How the sexual matters in HIV care: a case study of long-term survivors of the epidemic.

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Declaration of Authorship

I Agata Pacho hereby declare that this thesis and the work presented in it is entirely my own. Where I have consulted the work of others, this is always clearly stated.

Signed: Date:

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Abstract

Throughout the HIV/AIDS epidemic, engaging with the sexual desires and practices of gay men has been central to advancing health and medical responses to the epidemic. In this thesis, I investigate how sexuality, understood as embedded in specific political, social and historical discourses and practices of the epidemic, features in HIV medical care today. With the introduction of antiretroviral drug treatments, HIV care tends to be assessed in relation to the diagnostic benchmark of HIV viral suppression. In contrast to this approach, I draw attention to elements of care that occur outside or on the margins of what is required by biomedical treatment regimens. I do so by drawing on ethnographic observations and semi-structured in-depth interviews conducted with patients and healthcare professionals in a London outpatient HIV specialist clinic. My case study reveals the ways in which camp culture, in particular camp humour and celebration of gay sexuality, forge novel alliances between patients and healthcare professionals. These features are argued as directly pertinent to the specialist orientation of clinical care and thus enable me to draw out some of the implications of what is proposed by the UK health authority to shift HIV treatment into the setting of general medical practice.

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List of abbreviations

A&E Accident & Emergency
AIDS acquired immunodeficiency syndrome
AMR antimicrobial resistance
ART antiretroviral therapies
ARVs antiretroviral drugs
BHIVA British HIV Association
ECDC European Centre for Disease Prevention and Control
ESC extended-spectrum cephalosporins
FDA Food and Drug Administration
GASP Gonococcal Antimicrobial Surveillance Programme
GMFA Gay Men Fighting AIDS
GP General Practitioner
GRID gay-related immune deficiency
GUM genitourinary medicine
HAV hepatitis A virus
HBV hepatitis B virus
HIV human immunodeficiency virus
HTPN HIV Prevention Trials Network
IAPAC International Association of Providers of AIDS Care
KS Kaposi's sarcoma
MSM men who have sex with men
NHS National Health Service
NRES National Research Ethics Service
PCP pneumocystis carinii pneumonia
PHE Public Health England
PLHIV people living with HIV
PrEP pre-exposure prophylaxis
TasP Treatment as Prevention
WHO World Health Organization

Chapter One. Introduction

In this thesis I look at HIV[1] healthcare, and specifically at how sexuality matters when HIV care is provided for and negotiated by men who identify as gay. By looking at the role of sexual cultures in HIV care, I draw attention to elements of care that occur outside, or on the margins of, what is required by biomedical treatment regimens. I point to those elements of HIV care which could be overlooked by research concerned with measuring its success in terms of achieving viral suppression. In this way, I contribute to the understanding of HIV care as situated within certain social and sexual contexts rather than as isolated processes of the application of biomedical knowledge and technologies. I understand the sexual contexts as always shifting. In particular, the sexual has been conceptualised and negotiated differently in relation to the most significant change to have occurred since the early years of the epidemic: the introduction of the effective antiretroviral therapies (ART) that transformed HIV infection from a deadly, acute condition into a chronic disease. In his critique of discourses of the early HIV/AIDS[2] epidemic, Simon Watney (1997), British writer, art historian and AIDS activist, argues that while the discourse of AIDS revolved around the rhetorical figure of 'promiscuity', with the stigmatising implication that only gay men were engaging in 'promiscuous' behaviour, it also ignored how sex has been key to forming and sustaining gay communities (Watney 1997: 12). Watney quotes an American commentator who, when asked 'Why can't you people just fuck

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[1] HIV stands for human immunodeficiency virus. As explained by the World Health Organization (WHO), HIV infects cells of the immune system, destroying or impairing their function, leading to 'immune deficiency'. HIV is treated with antiretroviral drugs, which fight HIV by stopping or interfering with the reproduction of the virus in the body and reducing the amount of virus in the body (HIV/AIDS: WHO online Q&As about HIV/AIDS 2018).

[2] AIDS stands for acquired immunodeficiency syndrome. In medical terms, AIDS applies to the most advanced stages of HIV infection. AIDS is defined by the occurrence of any one of more than 20 opportunistic infections or HIV-related cancers (HIV/AIDS: WHO online Q&As about HIV/AIDS 2018).

less?', replied: 'For gay men, sex, that most powerful implement of attachment and arousal, is also an agent of communion, replacing an often hostile family and even shaping politics' (1997: 13). In this way, Watney suggests that the sexual has been historically central to gay communities and that within the discourse of the early epidemic understandings of sexuality were insufficient and/or incomplete.

