the sex and the specific use of this language to describe it so deliberately indicates to the reader that a double transgression against the ‘ideal of conduct’ has occurred (Foucault, 1984; Sacks, 1996).

Such preoccupations with sex and the type of moral serosorting it implied were reflected in the reported experiences of several interviewees. Certainly, it was felt that being asked how one acquired HIV always presupposed a value judgement based on norms of morality and living with HIV was likened to being ‘the walking embodiments of the shame we attribute towards sex’ (Danny). Others spoke of how they believed HIV was universally associated with ‘promiscuous’ sexual behaviour and thus responsibility for their status. While this type of judgmental thinking was held to be a problem for society in general, a number of gay interviewees specifically identified a culture of ‘slut-shaming’ that was prevalent within the gay community. Of note, the association between a hyperbolised aberrant sexuality and HIV acquisition was implicated in a lowered perception of risk of HIV for many people and may help explain why many expressed extreme shock at their initial diagnosis. Ultimately, there was agreement among a good number of interviewees that the silence and stigma in which HIV is enveloped was inextricably bound up with Catholic dominated views on sex and sexuality.

Discursive ‘dividing practices’ that subjectify PLHIV as sexually transgressive, ‘promiscuous,’ or otherwise outside of the bounds of culturally prescribed norms of behaviour thus operated on the basis of conferring shame on affected individuals. Interestingly though, none of the interviewees expressed any feelings of shame or accepted

¹³ I use the term ‘moral serosorting’ to describe how PLHIV from distinct cohorts are morally distinguished differentially within the social order. The term ‘serosorting’ originates from the dating world for PLHIV, referring to the practice of only dating people with the same serological status as oneself.

this characterisation in relation to themselves, at least at the time of interview. Rather, the perception was that this was a dominantly held view in Irish society, which had the potential to affect how they would be viewed by others (Earnshaw & Chaudoir, 2009). With some exceptions, this appeared to be based chiefly on an implicit awareness or sense of culturally generated knowledge/assumption, rather than an abundance of micro- level interpersonal interactions. Thus the shared knowledge/assumption that HIV was broadly associated with a socially embedded notion of deviant or atypical sexuality, rather than a personal endorsement of that characterisation or direct experiences, was sufficient inducement to remain silent about one's status. As such, the subjectification of PLHIV as sexually atypical promoted a stereotype that was more keenly involved with anticipated and perceived stigma rather than enacted or internalised forms (Earnshaw & Chaudoir, 2009; Earnshaw et al., 2012).

These findings are largely in keeping with recent sociological work that has characterised stigma as a dynamic and polyvalent process in which culture and symbolic violence are fundamental to the operationalisation of stigma (Hatzenbuehler & Link, 2014; Link & Phelan, 2014; Parker & Aggleton, 2003). Certainly media texts demonstrated how questions of morality in relation to sexual expression are implicitly and explicitly linked to PLHIV and implicated in the on-going epidemic (Lean, 2007; Persson & Newman, 2008; Ren et al., 2014; Sacks, 1996; Watney, 1997). In turn, the interviewees expressed an awareness of similar culturally held views (Bourdieu, 1991). This awareness strongly mediated experiences of anticipated and perceived stigma and consequently impacted on disclosure decisions (Murphy et al., 2015a; Turan et al., 2017). Moreover, the findings indicate that stereotypes of PLHIV as sexually transgressive can drive the epidemic by associating HIV to character types rather than specific behaviours, thus lowering perceptions of risk and testing for HIV (Earnshaw et al., 2012; Riley & Baah-Odoom, 2011). This is compounded by the limited extent of sexual education in many schools that have a Catholic ethos, which prevents counterpoints being offered: 'Catholic schools- they wouldn't even allow the likes of HIV Ireland to come in and give talks about sexual health or anything like that, because it doesn't fall in their ethos' (Joy).

The political logic of responsabilisation

Ultimately, good sexual health is down to personal responsibility but the Government can help by educating people to make better decisions about their sexual health, understand the personal and social cost of having an STI and by improving access to affordable testing and treatment (Leo Varadkar, Minister for Health, Press Release, 29/10/2015).

In Ireland, media discourses on HIV showed a pattern of ascribing causality for the increasing number of new diagnoses to individual 'complacency,' especially on the part of gay men and young people. A significant feature of this discourse is that 'complacency' is being driven by the existence of ARV medication and increased knowledge of the treatability of HIV. Minimal reference therefore tends to be made to policy frameworks, health systems, screening services, education or health promotion efforts. This trend towards characterising the epidemic as a matter of 'complacency' was, as such, divorced from the social and structural context. Consequently, responsibility both for acquiring HIV and for the burgeoning epidemic was disproportionately shifted towards the actions and behaviours of individuals and specific cohorts, rather than on the State, policy-makers and healthcare providers. The framing of the epidemic and the individual acquisition of HIV in this way invoked a discourse of responsabilisation of PLHIV that refracted and reconfigured the rhetoric of guilt and innocence that characterised much of the media reporting of AIDS earlier in the epidemic (Brown et al., 1996; Lupton, 1993, 1999a, 1999b; Sacks, 1996; Treichler, 1987a, 1999).

There are two primary implications of the discourse of responsabilisation: the stigmatisation of PLHIV via the reproduction of an additional binary construction of guilt and innocence and the elision of the social context of illness. In relation to PLHIV, the revival of prior discourses of guilt and innocence reinforces the type of moral serosorting that contributes significantly to embodied and enacted experiences of stigma. Certainly within the context of biomedicalisation, succumbing to such an illness as a result of neglecting to be vigilant of one's health signals an additional and discrete moral failure in the care of oneself (Clarke et al., 2003; Foucault, 1984).

At the same time, while the other binaries discussed had a homologous relationship predominantly to the micro- and meso- level experiences of stigma for PLHIV, the discourse of responsabilisation had a greater impact in shaping broader assumptions about the causal factors involved in the burgeoning HIV epidemic. Hence the theme of 'complacency' was continuously reproduced across several publications and genre types to account for rising HIV rates, despite little more than anecdotal evidence to support such claims. This reflects a specific ideological position that sought 'to focus blame on those who are 'guilty' for their illness' and thus 'deflect attention away from the social context of the spread of disease' (Sacks, 1996, p. 70). Such a discourse occludes that social inequality, gender-based violence (GBV), poverty and stigma are key drivers of the epidemic and the reason why HIV diagnoses are differentially distributed along lines of class, gender and sexuality (Farmer et al., 2006; Gruskin, Safreed-Harmon, Moore, Steiner, & Dworkin, 2014; UNAIDS, 2016b). This raises the question that Judith Butler has posed about forms of political exclusion and who counts as 'the people.' A reformulation of this question in the context of HIV might be whose 'health' counts in a politics 'that produce conditions of systematic negligence' that disproportionately affects individuals with traditionally less access to power (Butler, 2015, p. 11)?

Systems of power that produce such conditions are underpinned by an ideological rationale in which inequality is a default component and certain bodies are 'disposable' (Butler, 2015). The discourse of responsabilisation is closely aligned to this logic and reflects a broader shift in Irish political culture towards a 'neoliberal rationality' that 'demands self-sufficiency as a moral ideal' while at the same time effecting policies that diminish the attainability of that ideal (Butler, 2015, p. 14). This is a reflection of global trends and not confined to the Irish context, as health systems globally have increasingly been shifting towards models of care in which 'an enduring ideational alliance of neoliberalism and the bio-medical model...intensify the scope and scale...of disease, whilst simultaneously emasculating the capacity of actors to respond effectively' (Kay & Williams, 2009, p. 2). Among other things, this has resulted in a preponderance of health policy frameworks that tend towards 'life-style drift,' in which health promotion efforts have increasingly focused less on the social inequities that determine health outcomes and more on interventions that encourage individuals to assume responsibility for the health choices they make (Baum &

Fisher, 2014; Schrecker, 2016; Williams & Fullagar, 2018). Indeed the Healthy Ireland policy framework quite clearly reflects this trend, emphasising 'lifestyle' issues as the preeminent threat to health in Ireland and asserting that 'it is essential...to empower people and communities to improve and take responsibility for their own health and wellbeing' (DOH, 2013, p. 24).

One effective way of empowering people to take responsibility for their sexual health is by implementing appropriate policies, allocating sufficient funds and providing adequate services that are appropriately structured to meet the needs of the people most likely to require them (Allotey et al., 2011; Gruskin et al., 2007; Gruskin et al., 2014; UNAIDS, 2010a). In Ireland however, a succession of ambitious and forward-thinking policy recommendations have yet to be fully realised (Barry & O'Higgins, 2008; NASC, 2010; Seery, 1999). The State was slow to respond to the AIDS crisis when it first emerged during the 1980s and policy implementation has been sluggish since (NASC, 2010; Seery, 1999). For instance, a report on HIV policy and practice compiled in 1999 noted that 'co-ordination of services varies from region to region, depends upon individuals and structures and can be erratic' (Seery, 1999, p. 10). This was a point reiterated in 2009 by the medical director of the IFPA who noted 'that sexual health was currently delivered by a number of different agencies and services, with many aspects being ad hoc and inequitable' (Lynch, 2009). Similarly, the mid-term review on the recommendations of the 2008 HIV Education and Prevention Plan found little or no progress had been made on many of the Action Areas outlined as key priorities. In particular, it was noted that there had been 'no progress in the implementation of actions to expand opportunities for HIV screening and testing' (p. 4).