More recently, Gary W. Dowsett (2009) suggested there is an inadequacy in how the responses to the epidemic in the era of effective ART engage with the matter of sex. In his discussion of the efforts to prevent an ongoing spread of HIV among gay men, Dowsett argues that the introduction of ART allowed for new sexual ethics and new ways of negotiating the risks of HIV transmission to be developed among gay men. This, in turn, shows that sexual cultures are central to those who are the imagined recipients of prevention messages and, therefore, it is necessary to underline and explore the diverse ways in which gay men engage with sexual politics and use sexuality categories as spaces in which to exist. Yet, Dowsett argues, HIV prevention tends to focus on the behavioural intervention rather than on sexual ethics and sexual cultures. (Dowsett 2009: 228-229). Dowsett acknowledges gay sexuality as a site of embodied politics and creativity; for him, focusing on the sexual means understanding sexual desires and practices in order to create new possibilities of intervention in HIV prevention.

By contrast, looking at how sexuality features in the context of the provision of care for gay HIV-positive men offers a broadening of the discussions on HIV healthcare. Sara Paparini and Tim Rhodes (2016) suggest that the biomedicalisation of the epidemic encourages a narrow definition of HIV care (and its success or failure) in relation to the benchmark of viral suppression[3], resulting from patients being

[3] Viral suppression is necessary to keep people living with HIV in good health. It is achieved through antiretroviral therapy. The goal of antiretroviral therapy is to get the viral load down to where it is undetectable by standard laboratory tests. 'Undetectable' means that the concentration of HIV in the blood is lower than the test's limit of detection. This

satisfactorily and adequately engaged through a process of sequential care engagements – from HIV testing, to diagnosis, to linkage and access to antiretroviral therapies (ART), to retention in treatment (Paparini & Rhodes 2016). This suggests that in discussions on HIV care, a focus on individuals and how well they do at remaining is care and using available treatments to hinder the viral replication, is encouraged. Besides looking into patients' retention in care and adherence to treatment regimens, research efforts have also been invested in understanding how much power people living with HIV hold in the process of making decisions regarding their treatment choices[4]. It is now a widely shared idea that AIDS activism has ushered in a new way of democratising relations between care providers and those receiving care (Epstein 1996; Rose & Novas 2005). Steven Epstein (1996) shows how gay men, by teaching themselves epidemiological knowledge around HIV/AIDS, became experts in their own right. Consequently, in AIDS research, patients gained a participant's interest that extended beyond the mere protection of their rights as human subjects, and communities had a stake in the review of research protocols. They questioned the ways in which science's credibility is constructed and deconstructed and gained enough of a voice in the scientific world to shape research to a significant extent (Epstein 1996). Epstein's argument relies predominantly on the access to and understanding of medical information among gay men. In other words, the democratisation of doctor-patient relations in HIV care is understood as reducing disparities in the biomedical knowledge the two groups are believed to hold, and thereby also reducing disparities in power differentials. On the other hand, an understanding of HIV physicians and their patients in the context of the history of the negotiations of the sexual throughout the epidemic may contribute to an analysis of doctor-patient

means that with the older tests, 'undetectable' would mean below 5000 copies/ml, and with the newer tests, below 50 copies/ml (Bartlett & Finkbeiner 2007: 72).

[4] Decisions around initiation of treatment and switching therapies require careful consideration of various factors, e.g. patients' CD4 count and viral load, their ability to adhere, their sex partner's(s') response to previous treatments (NICE 2018). Those tend to be assessed by healthcare professionals. Simultaneously, standards of care defined by the British HIV Association state that 'people living with HIV should be actively involved in decisions relating to their own care and treatment as they wish' (BHIVA 2012).

relations in HIV care by introducing a different focus and set of concerns. Consequently, looking at how sexuality features in HIV healthcare may provide nuance to debates on what matters in the provision of *good* HIV care[5].

Negotiations of gay sexuality throughout the epidemic

While I will investigate how sexuality has political and ethical importance for gay men in the delivery of care, I will contextualise my arguments within a broader history of negotiations of gay sexuality throughout the epidemic. In my research, I consider the sexual as always embedded in specific political, social and historical practices. While not negating the importance of biology, socially situated accounts of sexuality reveal how sexual desires, practices and identities are conceptualised, deployed and regulated through social institutions and practices (Ritzer 2007). It has been assumed that if 'sex' and 'society' are not separate and independent domains, sexuality has a complex history which needs to be understood outside of the dichotomy of repression and liberation. In other words, sexuality is a result of diverse discourses and practices and multifaceted negotiations and struggles between those who are in a position of power to define and regulate and those who do not comply (Weeks 2009). The recognition of sexuality as an outcome of politicised negotiations is crucial to the research on the epidemic, during which – and I will discuss this in more detail in the next chapter – individuals' sexual identities, desires and practices have been scrutinised, disciplined and fought over.