Barriers to testing

Eight years since the mid-term review on the recommendations of the 2008 HIV Education and Prevention Plan (NASC, 2010) some improvements have been made to access to screening and testing. Most notably a community based peer led rapid testing initiative has been rolled out in Dublin, with screening occurring in popular gay bars, nightclubs and bath-houses (HPSC, 2017a)¹⁴. Similar, though smaller scale, initiatives are underway in Cork,

¹⁴ Funding was initially provided for a pilot only and so its future remains unclear. The programme is under evaluation and interim funding has been agreed in principle pending outcome of the review (see HPSC, 2017a, p. 24).

Limerick and Galway (HPSC, 2017a). An evening clinic specifically for gay men is also available in Dublin. Generally, however, opportunities for free HIV and STI testing remain limited, especially outside of urban settings (HPSC, 2017a). Services for young people (under 20) are scarce, with just one in Dublin and two in Cork operating on a limited basis by appointment only (Fullerton et al., 2016). Out of hours services are uncommon, with most services offering testing during the daytime and walk-in clinics operating only on certain days¹⁵. For example, Ireland's largest STI clinic in St. James' hospital in Dublin operates three free walk-in clinics per week on Mondays, Tuesdays and Thursdays. Attendees must present at 8am in order to get a ticket. The clinic opens at 9.30am on Mondays and Tuesdays and at 1.30pm on a Thursday. A maximum of approximately 30 people can be accommodated on clinic days and people are regularly turned away.¹⁶ This is a pattern that is replicated in most free walk-in clinics around Ireland. Service hours are not designed around the needs of service users who are predominantly young people, students, the unemployed and the low-waged- cohorts that are generally financially precluded from seeking private care or GP services. These inconvenient opening hours and lengthy waiting times are an obvious barrier to accessing testing (Hoffmann et al., 2016; Pecoraro et al., 2014).

Such barriers may help to explain why testing for HIV remains low in comparison with other European countries (Layte, 2006; McBride, Morgan, & McGee, 2010). The Irish Contraception and Crisis Pregnancy Study 2010 (ICCP-2010) found that 36% of Irish-born respondents (N=1043; 26% of men and 45% of women) had tested for HIV in their lifetimes, with this number comparing unfavourably with respondents from every other jurisdiction including the UK, Northern Ireland and Europe (McBride et al., 2010, p. 126). Additional findings of ICCP-2010 in relation to inconsistent use of contraception led the authors to conclude that 'there is a significant unmet need for STI and HIV testing' and they warned that 'sexual health policies in Ireland need to address these issues' (McBride et al., 2010, p. 156).

¹⁵ A mapping exercise of the STI services in Ireland has been carried out. The results, however, have not yet been published (SHCPP, 2017, p. 6). An unofficial list of free STI services is available at <https://spunout.ie/health/article/sti-clinics-ireland>.

¹⁶ Indeed, the HSE website cautions repeatedly that services for gay and bisexual men are in heavy demand and that places are not guaranteed (see <https://www.hse.ie/eng/services/list/5/sexhealth/gmhs/clinics/>).

More worryingly, perhaps, were the results of the Men who have Sex with Men Internet Survey (MISI)(O'Donnell, Fitzgerald, Barrett, Quinlan, & Igoe, 2015). Of the respondents in that survey (N=3090), 37% had never tested for HIV and 61% had not tested for HIV in the previous year (O'Donnell et al., 2015, p. viii). Amongst young men between the ages of 18 and 19, 84% had never tested for an STI, a figure which was noted as a 'cause of concern' by the MSM Outbreak Response Group (HPSC, 2017a, p. 24). Furthermore, MISI found that the groups least likely to have tested ever or in the previous year were men under 20, men living outside of Dublin, men who were born in Ireland, students, men with lower levels of education and men who were not 'out' (O'Donnell et al., 2015, p. viii). Older gay men (60+ years) were also significantly less likely to have attended for a sexual health check, with 76% reporting either never having tested or not having tested in the past year (O'Donnell et al., 2015). Thus there may be little surprise in the assessment of the ECDC's Dublin Declaration Monitoring Report (ECDC, 2017c), which showed that Ireland was one of only three countries in the European Union/European Economic Area, along with Croatia and Malta, that reported major gaps in testing for all key affected populations (p. 6). The ECDC's report on HIV and MSM in Europe further drew attention to the 'substantial' increase in MSM diagnoses in Ireland specifically (ECDC, 2017b).

Barriers to treatment, care, and support

In accessing treatment, care and support, particular structural difficulties can be encountered by PLHIV. While all participants were, at the time of interview, retained in care, some issues that were raised consistently are known to be barriers to care (Bennett, Jones, James, Roberts, & Perry, 2014; Hoffmann et al., 2016; Johnson et al., 2015). For example, experiences of clinics and clinic environments were regularly identified. While praise was generally directed at clinic staff, a frequent critique was the perceived lack of consistency of care, with a significant number of interviewees noting they rarely saw the same doctor twice and almost never had contact with their consultant. Perceived consistency of care and the ability to establish relationships with HCPs have been shown to be a highly valued aspect of care for PLHIV as chronic patients and as a significant factor in retention to care and ARV adherence (Bennett et al., 2014; Clouse et al., 2018; Cooper et al., 2016; Hoffmann et al., 2016). Furthermore, participants frequently mentioned long wait times and inconvenient clinic hours, a factor that has been shown to be a barrier to accessing care and

treatment (Bogart et al., 2013; Cooper et al., 2016; Pecoraro et al., 2014; Wessinger et al., 2017) . This was often compounded by a lack of effective communication (Bogart et al., 2013; Giordano, 2011). Conversely, good communication between PLHIV and HCPs and positive patient/provider relationships increase patient involvement in their own healthcare and has benefits for care and outcomes (Bennett et al., 2014; Cooper et al., 2016; Mallinson, Rajabiun, & Coleman, 2007; O'Brien et al., 2018). The lack of integration of services, particularly referral of patients to ancillary support services and communication between primary carers and specialists, further inhibits patient engagement with services and care (Clouse et al., 2018; Cooper et al., 2016). Similarly, the lack of availability of mental health services and counselling or a failure to link into such services outside of clinic settings should also elicit concern, given the clear negative implications for the mental health outcomes of PLHIV (Bennett et al., 2014; Burgess, 2015; Orza et al., 2015). Lastly, multiple studies have found that over-burdened and under-staffed clinic services have an adverse effect on patient retention and represent a considerable barrier to effective care and treatment of PLHIV (Bennett et al., 2014; Bezabhe et al., 2014; Clouse et al., 2018; Hoffmann et al., 2016; Johnson et al., 2015; Scheim & Travers, 2017; Wessinger et al., 2017). In the context of rising rates of HIV in the Republic of Ireland, these findings paint a picture of a fragmented, stressed and increasing dysfunctional system.

Barriers to prevention

One of the primary goals of the National Sexual Health Strategy is that 'Everyone living in Ireland will receive comprehensive and age-appropriate sexual health education and/or information and will have access to appropriate prevention and promotion services (DOH, 2015, p. 17). The findings from this study suggest however that much work remains before this goal will be reached. Participant concerns about the lack of effective prevention measures mostly revolved around provision of sex education and a perceived lack of visibility of health promotion efforts and information campaigns in relation to HIV and STIs more broadly.

Sex education

Many interviewees had not received sex education in schools, while others expressed concerns about the availability and quality that existed in schools now. Concerns

about sex education in the context of schools related mostly to the lack of LGBT relevant content and the influence of the Catholic Church's ethos in omitting aspects of the Relationship and Sex Education (RSE) programme that were not in line with the Catholic Church's teaching on sex and sexuality. This was compounded by the influence of pornography as a source of young men's information about sex and how this created unrealistic expectations in addition to encouraging unsafe practices (Tanton et al., 2015). The lack of positive messages around sex did little to tackle either of these issues or to present alternative viewpoints. Overall, interviewees were in near unanimous agreement about the importance of quality, evidence-based sex education as a crucial element in HIV prevention and lamented that current arrangements were insufficient.

This will come as little surprise to many. Formal sex education in Irish schools has only been available since 1998 when the Relationships and Sexuality Education (RSE) programme was introduced by the Department for Education. Schools are required to implement an RSE policy in conjunction with the board of management, teachers, parents and the wider school community, setting out a framework for how a programme will be delivered. The RSE programme thus acts as a 'menu of options' from which each school can develop a plan for delivery of the programme in line with its ethos and culture. Both implementation of RSE policies and delivery of programmes in schools, however, have been inconsistent, with boys' schools, in particular, singled out for poor implementation rates (Inspectorate, 2013; Mayock, Kitching, & Morgan, 2007b). A report into the implementation of the RSE programme in 2007 found that whilst most schools are implementing the RSE programme to some degree, it appears in many instances that this is limited to first and second years only (Inspectorate, 2013; Mayock et al., 2007b). It is estimated that almost half of schools are teaching no RSE in Senior Cycle (Mayock et al., 2007b, p. 92). It is also acknowledged that there is generally a fragmented approach to the provision of RSE for Senior Cycle students, with RSE often divided between religious instruction classes and biology (Inspectorate, 2013; Mayock et al., 2007b). Furthermore, RSE provision is often 'limited solely to presentations made by external facilitators, with no follow-up lessons to optimise students' learning (Inspectorate, 2013, p. 8; Mayock et al., 2007b).

Such inconsistency may help explain the findings of ICCP-2010 (McBride et al., 2010), which found that while 72% of Irish adults (N= 2193) had received some form of sex

education, this tended to be limited to the biology of sex and sexual intercourse (McBride et al., 2010). Two thirds of 18-25 year olds had received education around safer sex and sexually transmitted infections and only 35% of 18-25 year olds had received education around homosexuality (McBride et al., 2010, p. 112). Additionally, the relevance and suitability of content of the RSE programme has drawn criticism, both for its lack of sex positive messages (Kiely, 2005) and the dominant heteronormative focus of material (Mayock, Bryan, Carr, & Kitching, 2009). A broad-ranging study of Irish LGBT people (N=1110) found that sex education 'was limited or, more often, nonexistent in terms of its relevance to them' and that 'less than 5% of the overall survey sample, and less than 8% of current school-goers, were aware of coverage of LGBT-specific content in RSE curriculum' (Mayock et al., 2009, p. 66). There is evidence, furthermore, that external facilitators of the RSE programme have been requested to omit certain aspects of their programmes- such as contraception- that are not in keeping with school ethos (Mayock et al., 2007b, p. 172).

This suggests major knowledge gaps in relation to safe sex and LGBT issues among a substantial proportion of the Irish population. Given that boys' schools in particular are failing to implement RSE policies at a considerably higher rate than mixed or girls' schools, there is reason to believe that young men are at a particular disadvantage in this regard. Indeed, the MISI report (O'Donnell et al., 2015) found significant gaps in knowledge around STIs and HIV among gay men. Contrary to the assumptions in news articles about widespread knowledge about the treatability of HIV, MISI found that 32% of respondents (N=2875) were unaware that effective treatment of HIV reduces the risk of HIV transmission (O'Donnell et al., 2015, p. 78). Among younger men, however, this knowledge gap increased considerably, with 50% less likely to know about the prevention benefits of ARV treatment (O'Donnell et al., 2015, p. 78). Similar to the findings of HIV Ireland's knowledge, attitudes and beliefs survey (2017), MISI found that 23% of respondents (N=2875) did not know that HIV cannot be passed by kissing (O'Donnell et al., 2015, p. 78). Furthermore, knowledge gaps across all areas of HIV prevention increased in relation to age, educational attainment and peripheral residency, with younger men, those with lower educational attainment and those living outside of Dublin more likely to have gaps in knowledge. Almost 70% of 18-19 year olds, for example, were unaware of the existence of post-exposure prophylaxis (PEP) (O'Donnell et al., 2015, p. 83).

The picture that emerges then is one in which young people, and particularly young gay men, are entering adulthood without the skills and the knowledge they need in which to safely, and pleasurably, navigate the sexual landscape. Young people have consistently pointed out to researchers and reporters that their needs are not being met (MacNeela, 2018; Mayock et al., 2009; Mayock, Kitching, & Morgan, 2007a; Mayock et al., 2007b; McGuire, 2014a, 2014b, 2018; Murphy, 2018). A recent survey in NUI Galway found that a majority of respondents (n=2150) were unhappy with the sex education they received in school, with 65% of men and 71% of women expressing dissatisfaction (MacNeela, 2018, p. 8). Moreover, young people have demonstrated a willingness to be involved in curriculum design and, encouragingly, their ideas are often quite in line with best practice on effective sex education (O'Higgins & Nic Gabhainn, 2010).

Aside from the primary health promotion benefits of having a robust, evidence-based sex education curriculum in terms of the impact on reducing unplanned pregnancies and STIs, increased knowledge about HIV specifically has been shown to reduce stigma (Herek, 2002). Knowledge about UVL-induced non-infectiousness in particular has been shown to reduce stigma towards PLHIV. Furthermore, given that stigma has been shown here to be related to shame around sex, and specific types of sex, sex positive messaging in a revised RSE programme is likely to have an additional stigma-reducing impact. Although curriculum reform remains a contested topic, certainly at the political level at least, this will play a pivotal role as part of any societal level stigma reduction measures and have knock-on benefits in addressing the wider problem of the HIV epidemic.

Sexual health campaigns and promotional activities

Sexual health promotion campaigns in Ireland have been under the remit of the Sexual Health and Crisis Pregnancy Programme (SHCPP) since the inception of the National Sexual Health Strategy in 2015. As was noted by interviewees though, there has been little specific focus on HIV in recent years, with several nationwide campaigns, such as the 'Think Contraception' and 'Johnny's got you covered' campaigns, focusing instead more broadly on prevention of crisis pregnancy and encouraging condom use generally. These campaigns had TV spots and disseminated materials in diverse locations, such as college campuses and at music festivals, to target young people in particular. More recently the HSE and Man2Man

have instigated the ‘Luv Bugs’ campaign, producing information leaflets on STIs such as Chlamydia and Gonorrhoea for MSM. In 2015, however, the Gay Health Network (GHN) launched the ‘HIV Laid Bare’ campaign, which ran advertisements in wash-rooms and on social media aimed at MSM. This campaign underscored the need for testing and contained anti-stigma messages as well as messages about taking personal responsibility for one’s sexual health (GHN, 2018, p. 8).

It is difficult to provide a precise picture of what promotional activities are occurring throughout the State. However, a mapping and evaluation process is currently being undertaken by the HPSC and the SHCPP (HPSC, 2017a, p. 34). There is, however, some evidence to suggest that substantial gaps currently exist in relation to health promotion activities targeting MSM (HPSC, 2017a; O’Donnell et al., 2015). MISI (O’Donnell et al., 2015), for example found that 70% of respondents (N=3029) had not visited Man2Man, the main website for sexual health promotion for MSM (p. 84). Respondents were less likely to have visited the site if they had lower educational attainment, had never been tested for HIV and if they lived outside of Dublin. Similarly low numbers were aware of specific campaigns (see table below):

Figure 8.3 Awareness of health promotion campaigns

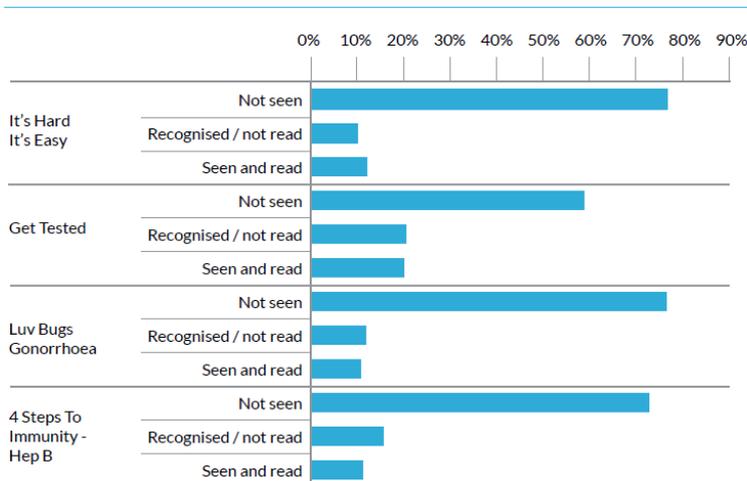


Fig 10: Awareness of specific sexual health campaigns among MSM (in O’Donnell et al., 2015, p. 86).

Younger men were more likely to have visited the site- with 35% of 25-29 year olds having consulted it as compared to 26% of the overall sample (O’Donnell et al., 2015, p. 84).

Younger men were also more likely to have engaged with promotions on Facebook and other social media sites, indicating potential to reach a greater audience (O'Donnell et al., 2015, p. 101). Indeed, plans are underway by the MSM outbreak response team to capitalise on social media to further health promotion goals and bridge information gaps (HPSC, 2017a). This would seem a fruitful area of engagement. As young people's lives are increasingly being conducted online, the opportunities afforded to reach this demographic seem obvious. Although this is an emerging area of research, there is some evidence to suggest that communicating health promotion messages online and on social media can have a positive impact (O'Donnell & Willoughby, 2017; Stevens et al., 2017; Todaro et al., 2018). Stevens et al, (2017) for example, found that young people were twice as likely to have used a condom during their last sexual encounter if they had been exposed to safer sex information on social media. Given that 70% of gay men in Ireland use a dating app such as Grindr, this would be an obvious platform from which to engage more men with sexual health and anti-stigma messaging (O'Donnell et al., 2015, p. 52).

Implications and recommendations for health promotion

Bearing in mind the principles outlined in the Ottawa Charter (1986), and indeed the goals of a critical public health perspective (Green & Labonte, 2008), there are several implications and recommendations of this research:

As the findings and analysis have shown, stigma is a complex and polyvalent process that operates across distinct levels in society, via discrete mechanisms that can elicit discrete outcomes. As such, any efforts to address HIV-related stigma will require more than one approach and involve 'top-down' as well as 'bottom-up' measures. Research on stigma interventions will need to be creative and adopt holistic and integrated approaches in order to address discrete stigma mechanisms. Capacity-building and increasing social and community support for PLHIV will form an important part of any intervention. The finding that stigma remains a problem within healthcare settings are troubling and specific efforts, such as training and education, for example- should be sought to address this problem.

The findings indicate that there is clear relationship between language use and the on-going experience of stigma by people living with HIV. Attempts to encourage societal level shifts in language use are often derided as 'PC culture' run amok. Policing of day to day

vernacular is neither practical nor desirable. However, there are steps that could be taken to encourage the use of non-stigmatising language. Health promoters and other HCPs can be mindful of the language that they employ as part of their own praxis when working with people living with HIV or on issues of sexual health more broadly. Additionally, it is recommended that guidelines around the use of non-stigmatising language are drawn up and disseminated to HCPs, newspapers, broadcasters and other media organisations. This could be accompanied by a request to the Irish press ombudsman to issue an advisory notice to all regional and national editors.