Gay men have been at the epicentre of the HIV epidemic since its first outbreak. Before HIV or AIDS were identified, the 1981 report on

[5] I will use the term 'care' for interventions in the lives and bodies of people living with HIV that are necessary for viral suppression and, therefore, for securing good health. For example, among those interventions would be: prescribing of antiretroviral and other drugs, health monitoring tests, supporting patients in managing their diet and mental health. In my analysis of HIV care, the concept will become slightly altered as I include elements that go beyond what is required for administering and monitoring treatment regimens.

pneumocystis carinii pneumonia[6] in previously healthy young men who have sex with men drew attention to the population (Bartlett 2006). The growing number of cases among gay men in the United States and the UK suggested that the cause of the immune deficiency was sexual, leading to the syndrome being initially termed 'gay-related immune deficiency' (GRID) (Waldby 1996: 117). David M. Halperin (2009) argues that, while throughout the AIDS epidemic, the topic of gay men's sexual risk-taking has opened a multitude of enquiries among scientists, journalists, community leaders and activists from the early 1980s onwards, those enquiries have often taken the form of psychological speculations about gay men's motives for engaging in risky sex. Arguably, this led to a revival of medical reasoning, which distinguishes 'healthy' from 'unhealthy' behaviour, and starts from the normative premise that no sane person would ever put his life at risk to gain sexual pleasure (Halperin 2009: 11).

To put it differently, during the AIDS crisis, gay men were not only facing a threat to their health, but additionally, representations surrounding the AIDS crisis and encouraging the de-sexualisation of gay culture posed a significant threat to gay identity and communities. Hence, queer sexual practices and pleasures have also been an important site of resistance to this de-sexualisation and illustrated by open expressions of sexuality. Indeed, it has been argued that the defiant and sex-radical politics of the early AIDS outbreak effectively provided a strong response to homophobia and the sex-negative early years of the health crisis (Gould 2009). It has been also argued that for gay men to engage with safer sex, it had to be eroticised and made into something more than a mere technique – it had to connect with self-love, caring and gay pride. For that reason, explicit

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[6] *Pneumocystis carinii* pneumonia (PCP) is caused by the yeast-like fungus *Pneumocystis jirovecii* (Aliouat-Denis *et al*. 2008). Being a source of opportunistic infection, it can cause a lung infection in people with a weak immune system. PCP has historically been one of the leading causes of disease among persons with AIDS. The introduction of HIV treatments in industrialised nations has brought about a sharp decrease in the incidence of AIDS-associated complications, including PCP. In the adult population living with HIV, the incidence of PCP has significantly declined, but it remains among the most common AIDS-defining infections (Morris *et al.* 2004).

videos and magazines as well as peer support played a major role in sustaining the culture of safer sex (Watney 1997: 147).

The unique position of long-term survivors of the epidemic

The longstanding negotiations that took place throughout the epidemic are particularly significant to long-term survivors of the epidemic who were a part of or affected by them. 'Long-term survivor' commonly refers to individuals who acquired HIV in the 1980s and 1990s, before the advent of ART[7], and have suffered from physical and social implications that are vastly different from those who were tested after 1996 and have been living with HIV for just over 10 years (Anderson n.d.). Long-term survivors occupy a unique position within the epidemic. Often actively participating in the development of HIV treatments by being subjects in clinical trials (Epstein 1996), they enabled biomedical advances and, as a consequence, permitted what social scientists working on the epidemic have proposed is a shift to HIV 'normalisation'. To put it differently, long-term survivors of the epidemic have lived through one of the most significant changes to have occurred in relation to HIV: its transformation from a deadly, acute condition into a chronic disease that, provided it is properly managed, need no longer preclude longevity or quality of life[8].

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[7] Even though the history of antiretroviral therapy (ART) begins with the first clinical trial of zidovudine that was conducted in 1986 (Bartlett 2006; Fischl *et al.* 1987) and dual therapy became well established during the next decade, the reality is that HIV treatment during these first 10 years of ART is viewed as having been unsuccessful (Bartlett 2006; Hammer 1996). During the 11th International Conference on AIDS in Vancouver, British Columbia in 1996, David Ho of the Aaron Diamond AIDS Research Center, New York, NY, and George Shaw of the University of Alabama at Birmingham School of Medicine, presented viral dynamics data suggesting that HIV required uninterrupted antiviral treatment (Bartlett 2006). After it was incorporated into clinical practice, the concept of 3-drug therapy demonstrated impressive benefits with a 60% to 80% decline in rates of AIDS, death, and hospitalisation (Bartlett 2006; Palella 1998).