It is clear from the research that HIV-related stigma, and HIV and sexual health more broadly, have been neglected as a public health priority by successive Irish governments. Consequently, a concerted effort of coordination between health promoters, researchers, academics, voluntary organisations, groups of people living with HIV and activist organisations is needed to advocate for sensible policies- and the implementation of such policies- that acknowledge and address HIV-related stigma as a legitimate public health goal and an important part of the HIV response in Ireland. The meaningful involvement of people living with HIV in formulating policy and practice guidelines should be a priority going forward. Additionally, such policies should take their cue from international best practice to advocate for a tri-partite combined approach to include structural, behavioural and biomedical prevention strategies. Overcoming structural barriers to testing, for example will involve advocating for increased funding for and improvement of existing services, as well as promotion and mediation efforts to 'normalise' testing through education, advertising and promotional activities. Similarly, the roll-out of proposed PrEP services will need to be accompanied and complemented by robust sexual health counselling services.

It is further clear from research that support services for people living with HIV are inadequate. The establishment of peer support networks would go a long way to addressing this gap and would have considerable benefits for PLHIV in terms of health and well-being outcomes. There is scope for a participatory action research project to explore this. This could form part of any future stigma intervention research, but funding and support from the HSE and the voluntary sector would be essential in setting up such a project and assuring its on-going coordination.

Health promotion has long acknowledged that legal and policy environments play a key role in determining health outcomes. A mechanism exists via the Equality Tribunal for people living with HIV to bring complaints about unfair treatment or discrimination, whether in work or whilst engaging with healthcare services. However, this appears to be unfit for purpose where PLHIV are concerned given the necessity to openly disclose one's condition and identity. This represents somewhat of a 'chicken and egg' dilemma- while HIV remains highly stigmatised, people living with HIV will be reluctant to openly reveal their status in order to seek redress for infractions against them as per the Equality Act. Similarly, so long as barriers exist to seeking redress, there is little to prevent employers and others from continuing to engage in discriminatory practices. Consequently, other frameworks or strategies may need to be explored so that PLHIV can seek legal redress for any violations of the Equality Act that they experience.

Conclusion

Speaking at the sixteenth International AIDS Conference in 2006, then UNAIDS Executive Director Dr Peter Piot remarked:

Since the beginning of the epidemic, stigma, discrimination and gender inequality have been identified as major causes of personal suffering, and as major obstacles to effective responses to HIV. Yet there has never been serious political and programmatic commitment to doing anything about them (Piot, 2006).

Now, in the fourth decade of the HIV crisis, this statement remains true. Despite the leaps and bounds that have been made in the treatment and prevention of HIV, stigma and discrimination continue to impact on the lives of PLHIV and to hinder prevention and treatment efforts. In Ireland, amid an apathetic State response, the HIV epidemic has deepened considerably in recent years and, as this study has shown, stigma is still routinely faced by PLHIV.

This study has shown how stigma is keenly bound up with discursive constructions of HIV that both shape and reflect deeply embedded cultural notions of sex, morality and health and illness. As an important cultural and political actor, the print media play a key

role both as the conduit through which dominant societal views are disseminated and as interlocutors in their own right. Unpacking the discourses of HIV that occur in the print media, a pattern emerges in which PLHIV are circumscribed as potential sources of physical and moral contagion via frames of risk and responsibility. Furthermore, it is clear that the epidemic itself is framed in ways that reflect a dominant political paradigm in which health becomes a matter of individual responsibility and the role and function of the State in creating the right conditions for citizens to attain good sexual health is set aside.

Indeed, this study has demonstrated that such constructions mediate the embodied and enacted stigma experiences of PLHIV and how symbolic and structural violence are implicated in this process, working in tandem to negatively affect the health and well-being of those disproportionately affected by the HIV crisis. Furthermore, by unpacking and identifying the precise contexts in which stigma occurs, the type of stigma experienced and the outcomes it elicited, this study provides insight into the lived experiences of PHLIV and how stigma has colonised their lives. Such insights into stigma are essential to designing robust and effective interventions going forward.

At the same time, culture is both difficult to define and predict. Certainly, in a world where the pace of social change is subject to increasingly more rapid shifts, it can be difficult to say with a large degree of certainty what the national mood is or where people are standing on any particular issue. In Ireland the rate of social change has been especially dramatic over the past few years. Since this research was started four years ago, for instance, significant changes have occurred in Irish society in relation to outlooks on sexual morality and sexual and reproductive health, with the passing of the marriage equality referendum in 2015 and the repeal of the Eighth Amendment in 2018. Many of these changes have been driven by a persistent and determined grassroots activism. A similar grassroots movement is emerging to campaign for better sexual health services and the destigmatisation of HIV. If past is prologue, then there are reasons to be optimistic.

Indeed, statutory responses to the burgeoning HIV and STI crises have picked up pace in the past two years and it is evident that there has been increased coordination among State agencies such as the SHCPP, service providers such as GMHS and voluntary bodies like GHN and HIV Ireland. An MSM outbreak group especially formed in 2017 and a

number of mapping, evaluation and intervention planning initiatives are underway. Creative approaches to outreach, communication and service delivery will nonetheless need to be sought if current gaps in testing, health promotion and behavioural interventions are to be bridged, particularly among key populations such as MSM. This, however, will require greater funding than has been available over recent years (Burke et al., 2014). While funding for the health system overall was reduced by 22% in the wake of the recession, funding for the Gay Men's Health Service (GMHS) was especially hit hard, effectively halved since 2009 (HSE, 2013). During the same period diagnoses of HIV among gay men nearly doubled (HPSC, 2017b).

This did not go unnoticed by some members of the community. In response to the crisis, a resurgent HIV activism has arisen. In 2016 the first Irish chapter of ACTUP was formed in Dublin. Similar to the original chapter in New York over three decades ago, the group is mostly comprised of young gay men and people living with HIV who have come together out of frustration and anger at the perceived neglect of HIV by the Irish political and health systems. Since their formation, ACTUP has engaged in a sustained campaign to draw attention to the growing numbers of new HIV diagnoses, as well as advocating for increased access to testing, better funding for gay men's health services and the introduction of PrEP. During this time they have inserted themselves into the national discourse with increasing urgency. All too aware of the impact of the crisis, activists have not shied away from highlighting the silence of politicians. The question remains whether or not those voices will ultimately break the silence.

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Appendices

Appendix A: Sample texts- Excerpts from newspaper data sample

Excerpt A:

Teens lose count of sex partners as HIV cases rise daily

(1) Teenagers are losing count of the number of sexual partners they have had and many don't even get a name or telephone number of the person they've just had sex with.

(2) Children as young as 14 years of age are going for STI (sexually transmitted infection) check-ups, while older men in their 70s are coming home from holidays in South East Asia after contracting sexual diseases such as HIV.

(3) The shocking testimony comes from the country's top expert on STIs as latest figures show that there is one new case of HIV every day in Ireland -- the majority of which are as a result of heterosexual intercourse.

(4) Dr Derek Freedman, a consultant in genitourinary medicine and one of Ireland's leading specialists on STIs, has painted a frightening picture of Ireland's current one-night stand culture where many are regularly indulging in high-risk sexual behaviour.

(Irish Independent, 04/05/2008)

Excerpt B:

HIV treatment: pre-empting infection or encouraging risk?; Truvada is taken by healthy but high-risk people on a pre-exposure basis and can prevent the virus taking hold

(1)The evidence is in, and it's conclusive. Trials from the UK, US, France and Thailand show that PrEP (pre-exposure prophylaxis) dramatically reduces HIV infection in high-risk categories, including men who have sex with men, sex workers and intravenous drug users.

(2)The drug, Truvada - the same medicine that is used to treat HIV-infected patients - also prevents infection in healthy people if taken daily before and after exposure to HIV.

Although widely available as a preventative measure in the US, it is not licensed for the prevention of HIV transmission in Europe.

(3)But if it is introduced here, it won't be without controversy.

(4)Who should have it? Who will pay for it? And is there a risk that it could actually increase sexually risky behaviour?

(11) One UK study, Proud, showed that it cut the risk of infection among gay men by 86 per cent. The same study also showed the concerns that those on PrEP would engage in riskier sex were unfounded: men reported that they did not change their condom use. Advocates here argue that Ireland's health authorities should bear the same considerations in mind.

(18) A certain complacency around HIV may be responsible for increasing infection rates.

Shanley regularly fields calls from young gay men

(Irish Times, 09/06/2015)

Excerpt C:

HIV Rise: Being man enough to stay safe

(Sub-heading) Once considered a death sentence, HIV is now a chronic, treatable illness. But does this mean young gay men are becoming complacent about the disease, as a rise in HIV diagnoses suggests?

(1) The increase in new cases of HIV among gay and bisexual men outlined in a recent report by the HSE came as no surprise to those working in the area. The *HIV in Ireland 2012* report found a 160 per cent increase in HIV diagnosis among gay and bisexual men between 2005 and 2012, and said the average age of diagnosis had also dropped, from 38 to 32.

(2) Increased testing contributes to the rise, but why are young gay men still such a high-risk group given the virtually global emphasis on safe sex? The key word among medical professionals is 'complacency'.

(3) HIV/Aids, once a death sentence, is now a chronic, treatable illness. The virus has stayed the same, but the drugs have improved. However, education about HIV appears to be intermittent, particularly for young men born after HIV peaked as an international talking point.

(4) Open Heart House, an organisation that offers support to people living with HIV, has more than 1,100 members. 'There is definitely a complacency . . . People think: 'I can take a pill and address it.' The other issue is we haven't had a campaign for years. I have students in and their lack of knowledge astonishes me,' says Paula Gilmore, the organisation's chief executive.