[8] Overall, where people living with HIV have full treatment access, the medical profession considers HIV to be a chronic and long-term condition, where patients can be guaranteed a 'normal' life through adhering to the ART regimen. Near to normal life expectancy (Public Health England 2017; What is the life expectancy for someone with HIV 2015) and treatments with minor side effects, are the core arguments behind positioning HIV as a normalised condition in the UK, that can be treated like any other manageable and asymptomatic chronic disease (Squire 2013).

I argue that engaging with HIV specialists working in the field of HIV medicine since the outbreak of the epidemic, and with patients who can be described as long-term survivors of the epidemic, offers an important vantage point for approaching the debates on HIV care. At the same time, I show how the discussion of HIV care can be extended beyond the biomedical changes and ways in which they affect the lives of people living with HIV. Just as it can be argued that long-term survivors experienced two versions of the epidemic that could be considered profoundly different, pre- and post-treatment, it can also be suggested that they were affected by the different ways in which the sexual has been negotiated throughout the epidemic. The uniqueness of the position of long-term survivors of the epidemic may be of wider relevance. Ongoing developments in HIV medicine mean that men diagnosed with HIV today face different challenges and their HIV healthcare requirements may vary too. Yet, looking at how sexuality matters when care is delivered to long-term survivors supports a nuanced understanding of HIV healthcare, suggesting that an HIV patient needs to be understood in the context of complex social and sexual negotiations that have been taking place throughout the epidemic.

In the early response to the epidemic, activists worked together with biomedical scientists to lower the number of new infections and deaths in those already living with HIV. Healthcare strategies applied early in the epidemic, when treatments had only a modest influence on prognosis, have been branded HIV exceptionalism. HIV exceptionalism refers to a set of policies shaped by an alliance of gay leaders, civil libertarians, physicians and public health officials that treated HIV infection as fundamentally different from all other public health threats (Bayer 1991). It has been argued that the exceptional status of HIV/AIDS has improved communication between doctors and patients, strengthened patients' autonomy and their involvement in treatment decisions, led to more ready acknowledgements of individuality and increased respect for consent and confidentiality (De Cock & Johnson 1998). For instance, anonymous HIV testing can be seen as a moment of parting between the epidemiologically

driven concept of public health that stresses collective good at the expense of the individual and the ethical concern for individual rights, with the latter position eventually winning out (Berridge 1996: 151). Exceptionalism of the early responses to the HIV/AIDS epidemic may also be seen in relation to the changes to the sexual cultures of gay men. For example, while I have already suggested that stigmatising representations surrounding the AIDS crisis threatened gay identity, it could be argued that HIV exceptionalism encouraged confidence-building and a sense of autonomy through forming a more democratic model of healthcare.

In contrast to HIV exceptionalism, the 'normalisation' position is often described as having shortcomings in reflecting the reality of living with HIV through ignoring the social stigma surrounding the infection, the side effects of HIV treatments that often affect patients' everyday responsibilities and activities and the psychological impact of being diagnosed with a long-term condition (see for example Persson 2013; Squire 2013). The emerging discourse of 'HIV normalisation' echoes wider trends of 'biomedicalisation' (Persson 2013), which is understood as an increasing reliance on biomedical interventions to treat and prevent diseases, manage risk and improve daily life more broadly. Within biomedicalisation, such interventions have the ambition and the potential to 'transform' and 'normalise' medical phenomena, bodies, identities and socialities (Clarke & Shim 2011; Clarke *et al.* 2010). For example, in recent years, debates on the epidemic centred around the ability of ART to make HIV-positive bodies non-infectious[9] and the use of Truvada, an anti-

[9] The HIV Prevention Trials Network (HTPN) 052 study observed a 96% reduction of transmission from the HIV-infected partner to the uninfected partner in couples who initiated ART when they entered the study. The hopeful result of the HTPN 052 was called the scientific breakthrough of the year for 2011 by *Science* and led the World Health Organization (WHO) to publish guidance on the testing and counselling of HIV serodiscordant couples that involves the use of ART to reduce the risk of transmission. Treatment as Prevention (TasP), defined by the International Association of Providers of AIDS Care (IAPAC) as 'the provision to and use of ART by HIV-infected individuals to reduce morbidity and mortality as well as the risk of onward HIV transmission through durable viral suppression' came into being (Thompson *et al.* 2012: 3).