(5) Rory O'Neill, a prominent figure in the LGBT community, has spoken out frequently about the stigma surrounding HIV. 'This is just my opinion, but I strongly suspect that young

people don't view HIV as quite the horror that we did 10, 15 or 20 years ago. They didn't grow up with the tombstone ads on TV. They don't know anyone who has died from it.'

(6) 'If they do come across somebody who is HIV positive, they are living their life, taking their drugs, and it makes it look like a manageable, chronic condition. I think the younger gays don't fear HIV in the ways that we did . . . And it's a big mistake on their part.'

(7) At a busy gay bar in the middle of last week, the crowd is spilling in, a mixture of mostly young gay guys and gay girls and their straight friends. A remix of Daft Punk's *Get Lucky* is playing, and the smoking section is the perfect illustration of the LGBT scene: a convergence of backgrounds, ages and ethnicities.

(8) Declan (19), one of the young men in the bar, says he doesn't know anyone with HIV. 'If one of my friends had HIV, I'd be really shocked. I've never been into casual sex, and that's one of the reasons because it is seen as a life-ruiner.'

'Like leprosy'

(9) Although there are no physical signs evident if someone has a positive HIV status, Declan says that among his peers there is a belief that you can tell if someone is HIV positive or not. 'One of my friends came up to me in [a gay bar] the other night and said "they definitely have it" about this guy and told me "you need to be careful." People think it's like leprosy or something, that you can tell if people have it . . . I've been told it's a big problem, but you don't really have to know about it.'

(10) Also in the bar is John (21), who uses Grindr, a geo-location smartphone app for gay and bisexual men to access dates and sexual encounters. He says '70 per cent of the guys' on Grindr ask for sex without a condom. 'I've got drunk and had sex without a condom . . . twice. If someone told me a year ago you could get all this stuff just one time, I would never have done it. But being honest with you, I didn't even know.'

(11) 'After getting tested I'll never do it again. But I didn't know. I'm not stupid, but no one ever told me . . . I've never seen an ad in the mainstream media about gay men and protection, I've only ever seen it in *GCN* [*Gay Community News*].'

(12) Another man in the bar is Michael (21). 'I don't know anyone Irish with HIV. For most people, getting chlamydia, syphilis, the curable things, that's what most people will use condoms for when it comes to penetrative sex. Most people fear getting the smaller things more than the serious things.'

(Irish Times, 25/06/2015)

Excerpt D:

Complacency Danger on HIV

(5) Ironically, the increased survivability of HIV made possible by the successful development of anti-retroviral drug treatments appears to have encouraged many young men to take the sort of risks which only four or five years ago their counterparts would have thought twice about.

(Irish Times, 02/12/2009)

Excerpt E:

Rapid Testing Service to Fight HIV Spread

(8) Mr Varadkar said the strategy has not been costed. It will be funded obviously within the context of the existing budgets, he said. He said HIV was a particular concern because the age at which it was being diagnosed was falling it was becoming a young person's disease.

(9) What has happened is that people are less afraid of it than they were in the past. It is now effectively a chronic disease, said Mr. Varadkar. Because there was not the same level of fear about the disease as there was in the past, the incidence of the disease was increasing again and that should be of enormous concern to everybody.

(Irish Examiner, 30/10/2015)

Excerpt F:

Ignorant youth deliberately seek twisted 'gift' of HIV

(Sub-heading) A worrying new trend is seeing young gay men intentionally setting out to contract HIV, writes Nicky Larkin

(1) There is a shocking new phenomena called 'pozzing-up,' where very young gay men intentionally set out to become HIV positive. They see being HIV positive as a badge of honour. They even call HIV "The Gift".

(2) These warped bug-hunters refer to their chosen HIV-positive partners as gift-givers. A gift you can't give back...

(3) HIV is now a chronic, treatable condition, as opposed to the fatal condition it was in previous decades. But as a result, HIV has slipped off the radar. A certain complacency has set in.

(4) Because of our casual swaggers, 2015 saw the highest number of newly diagnosed HIV cases in Ireland in five years. Even more worrying, it is estimated that a sizeable proportion of Irish people are HIV positive but have never had a test - so are not aware of their status - and are therefore, unknowingly passing on HIV to their partners. All the old myths that HIV and Aids are the exclusive preserve of gay men and intravenous drug users are nothing but fairy tales to give the common upstanding citizen a sense of security - it could never happen to them. But contrary to this fairy tale, the rates of heterosexual infection have risen by over 400pc in the past five years.

(5) After he finished college in Dublin, Martin travelled the globe - pure Paddy-style - 20 drunk GAA jerseys clogging-up the departures lounge, herded like cattle onto a plane, then herded off again in some other, warmer, part of the world.

(6) But when he came back, Martin had to go for a test.

(7) He'd been an adventurous boy with some local ladies in the more shady corners of the globe, fuelled-up on the local hooch. When he told his doctor the gory details and geographical locations of all his conquests, she told him he was at extremely high risk of being HIV positive. So she took a blood sample, and Martin had to wait 72 long hours for his result.

(8) He couldn't eat or sleep with the stress and worry. He couldn't talk about it to anybody. He was a quiet, educated, straight, middle-class boy with a good job from respectable stock in rural Ireland. How would he tell his mother he was HIV positive? What would his father think of him? He practised in the mirror, announcing to them he had Aids. He passed sleepless hours online, researching the latest advances in HIV treatment. He prepared himself for the absolute worst. From the doctor's reaction and his 'high-risk' status, he expected the worst.

(9) Three long sleepless nights later, Martin was told his result was negative; he was not carrying the HIV virus. He felt like he'd won the Lotto.

(10) Martin was right to feel lucky. Because people remember the horrors the early days of this new disease brought. They've seen the footage of grim hospital wards, populated by gaunt, dying figures. (11) The pre-corpse club, with legions all over their fragile, skeletal

bodies. Immune systems non-existent, ravished by what used to be quite brutally - but truthfully - termed 'full-blown Aids'.

(12) And so, remembering all that, the older generation who've seen those horrors refuse to engage in Russian roulette with a stranger the way the younger, less aware generation tend to. Maybe if they too saw that footage of the worst type of slow and agonising death possible, they might think twice.

(19) What would any of the 39 million people who've died slow, agonising Aids-related deaths say? These ignorant, arrogant young men who voluntarily want to become "pozzed-up" are giving two fingers to The Diceman, and all those before them that succumbed to this terrible disease.

(Sunday Independent, 06/12/2015)

Excerpt G:

Anxiety over HIV has faded, but the danger has not

(1) In the 1980s it was known as the "plague" and those infected with the HIV virus faced isolation, stigma and agonising death.

(2) By 2010, HIV has joined that list of illnesses which barely command a few paragraphs in newspapers as the latest statistics on the number of people infected are reported.

(3) We have gone from one extreme to another, but has a dangerous complacency set in? Those on the frontline treating HIV are very concerned.

(4) The most recent report, for 2009, showed a continued rise in the number of gay and bisexual men testing positive for HIV, with the highest ever level of new cases.

(Irish Independent, 05/07/2010)

Excerpt H:

'I always practised safe sex, so I couldn't believe it when the doctor told me I was HIV positive'

(1) New figures show a startling increase in the numbers contracting HIV. Liz Kearney meets two people who are learning to live with the virus

(2) Just four short years ago, Rachel's world was as near to perfect, she reckoned, as it was possible to get. She was 28, loving her job in a big internet firm and best of all, thanks to a

tidy lump sum from a previous redundancy package, had just put down a deposit on her first house.

(3) It felt like a whole new beginning -- and so Rachel decided to do something she'd been meaning to do for a long time: she made an appointment at the Well Woman clinic for a sexual health screening. It had been a topic of conversation for the girls in the office lately, and despite being '100pc sure' that she had nothing to worry about, Rachel felt there'd be no harm in checking.

(4) So she took herself off to the city-centre clinic and thought no more about it until a few days later, the nurse called and asked her to come in for her results. Immediately.

(5) 'When I arrived and saw the counselling sign on the door, I knew it was bad news,' Rachel recalls. 'I thought maybe it was cancer. But the worst thing they could have said to me was what they did say: I had HIV.'

(6) Rachel was convent-educated, with a third-level degree, a good job, and a cautious approach to her health. She'd had several sexual partners, but she'd always asked boyfriends about their sexual history. If there was any chance they might have an infection, she'd insist on using a condom. 'I'd never even smoked in my life,' she says. 'I just thought, "how could this happen to me?"'

(7) That's a question that doctors are hearing more and more from people like Rachel. According to figures from the HSE's Health Protection Surveillance Centre, 405 people were diagnosed with HIV in 2008, the highest number since records began in the 1980s. And of that number, almost half -- 178 -- were infected through heterosexual activity.

(8) Those figures are a stark reminder that HIV is not just a disease for drug addicts and gay men. But it's precisely that longstanding misconception, doctors say, that underpins a lax approach to sexual health among the heterosexual community.

(9) That complacency has been cemented by the huge strides in the clinical management of HIV and AIDS. Today, anti-retroviral drugs can give HIV victims a life expectancy similar to that of the uninfected population. Consequently the message about safe sex, drilled home at the height of the AIDS crisis in the mid-1980s, no longer seems relevant to a younger generation.

(10) Younger women, in particular, appear willing to simply rely on the contraceptive or morning-after pill to prevent pregnancy, but often don't bother to use a condom.

(Irish Independent, 09/12/2009)

Excerpt I:

How to tell a positive HIV story in Africa

(1) It is a brutal truth that some topics, no matter how important, struggle to engage the public. One such, as reported in the western media, is HIV in sub-Saharan Africa: both the subject and location seem so distant from us in every sense.