HIV drug in HIV-negative people as pre-exposure prophylaxis (PrEP)[10]. These considerations emphasise the capacity of antiretroviral drugs to transform: bodies from 'risky' to non-infectious (Persson 2013); an HIV-politicised activist identity to an HIV-positive identity, reduced to a sense of responsibility (Johnston cited in Race 2001); or social negotiations of confidentiality and the redistribution of healthcare (Hutchinson *et al*. 2016). The transforming capacity of ART and the promise of HIV normalisation have already become a part of how HIV care is being provided. Yet, the discourses and practices of HIV normalisation seem to view its subjects exclusively as users of ART, ignoring, for example, their social contexts, such as sexual cultures. On the other hand, as the HIV epidemic continues to disproportionally affect gay men[11], sexual politics remain an important feature of the epidemic and, potentially, of HIV care. Placing gay sexuality and its politics at the centre of the analysis may, therefore, add to and strengthen a critical approach to the biomedicalisation of the epidemic, the discourses and practices of HIV normalisation and their implications for individuals.

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[10] PrEP stands for Pre-Exposure Prophylaxis, and it refers to the use of anti-HIV medication that keeps HIV-negative people from becoming infected. In the UK, PROUD Study has shown that a daily pill can effectively protect people from HIV infection and that the approach could play a major role in reducing the number of new infections among men who have sex with men (PROUD). Yet, PrEP remains unavailable through the National Health Service (NHS) on prescription (NHS England). While a private PrEP service is now available where a prescription can be purchased following an assessment, the monthly cost for users amounts to £400 (Get PrEP 2017).

[11] According to Public Health England (PHE), in 2015, a total of 6,095 new HIV diagnoses were made in the UK, similar to numbers reported in recent years. This figure includes 305 people who were diagnosed with AIDS at their HIV diagnosis. PHE also reports that 613 people with HIV infection died in 2015 with under half of these deaths likely to be AIDS-related. Among all diagnoses made in 2015, 54% were reported among gay, bisexual and other men who have sex with men (MSM). Although a slight decline compared to the previous years, new HIV diagnoses among MSM remained high. PHE suggests that this may reflect an increase in levels of HIV testing as well as ongoing transmission in this group (Public Health England 2016).

The space of the clinic

NW[12] clinic, where I conducted my ethnography, was based in a large hospital, an hour's commute from where I live. For six months, I went there three times a week and spent mornings and early afternoons writing field notes about my observations as well as recruiting interviewees and conducting interviews. The clinic consisted of three corridors linked by a U-shape, corridors, two relatively spacious waiting areas with chairs lined against the walls, a small pharmacy, a number of consultation rooms and a larger, a larger section hidden behind a curtain where patients could lie down if, for example, they were not feeling well after their blood had been taken. The nurses had their desk in one of the two waiting areas, which meant that they were always visible to the patients and it was easy for them to interact with those waiting for their appointments. While doctors and research nurses had little time to stop and chat with patients and spent most of their day in consultation rooms or in meetings, nurses would often greet and chat casually with patients, especially with those patients they seemed to be familiar with. Yet, it was not uncommon for doctors to stop to greet their patients, exchange a few words or even give them a quick hug. The corridors had a few stations placed around, with booklets explaining in lay terms issues around HIV treatments or clinical trials. There were also magazines for HIV-positive people, especially produced by and for gay men, and leaflets with contact details of London charities (Field Notes 15th April, 2014).

The part of the clinic most unique in terms of its design was a little patio in the middle of it. The patio had a few tables and lavish plants cared for by volunteers. Especially in summer, it offered a pleasant alternative to enclosed waiting areas. The atmosphere there seemed more social; it somehow encouraged conversation among those who shared tables or were trying to get a suntan (Field Notes 7th July, 2014). During the cooler

[12] Throughout the thesis I will refer to the clinic as 'NW' as a precaution taken in order not to disclose the identity of those reported in the thesis.

months, the most social space was a small tea room used by both the staff and the patients. Everyone was welcome to help themselves to a cup of tea and a pack of biscuits. Often, once someone was making tea for themselves, they would ask others sitting outside if they fancied a cup of warm beverage too. For me, it became a way of keeping myself occupied on quiet days. However, using the tea room generated some anxiety for me. This was because the room was located next to where patients were queuing to have their blood taken. I learnt from one of the patients that sometimes they had to fast before having the tests done. For that reason, I would avoid helping myself to the biscuits in the clinic and would often take my tea outside (Field Notes 14th April, 2014). It seemed that some patients saw the tea room as an important space within the clinic. This was suggested to me when an argument broke out after patients present at the meeting found out about the plans to remove the tea room during the upcoming renovation works (Field Notes 19th May, 2014).

Areas functioning as social spaces, like the tea room or the patio, and having nurses always interacting with patients in a friendly manner, often having conversations about topics unrelated to healthcare, created an atmosphere that, for me, was strikingly distinct. In my early field notes, I described the clinic as having the feel of a community centre rather than any other medical space I had been familiar with. Already on my first visit, I felt as if I had entered a space that belonged to a group of people who had more in common than their HIV-positive status. I often wondered if the sole reason behind it was the fact that patients who had been attending the clinic for years, sometimes decades, were familiar with each other and their healthcare providers.

Doctors and patients

Very early into my research it was explained to me that different clinicians led the treatment of patients from different populations. For example, some clinicians, being gay men themselves, tended to provide care to gay patients while Lauren, who spoke French in addition to English, was a

leading clinician for many of the African patients. Primarily, I followed Mark who was my gatekeeper. He was one of the clinic's consultants and, similar to many other healthcare professionals working with him, Mark had been working in the HIV epidemic since its outbreak in 1980s. Very early into my research, based on conversations I had with his colleagues and patients, I realised that Mark seemed to be surrounded by what felt like 'legends' – something more elusive than just evidence of his contributions to the development of HIV treatments and his activism. Many pointed out his many years of experience and even commented on the dedication and bravery he displayed in the early years of the epidemic (Field Notes 11th June, 2014).

Most of Mark's patients had been in his care for many years; some of them followed him from his previous place of employment in the mid-1990s. Those who I focus on in my research can be identified as long-term survivors of the epidemic. As I learned from Mark, most of them identified as gay men. It has to be stressed that the atmosphere and the events I describe, while painting a certain picture of the clinic, reflect only partially the life of the clinic. I suspect that if I had followed Lauren and other clinicians whose groups of patients were not predominantly male and gay, my observations could have been considerably different. While other patient populations are absent in this thesis, it is important to remember that they were present in the space of the clinic at all times, even if sometimes remaining a minority. In my research, they had a role as silent witnesses to the interactions and events I was observing.

Chapter overview

In Chapter Two, I reflect on the literature on HIV, which enables me to build a framework for approaching and understanding HIV care and the ways in which the sexual features within it. In doing so, I highlight differences among various perspectives and lead to research questions which direct the analytical process in the subsequent chapters. The chapter is divided into two parts that review distinctive bodies of literature.

Thus, they offer a greater understanding of issues already introduced here, such as the impact of the epidemic on gay communities, the workings of normative and medicalised discourses around HIV and early AIDS activism and its role in revalorising gay sexuality and strengthening community bonds. Furthermore, I expand on the debates around doctor-patient relations and the democratisation of healthcare. I then move on to an analysis that points out the limits of that democratisation, revealing how biomedical discourses and practices embedded in HIV care and its technologies continue to recreate a particular patient who is individually responsible for failing his treatment.

In Chapter Three, I map out the methodology on which this thesis was built. I primarily explore the intricacies that are involved in my ethnographically oriented research. I also draw attention to differences between how I understood the objectives and methods of this study and how healthcare professionals and patients saw my role as a sociologist in the HIV field. Throughout the chapter, I consider how I emerged as a certain agent in relation to the field and to considerations much greater than the breadth of my research, such as the debate around the relationship between the social and medical disciplines. I then discuss my experience of acquiring access to the research site and challenge some of the assumptions embedded in the process of gaining ethical approval. In particular, I point out the implications of the standardised definition of a research participant for the question of what ethically conducted research entails.

Chapters Four and Five reveal how, by putting gay sexuality at the centre of the analysis, it was possible for me to understand patients' uses of humour and a flirtatious atmosphere not as isolated phenomena, but as a part of the queer cultural practice in which gay men have been engaging in various ways since the outbreak of the epidemic. The chapters look at the presence of the subversive camp culture in NW clinic and what this does to the negotiations of care. I then point out links between the current uses of camp in a specialist HIV clinic and the cultural subversion of ACT UP. I

argue that physical closeness between patients and HIV physicians and the use of camp humour reveal HIV care as involving affective and collaborative efforts that are situated in the broader context of the epidemic and communities affected by the health crisis.