(2) But what does the HIV story look like as reported from the place where it is a daily reality? Last month my photographer colleague Frank Miller and I travelled to Zambia, 15 per cent of whose 14 million people are HIV positive, to try to find out.

(6) What it does mean is that the challenge for Zambian media in covering the HIV story is the same as that faced in the West: readers' fatigue with a topic that has been around for close to three decades.

(7) Unlike in the West, however, the local media have an essential role in helping to save lives, raise awareness of the need to go for testing, and reduce the stigma of a diagnosis. The Zambian media, whether privately or state owned, recognise how crucial their role is in keeping readers engaged with the biggest public-health story in Africa of the past century.

Troubled and angry

(14) Manasseh Phiri is a doctor who has been writing a weekly column for the Post, reflecting on Aids for the past eight years. The Post is privately owned. On the day we meet at his pig farm, an hour outside Lusaka, he is troubled and angry.

(19) He is worried about coverage in general of the HIV story in the Zambian media. That shock element of seeing people get very ill and die is gone. There is a level of complacency now. But it continues to be a story as long as people continue to get infected and die.

(20) Like Chomba, he also wants to see HIV stories focusing on aid money. Nobody is looking at where the money is going. This year Zambia has received \$380 million alone from US aid. The people on treatment in this country are alive because of the kindness of aid. If it is withdrawn, our people will die.

(21) People in the Zambian government should be losing sleep over this. We need to raise this money ourselves, from our own resources, over time. Depending on aid means the government is not in control of its own health programme.

(24) 'If we publish stories saying homosexuality should be legal, then that has a political impact on government. We thought we would leave the topic alone for a while,' says Saluseki, who refuses to be drawn on the subject further.

(25) Saluseki would like to see more investigative reporting, especially around aid money.

(26) There is a lot of NGO money in HIV-Aids, but I don't think the money trickles down to those who need it. It's difficult, because there isn't any law that allows for reporters to search for documents.

(27) About the Post's other HIV coverage he says, 'We have moved beyond statistics. The human cost is already known. Human-interest stories work the best. We ran a story on an HIV-positive prostitute who slept with 49 people, and that was of interest to readers. We are in business. At the end of the day we need to run stories that will sell papers.'

Rosita Boland and Frank Miller travelled to Zambia with the support of the Simon Cumbers Media Fund

(Irish Times, 01/12/2012)

Excerpt J:

South African policy shift on HIV likely to see fall in deaths, says UN

(1) The South African government's decision late last year to introduce a new policy to combat the HIV virus is expected to cause a dramatic turnaround in the fight against the disease by 2020, a United Nations official said recently.

(2) Late last week UNAIDS regional director for east and southern Africa, Sheila Tlou, told a conference in Geneva that South Africa's status as the country with the world's highest number of HIV cases- with 5.6 million infections- was because of a lack of political commitment by past governments.

(3) Previous administrations under former president Thabo Mbeki and his health minister Manto Tshabalala-Msimang had been accused by Aids activists of ignoring expert medical advice on how best to tackle the epidemic.

(4) Former minister Tshabalala-Msimang, who is now deceased, was nicknamed Dr. Beetroot by many South Africans for advocating the use of vegetables rather (sic) medication to treat Aids.

(5) However, there is a turnaround in the new [African National Congress] government under President Zuma which is committed to tackling HIV and AIDS, said Ms Tlou. By 2020 there will be massive reductions [in HIV deaths and infections] in South Africa, she said. On December 1st last year Mr Zuma officially launched the new South African National Strategic Plan on HIV and TB, 2012-2016, which has five goals.

(Irish Times, 21/12/2012)

Excerpt K:

New South Africa health appointment gives fresh hopes for HIV/Aids control

(1) There is fresh hope that HIV/Aids will be brought under control in South Africa with the recent appointment of Barbara Hogan as health minister, Oxfam's programme officer in South Africa, Thabi Khosa, said at the weekend.

(2) Highlighting the 20th World Aids Day, which falls today, Ms Khosa said people working in the HIV/Aids field believed that the new health minister was willing to look seriously at improving access to treatment.

(3) When Ms Hogan took on the job in October, the veteran anti-apartheid activist said she would tackle HIV/Aids head on, after many blunders by her predecessor and by former president Thabo Mbeki. The former leader drew international criticism when he questioned the link between HIV and Aids, while former health minister Manto Tshabalala-Msimang had been called Dr Beetroot for promoting the benefits of products such as beetroot and lemons for treating Aids.

(4) South Africa has one of the most severe HIV/Aids epidemics in the world, with some 5.7 million out of a population of 47 million believed to be HIV-positive.

(Irish Times, 01/12/2008)

Excerpt L:

Why Charlie Sheen is no HIV hero; Charlie Sheen has never claimed to be a good guy, writes Sarah Caden, and his HIV status won't make him a saint

(1) Charlie Sheen has never invited anyone to feel sorry for him. Not through his drinking, his drug-taking, his divorces, nor his domestic-violence issues. In fact, perversely, he has always invited admiration for seeming proudly indifferent to disapproval. His revelation last week that he is HIV positive hasn't changed that.

(2) It hasn't changed Charlie Sheen; but it's going to change how people view him - and he knows that. That's partly why he kept it quiet for nearly four years.

(3) Up to now, Charlie Sheen has enjoyed affectionate public opinion. Despite foul online tirades against his exes, despite his revolting attitude to his "goddess" porn-actress girlfriend, despite his refusal to grow up at 50 years of age, he's managed to maintain a loveable-rogue image. 'Oh, that incorrigible Charlie Sheen' has been the attitude - and he has revelled in it. And he knew last week, as he revealed his HIV-positive status to NBC's Matt Lauer, that the game was up.

(4) Rumours that a Hollywood actor was secretly HIV positive began circulating internationally earlier this month. It was said that the actor had been hiding his status for fear of how it would affect his career and that he knew once it was out, it would be a tag that could dog him for the rest of his life.

(5) The rumour went that it was an actor whose drug-taking and sexual past were widely documented, and that there would be a lot of former sexual partners who would be worried by the news.

(6) Last Tuesday, Charlie Sheen told Matt Lauer on the Today Show that he was that actor. 'I have to stop this onslaught of attacks and subtruths and very harmful and mercurial stories about threatening the health of so many others which couldn't be further from the truth,' Sheen said.

(7) Not that he intends to become a reformed character. No, in fact, if anything was clear from his TV interview it's that Charlie Sheen doesn't believe that HIV has the power to make him a better person. Nor does he seem to want it to. And he knows that this flies in the face of the modern belief that bad luck and disease and disability and tragedy are given to us in order that we do some good with them. Charlie Sheen isn't having that.

(Sunday Independent, 22/11/2015)

Excerpt M:

30 Years of Despair and Hope

(Sub-heading) It has been three decades since the discovery of HIV and Aids, and in that time it has had a horrifying global impact. Diagnosis might no longer mean a death sentence, but the thousands of Irish people with the virus still suffer from stigma and discrimination. Here, some of them tell their stories to Cian Traynor.

(1) Hanging behind an unmarked door in Dublin's inner city is a sign with a simple code: 'What I see here, what I hear here, let it stay here.'

(2) This is Open Heart House, a confidential support network for people with HIV and Aids. Roughly half of its 1,025 members, aged between 18 and 77, have kept their medical condition secret.

(3) Thirty years after HIV first appeared as a mysterious new virus, the condition is no longer fatal. With as little as one pill a day, the viral load can be reduced to non-infectious levels and those diagnosed early can expect to live into their 70s. Yet the depth of isolation has remained largely unchanged as stigma and misconceptions linger on. Where many once avoided testing for fear of a death sentence, now it's for fear of how they will be perceived.

(57) Goulding took a prima facie case to the Equality Authority, who ruled in his favour in 2009 and acknowledged that people living with HIV are incorrectly perceived as being unhealthy or a threat to public health.

(58) 'People won't take a case like that if they're married, have kids in school or a job they don't want to lose,' he says. 'I knew if I did it for the right reasons, we'd get the right result. But it's still happening today. I heard of a case recently where a girl was refused a tattoo because she had HIV.'

(59) Goulding was diagnosed with HIV in 1990, at a time when he believes he was in self-destruct mode. 'I had no value on my life. When I was diagnosed, it was like, 'Here's what you're looking for: a death sentence, your ticket off this planet.'

(60) Since turning his life around during the late 1990s, Goulding has been campaigning for the rights of and services for those living with HIV through Positive Now, a new lobbying group, and through his monthly column for Gay Community News.

(61) 'It's not talked about in the gay scene . . . There are even still people out there looking for unprotected sex with a gay man,' he says.

(62) 'The clinics are full with a younger generation. I mean, okay, there's a treatment for it but there are horrific side-effects: constant fatigue; bowel trouble; joint pains. It feels toxic.'

People think, 'Ah, I'll do it just the once, but taking that one chance could be your last.' (Irish Times, 06/08/2009)

Excerpt N:

An Irishman's HIV story

(1) Holding hands, Saba and I walk into the room where, two days ago, I was told that I was HIV-positive. With a few sharp sentences the doctor tears our unity apart. She separates us because Saba is black and I am white. Because she is African and I am European. Because she is from a poor country and I am from a rich one. Saba is not expected to live anywhere near as long as I am.

(2) I have just been told I am HIV-positive. The doctor looks at me, and I feel sorry for her. She is nervous. I realise I am supposed to say something.