In Chapter Six, I continue to illustrate the specificities of the HIV care delivered and negotiated in NW clinic. I then investigate more closely the doctors' self-narratives in order to offer a contextualised understanding of the ways in which they deliver HIV care. I show that looking at the significance of HIV practitioners identifying as gay men, allows for HIV healthcare professionals to be recognised not solely in relation to medicine and its discourses and practices, but also, in the context of the history of the epidemic and AIDS activism. I conclude this chapter by introducing the concept of alliances of long-term survivors, which, apart from people living with the infection, includes healthcare practitioners who have been working in the HIV epidemic since its early days. The concept emphasises that the shared political commitment between HIV doctors and their patients defines one of the specificities of NW clinic. I argue that, while the alliance is enabled by a shared sexuality and a willingness to be subversive and to reveal the social roles of a doctor or a patient as cultural performances, it creates a certain culture within which *good* care and what is necessary for *good* care is being renegotiated.

Chapter Seven follows on from the proposition guiding previous chapters: that putting gay sexuality and its politics at the centre of the analysis facilitates a better understanding of what constitutes HIV care when long-term survivors are at its receiving end. Chapter Seven alludes to the ways in which gay communities have rethought their relationship with their past, following the AIDS crisis. In this chapter, I explore how the AIDS crisis continues to be remembered and unremembered in the clinic. In contrast to early AIDS memorials, I point out the significant difference in the ways in which memories of the past AIDS crisis are being mobilised in the clinic. In particular, I focus on the uses of the past in encouraging adherence to

ART and how they contribute to the processes of the individualisation of responsibility of an HIV patient for the success of the treatment.

Chapter Eight underlines the contributions of this research to the broader debates on HIV care and the HIV epidemic. I consider the implications of foregrounding gay sexuality in my analysis for the discussions on the doctor-patient relationship and, somewhat linked to it, the debate on the biomedicalisation of the epidemic. I use the concluding chapter to rethink the definition of HIV exceptionalism and propose one that highlights some of the potential tensions arising from endorsing a greater involvement of general medical practitioners in delivering healthcare to people living with HIV. Further, I reflect on the value of considering the events of the early AIDS epidemic in HIV research and suggest how it may enhance researchers' critical insights.

Chapter Two. Long-term survivors in the epidemic

When Watney (2000) describes how gay men were affected by the outbreak of the AIDS epidemic, he emphasises two phenomena: strengthened solidarity amongst them and the assertiveness that characterised their engagement with strategies of hindering the crisis. Watney writes:

> Like many other early AIDS workers of my generation, I also had a developed sense of gay identity, which typically involves a strongly motivating sense of solidarity with others. Many of us involved in the early days of the epidemic had known one another as young men on the gay scene. (Watney 2000: 6)

The sense of solidarity with others, Watney explains, rested on a collective gay identity. It came from a shared anti-conservative political culture and an already existing familiarity with each other. It became the basis for mobilising actions against the epidemic – actions which required engagement with epidemiological knowledge, as well as the skill of translating that knowledge into practice. Watney emphasises that bringing the epidemic under control required that the affected communities understood the scientific knowledge of modes of transmission, degrees of infectiousness and average life expectations, as well as ethical conduct in clinical trials that could generate the treatments (Watney 2000: 7). What Watney describes is how shared gay identity was translated into shared experiences under the conditions of the AIDS/HIV epidemic. Those who were in their twenties and thirties in the early days of the pandemic and began receiving ART in 1996 are now approaching middle age or older. As mentioned in the previous chapter, long-term survivors occupy a unique position in the context of the epidemic, as they have experienced two versions of the epidemic that could be considered as profoundly different. Long-term survivors lived through the early AIDS crisis, which saw the mobilisation of efforts in the biomedical sciences and by activists

to lower the number of new infections and deaths in those already living with HIV. Today, they are living through the epidemic at a time when the biomedical establishment has made a promise to *normalise* HIV by turning it into a manageable and non-infectious condition.

As will become evident in this chapter, much of the literature on HIV discussed here refers to debates from the two first decades of the epidemic that focused on communities of gay men affected by HIV/AIDS. I will assess the usefulness of this for understanding how gay men and long-term survivors currently negotiate HIV healthcare. However, the aim is not solely to produce a 'follow-up' analysis, but to propose a set of questions that will enable HIV care to be examined through looking at how it is being delivered to and negotiated by long-term survivors in the specialist clinic. In this chapter, I reflect on debates which will enable me to build a framework for approaching and understanding how HIV care is delivered and negotiated in NW clinic. In particular, I will focus on discussions around gay sexuality and its surrounding politics. I will also expand on the topics of the history of the epidemic and the biomedicalisation of HIV care as both are relevant to the lives of long-term survivors. In doing so, I highlight differences among various perspectives which build up to questions that will be considered in the analysis offered in the following chapters.