(5) I came to Ethiopia, to work as a journalist for the UN, only six months ago. I met Saba shortly after arriving. She is beautiful, intelligent and the warmest person I've known. And she is the only person I've had unprotected sex with. I realise she is HIV-positive too. That's all I think about on the drive home from the clinic. Saba went home tonight thinking everything was fine. She was happy. And now I have to tell her the horrible truth. It has to be her. She has infected me with this disease.

(6) When I get home I look at myself in the mirror. There is no difference. I sit on the sofa and think about my new life. I look across the room and see the St Christopher medals lined up on top of my television: five of them, from friends and family in Dublin. 'Stay safe,' they had said. 'Come back to us.' I feel ashamed. I've let them down.

(7) I make one phone call tonight, to my best friend. He is full of stories from home. Then I tell him. There is a muffled intake of breath, and his voice becomes slow and deep. We talk about what I should do. Then, strangely, we begin to joke. 'I only had unprotected sex once,' I say. 'I mean, fair enough if I was Mick Jagger.' He laughs. Then there is a pause. 'Ah, it was worth it,' I say. 'The girl was a ride.'

(13) We go back to the room where I received the news two days ago. We walk in holding hands, but with a few sharp sentences our unity is torn apart. The doctor separates us because Saba is black and I am white. Because she is African and I am European. Because she is from a poor country and I am from a rich one. We told ourselves that we were the

same, that none of this mattered, that we were equals. But we were wrong, and none of our multicultural beliefs could protect us.

(14) Things will not be so bad for me, the doctor says. I'll have access to the best treatment and doctors in Ireland, all of my medicine will be free, and there are organisations that can support me and my family. But for Saba things will be different. She might have access only to poor-quality treatment, she will have little financial help, and support services are stretched to capacity. She is not expected to live anywhere near as long as I am. It is the neatest illustration of inequality I have witnessed. We squeeze each other's hands tighter, and I tell Saba she is coming to Ireland.

(20) The call is due at 5pm, but 5pm comes and goes, as does 6pm. I try to keep Saba talking, try to keep her mind off the delay. The doctor had said that they were sure I was HIV-positive, that they'd tested my blood three times. Why is it taking so long to check Saba's sample? At 7.11pm my mobile begins to vibrate on the table. I pick it up and, for some reason, leave the room.

(21) 'I have some good news, Barry,' says the doctor. 'You're negative. Both you and the girl. We made a mistake. I'm sorry.'

(22) After a lot of excited swearing I hang up, then pause outside the sitting-room. I have never had anything so wonderful to tell anyone. I open the door and find Saba on her knees, praying, her fingers stuck in her ears. She is crying. I kneel down and take her hands. 'They're both negative,' I say. 'You're okay, Saba. We're both okay.' She jumps up, and we are in a fantastic blur of laughing and crying and hugging and babbling and dancing.

(23) The next day we contact the clinic again, to make sure it will find out why my first tests were positive. We also go to a different clinic to confirm our negative status.

(24) For three days I was HIV-positive, and now I am healthy. I am normal. I am free.

(25) I want to call everyone I know, to share my good news. I want to throw a party. But I hadn't told many people. Neither had Saba. So in the evening we watch television, Saba's head on my chest. When we go to bed we snuggle together. We sleep soundly, then wake to the freshest morning we have ever seen.

(26) And now I'm home with this story that amazes people in the pub. The perfect anecdote: one that draws pints from men and hugs from women.

(27) But there are 4,000 people in Ireland, 25 million in Africa and 40 million worldwide for whom there is no happy twist in the tale. Just normal lives that, in a moment, change forever. We should do everything we can to support them.

(Irish Times, 27/01/2007)

Excerpt O:

Activist and public face of HIV-positive women

(1) Linda Reed: The life of Linda Reed, who has died at the age of 45, was a journey from a comfortable middle-class background in south Dublin into hell, then back again to a form of redemption which inspired thousands of others, but which was endured through a pitiless and increasingly debilitating illness with Aids, which eventually killed her.

(2) Diagnosed as HIV-positive in 1988 while she was in prison in Germany for a drug-dealing career brought on through chronic heroin addiction, Ms Reed was told she would be dead in three years. Deported to Ireland, she discovered that Aids was a disease associated in the public mind almost exclusively with gay men and intravenous drug users.

(3) Ms Reed, who had contracted the disease through extra-marital heterosexual intercourse in Germany, determined to become, if necessary, the public face of HIV-positive women in this country.

(Irish Times, 31/03/2007)

Excerpt P:

Pregnant and HIV positive. So how can Amanda say it won't matter if she infects her baby?; It sounds grotesque - but read this startling interview before you judge

(1) WITH a neat little bump already showing beneath her dress and a toddler jumping around at her feet, Amanda Mammadova looks just like any other healthy mother excitedly awaiting the birth of her second child.

(2) The red 'Aids Awareness' ribbon she often wears pinned to her chest suggests, however, that beneath the surface of her glowing pregnancy lies a rather more complex story.

(3) Amanda is HIV positive, a carrier of a potentially deadly virus which might be passed onto her unborn child. Despite this worrying fact, the 34-year-old personal trainer has wholeheartedly embarked on parenthood with her 30-year-old husband, Ali.

(4) The couple, from Milton Keynes in Buckinghamshire, already have one child, 21-month-old Saabira, who thankfully does not have the virus. Neither does Waitrose worker Ali, who has risked having un-protected sex with his wife so that they can become parents twice over.

(5) While their baby is due in June, they will have to wait much longer to learn if their second child is as lucky as their first. The newborn will be tested straight away, and then again at three months, 12 months and 18 months.

(6) If it's another girl, then they'll probably try for a third child, they say, because they'd like to have a boy. And, no, Amanda does not think she is being remotely reckless in exposing her babies to a disease which continues to strike fear into the hearts of most adults.

(7) 'There are risks with all pregnancies,' she says. She points out that thanks to the antiretroviral medication taken during her pregnancy, the chance of her unborn child having HIV is less than one in a hundred. This, she says, is less than the risk of a 40-year-old giving birth to a baby with Down's syndrome.

(8) 'If, in my heart, I want to have a child, why should I deprive myself?' she continues. 'Why should I deprive a child of having a loving, stable home with parents who really want that baby?' A bold argument, indeed, but what is perhaps still more controversial is Amanda's assertion that even if her child were born with HIV - an incurable virus which attacks the immune system - 'it wouldn't be the end of the world'.

(9) Medical advances mean babies with HIV now have the same life expectancy as those without it, but having the virus would consign any child to a lifetime of daily medication.

(10) The cost of HIV treatment is typically £7,000 a year, so a lifetime of treatment could cost £500,000. There is also a risk that the condition could develop into full-blown Aids.

(The Irish Daily Mail, 02/12/2014)

Excerpt Q:

'The monster no longer looms';

(Sub-heading) Singer-songwriter John Grant has enjoyed huge acclaim, while living with the spectre of being diagnosed HIV Positive. As he begins the Irish leg of his tour, he talks to Donal Lynch about life, family, sex and music.

(Sunday Independent, 02/03/2014)

Appendix B- Participant Information Sheet



Participant Information Sheet

Title of the study: Living with HIV in Ireland Today

Introduction:

For individuals living with HIV there can be many challenges that are not health-related. Working, travelling abroad, obtaining life-assurance for a mortgage- all of these things can be affected by a person's HIV status. The aim of this research study is to gain a greater understanding of the reality of living with HIV in Ireland today, with a special focus on the impact of stigma on the day to day lives of people living with HIV. This research study will form part of the researcher's doctoral thesis on HIV and stigma in Ireland today.

Invitation to take part in the study:

We would like to invite you to take part in this research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. This Participant Information Sheet will tell you about the purpose, risks and benefits of this study. If you agree to take part, you will be asked to sign a Consent Form. If there is anything that you are unsure about, we will be happy to explain it and answer any questions you may have. Please take as much time as you need to read the information provided. You should only consent to participation in this research study when you feel that you understand what is being asked of you, and you have had enough time to think over your decision.

Purpose of the study:

The purpose of this research study is to explore how stigma has impacted on the lives of people living with HIV in Ireland today. Other topics of interest to the researcher are-

- participants' experiences of health services, including sexual health services, GPs, dentists and other health service providers
- participants' experiences with legal and social services

-participants' views on media coverage of HIV in Ireland

-participants' views on media coverage of HIV in Ireland

Taking part-what it involves:

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

What does taking part involve and how long will it take?

Taking part in this research will involve you partaking in a one-to-one interview with the researcher. The interview should last between 30 minutes and 1 hour. With your permission, the interview will be recorded and transcribed word for word. Recordings and responses provided by you will only be available to the researcher and will be made anonymous. As such, no individual will be identifiable in any publications from this research.

What are the possible benefits of taking part?

Taking part in this research will help the researcher gain an insight into some of the challenges experienced by people living with HIV in Ireland today as a result of their positive status. By taking part in this research, you can help contribute towards creating an evidence base that could be used to advocate for improvements in policy and practice that affect people living with HIV.

What are the possible risks of taking part?

There are no foreseeable risks attached to taking part in this research study.

What happens at the end of the study?

At the end of this research the information will be analysed and interpreted. The results of the analysis will form part of the researcher's PhD thesis. Throughout this process, confidentiality and anonymity will be a priority and no individual will be identifiable in publication or presentation.

What happens if I change my mind during the study?

You can change your mind about participating at any point during this study without disadvantage or penalty. If you withdraw any data related to you, such as interview recordings, will not be used and the data will be deleted/destroyed.

What if I have a complaint during my participation in the study?

If you have any complaints in relation to the research process you may refer these to the NUI Galway Research Ethics Committee.

Ms. Elena Vaughan, B.A., M.A., Department of Health Promotion, School of Health Sciences, NUI Galway

A handwritten signature in black ink that reads "Elena Vaughan". The signature is written in a cursive style with a long horizontal line extending to the right.

Researcher signature _____

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact ‘the Chairperson’ of the National University of Ireland, Galway Research Ethics Committee, c/co Office of the Vice President for Research, National University of Ireland, Galway.

Appendix C- Table of newspaper articles & titles

<u>Case Profiles- Newspaper Data</u>	<u>Article Type</u>	<u>Date of publication</u>	<u>Title of Newspaper</u>
001-Charlie Sheen	Entertainment	08/11/2015	Daily Mail
002-Charlie Sheen	Feature	12/11/2015	Daily Mail
003-PrEP & NSHS	Report	30/10/2015	Daily Mail
004-St James Screening Protocol	Report	29/07/2015	Daily Mail
005-Pregnant & Positive	Feature	02/12/2014	Daily Mail
006-Ebola v HIV	Opinion	08/10/2014	Daily Mail
007-HIV Priest	Feature	20/12/2013	Daily Mail
008-Woman Sues	Report	21/09/2013	Daily Mail
009-Govt AIDS Argument Norris Case	Report	01/01/2016	Irish Times
010-Reactions to Sheen & HIV status	Opinion	21/11/2015	Irish Times
011-Russia Halts Condom Imports	Report	10/08/2015	Irish Times
012-Chemsex	Report	03/07/2015	Irish Times
013-HIV PREP	Feature	09/06/2015	Irish Times
014-Breaking down barriers...	Opinion	01/12/2014	Irish Times
015-Varadkar Rules Out...	Report	10/11/2014	Irish Times
016-Teen Clubs...	Feature	03/12/2013	Irish Times
017-HIV and Old Age	Feature	06/12/2013	Irish Times
018-HIV rise-being man enough...	Feature	25/06/2015	Irish Times
019-My first HIV test...	Feature	01/05/2013	Irish Times
020-Prospects for HIV patients...	Report	16/04/2013	Irish Times
021-Researchers Optimistic...	Report	05/03/2013	Irish Times
022-Rapist told woman...	Report	01/02/2013	Irish Times
	Feature	01/12/2012	Irish Times

023-How to tell a positive HIV story			
024-Protest at HIV care service	Report	10/08/2012	Irish Times
025-South African policy shift on HIV	Report	27/01/2012	Irish Times
026-Tracking Dublin's HIV scene	Feature	29/11/2011	Irish Times
027-Letter to Ed re Vincent Hanly	Letter	09/08/2011	Irish Times
028-Doctor who contracted HIV...	Report	27/01/2011	Irish Times
029-HSE obtains court order...	Report	22/11/2010	Irish Times
030-Condoms-Africa-Catholic Church	Feature	22/11/2010	Irish Times
031-HSE seeks order over...	Report	20/11/2010	Irish Times
032-Protective gel hailed as...	Report	03/08/2010	Irish Times
033-Needle exchange...	Report	22/07/2010	Irish Times
034-Sterile future for women...	Report	20/07/2010	Irish Times
035-Compelling literary...	Review	02/07/2010	Irish Times
036-Complacency danger...	Opinion	02/12/2009	Irish Times
037-HIV still figures as a risk...	Feature	23/06/2009	Irish Times
038-Mouth swab test for HIV...	Report	02/06/2009	Irish Times
039- 30 years of despair...	Feature	06/08/2009	Irish Times
040-Awards to gardai...	Report	21/04/2009	Irish Times
041-Orphan children China...	Feature	02/03/2009	Irish Times
042-Catholics, condoms & HIV	Letter	12/02/2009	Irish Times
043-Rate of HIV diagnosis...	Report	09/12/2008	Irish Times
044-New South Africa health...	Report	01/12/2008	Irish Times
045-More than 1,500 Chileans...	Report	24/11/2008	Irish Times
046-Was money for HIV/AIDS...	Opinion	21/08/2009	Irish Times
047-HIV/Aids finally on...	Feature	04/03/2008	Irish Times
	Feature	19/02/2008	Irish Times

048-A positive approach...			
049-Africa Focus...	Review	18/08/2007	Irish Times
050-66 dental patients tested...	Report	21/07/2007	Irish Times
051-Activist Linda Reed...	Obituary	31/03/2007	Irish Times
052-An Irishmans HIV_story	Feature	27/01/2007	Irish Times
053-UN praises Ireland Stigma...	Report	02/12/2006	Irish Times
054-South Africa...	Feature	31/10/2006	Irish Times
055-Delivering unborn babies...	Feature	22/08/2006	Irish Times
056-Turning the tables...	Report	26/01/2006	Irish Times
057_Metro Herald_1	Feature	06/02/2014	The Metro Herald
058_Metro Herald_2	Feature	27/11/2013	The Metro Herald
059_Sunday Tribune_1	Feature	28/09/2008	The Sunday Tribune
060_Sunday Tribune_2	Feature	02/12/2007	The Sunday Tribune
061-Clare firm AltraTech...	Report	23/11/2015	The Irish Examiner
062-Rapid testing...	Report	30/10/2015	The Irish Examiner
063-Campaign aims...	Report	15/06/2011	The Irish Examiner
064-HSE seeks order...	Report	20/11/2010	The Irish Examiner
065-Vaccine Thailand Report	Report	25/09/2009	The Irish Examiner
066-HIV sufferers...	Opinion	07/12/2015	Irish Independent
067-HIV saved my life...	Feature	01/12/2008	Irish Independent
068-Teens lose count...	Report	04/05/2008	Irish Independent
069-Gift-giving Article	Feature	15/03/2008	Irish Independent
070-HSE waited nine months...	Report	21/07/2007	Irish Independent
071-Charlie Sheen...	Feature	01/12/2015	Irish Independent
072-Sheens former lovers...	Report	19/11/2015	Irish Independent
073-HIV Rapid testing	Report	30/10/2015	Irish Independent

074-Women and HIV	Feature	10/06/2013	Irish Independent
075-John Grant Article	Feature	03/05/2013	Irish Independent
076-OCD...	Unassigned	14/03/2013	Irish Independent
077-Anxiety over HIV...	Report	05/07/2010	Irish Independent
078-I'd always practised safe sex...	Unassigned	09/12/2009	Irish Independent
079-I was treated like a leper...	Feature	28/11/2009	The Star
080-The Clinic TV Show	Feature	26/09/2009	The Star
081-Gardai in HIV and Hep C Agony	Report	27/05/2009	The Star
082- Ulster Doc said...	Report	29/04/2009	The Star
083-I watched...	Feature	28/11/2007	The Star
084- I had HIV...	Feature	16/08/2007	The Star
085-Liz Martin Interview	Feature	12/06/2007	The Star
086-Did I inject my son...	Feature	19/04/2007	The Star
087-One person tests...	Report	01/12/2006	The Star
088-HIV Mum trying again for baby	Feature	27/11/2011	The Star
089- Grace got HIV...	Feature	26/10/2011	The Star
090-Alice Welbourne Interview	Feature	20/09/2011	The Star
091-I want to be proof...	Feature	15/08/2011	The Star
092-Once you have revealed...	Feature	25/06/2011	The Star
093-I've seen friends...	Feature	01/12/2010	The Star
094-I know things are bad...	Feature	22/11/2010	The Star
095-How could I admit...	Feature	17/08/2010	The Star
096-Gifting	Feature	06/12/2015	The Sunday Independent
097-Testing our last taboo	Opinion	15/10/2006	The Sunday Independent
098-Charlie Sheen...	Feature	22/11/2015	The Sunday Independent
099- Routine hospital tests...	Report	17/05/2015	The Sunday

100-HIV+ men...	Feature	24/08/2014	Independent The Sunday Independent The Sunday
101-John Grant Interview	Feature	02/03/2014	Independent The Sunday
102-Getting to a good place...	Feature	19/05/2013	Independent The Sunday
103-Gay marriage a springboard...	Opinion	31/03/2013	Independent

Appendix D- Sample Interview Schedule

Q.1: You were diagnosed in...- can you tell me what led to you getting tested?

Q.2: What was your reaction to the diagnosis?

Q.3: To whom did you first disclose your status?

Q.4: What was their reaction?

Q.5: Can you tell me about your experiences disclosing to family/friends/healthcare workers?

Q.6: Have you children/plans to have children?

-If so, how do you think your status affects/may affect them?

Q.7: Would you mind if I asked you about your relationships/sex/dating?

Q.8: Since your diagnosis have you spent any time in hospital?

-If so, what was your experience?

Q.9: Can you tell me a bit about your clinic visits?

Q.10: Have you ever engaged with any support services and if so what was your experience?

Q.11: Do you think there are sufficient support services for PLHIV in Ireland?

Q.12: Do you feel adequately supported?

Q.13: Have you ever experienced anxiety or depression since your diagnosis? How have you coped with that?

Q.14: Has your status ever impacted upon your work or career plans? *(If working)

-If so, how?

Q.15: Has your status ever prevented you from fulfilling other life-goals? (for example, travel, buying a house, pursuing a relationship, etc)

-If so, how?

Q.16: What do you think about the way HIV is portrayed in the media/on television?

Q.17: What do you think about the standard of health education and/or sexual health promotion in Ireland today?

Q.18: How do you think PLHIV are perceived by people in Ireland?

Q.19: Have you ever felt concerned for your safety as a result of your status?

Q.20: What do you think the greatest challenge is for PLHIV in Ireland today?

Q.21: What do you think could be done to improve the lives and well-being of PLHIV in Ireland today?