This chapter is divided into two parts, which review distinctive corpora of literature. Firstly, I discuss the impact of the outbreak of the epidemic on gay communities and the ways in which gay men's sexual practices and pleasures have been conceived in normative and medicalised discourses around HIV. I look at how openly expressed sexuality became a part of early AIDS activism, allowing gay sexuality to be revalorised and community bonds to be strengthened. In this way, the first part of this chapter argues for an approach which recognises sexuality as a site of politics and creativity that has been crucial to the affected community's efforts to challenge the normative discourses of epidemiology and biomedicine. The second part focuses on the complexities and specificities

of HIV care. It begins by looking at the process of its formation which arguably led to the democratisation of healthcare, then moves on to works that emphasise the limits of that democratisation, before revealing how biomedical discourses and practices embedded in HIV care and its technologies continue to recreate a particular patient that is individually responsible for failing his treatment.

Part One

The outbreak of the epidemic: the impact of the health crisis on gay men and the early AIDS response

Here, I will focus on the specific ways in which the lives of many gay men have been affected by the growing health crisis in the 1980s. In doing so, I will draw on historical interpretations that are centred around gay men. That will illustrate the magnitude of the impact of the epidemic and how it was experienced by individuals in different ways. Patients I met and interviewed during my research shared with me their memories of the early AIDS crisis and told me about the consequences of the epidemic for their personal lives as well as their communities. The history of the epidemic can be told from different perspectives, rooted in different experiences of the events and/or representing different interests. The choice of which account to engage with became a question I had to consider early into my research. As this project is invested in the understanding of gay sexuality as a site of negotiations, I chose to engage with historical accounts of the epidemic that describe how gay men and their sexual practices have been framed in discourses since the outbreak and what political decisions followed on from those discourses. I came to see my decision as a political one as this project discusses people living with HIV within complex social and sexual contexts and challenges the increasing trend to present them solely as users of biomedical technologies.

Accounts of the AIDS epidemic in the 'West' often begin in 1981 when doctors in New York and Los Angeles independently reported clusters of previously rare health conditions: *pneumocystis carinii* pneumonia (PCP) and Kaposi's sarcoma[13] (KS). Shortly after, a number of other rare diseases were reported among otherwise healthy young gay men. All conditions were known for their association with deteriorating immunological defences. In the UK, the first incidence of related serious deficiencies in the immune systems was reported in December 1981 (Dubois *et al.* 1981). As observed conditions were primarily identified among gay men, they were collectively described as Gay Related Immune Deficiency (GRID). Later, it was recognised that their underlying cause was not specific to gay men and could also be transmitted via blood transfusion. In 1982, the Centers for Disease Control in Atlanta officially defined the conditions as AIDS. A year later, HIV was isolated as the agent responsible for AIDS. The scientific breakthrough was followed by another: the development of a diagnostic test in 1985. By the late 1980s, studies had identified drugs demonstrating activity against the causative virus. Yet, it was not until 1996 that the effective combination antiretroviral therapy became widely used in HIV patients.

Data on the early dissemination of HIV among gay men in the UK was deduced from HIV antibody testing of blood samples collected initially for the investigation of possible hepatitis B infection and preserved by the Public Health Laboratory Service Virus Reference Library in London and similar public health laboratories in provincial centres. Data from those samples, along with others submitted specifically for HIV antibody testing, were analysed in 1985. The procedure allowed researchers to estimate that of a specimen out of a sample of gay men in London, 5.2% were already HIV positive in 1980, with an increase to 34.1% in 1984 (King 1993: 23). In 1988 the Department of Health and Welsh Office Working Group published a report that concluded that between 15% and 25% of

[13] Kaposi's sarcoma is a multi-focal vascular tumour involving skin and the other organs. It is one of the AIDS-defining conditions (Mehta et al. 2011). Its incidence has declined since the introduction of ART (Reyners et al. 2006).

gay men attending London sexual health clinics were HIV positive (1993: 25).

Ten years into the epidemic, Edward King (1993) reported on the scale of the epidemic among gay and bisexual men:

> By the end of 1992 there had been a total of 19,065 reports of HIV-infected people in the United Kingdom. Of these, 60 per cent are believed to have become infected through sexual intercourse between men. During 1992 alone, 2487 cases were reported, of whom 62 per cent were gay or bisexual men. If heterosexuals who are believed to have become infected overseas are excluded, in order to get as clear a picture as possible of transmission patterns within the UK, the proportion of gay and bisexual men rises to over 70 per cent. Two-thirds of people with AIDS in the UK are still gay or bisexual men. In other words, there can be no doubt that the epidemic in Britain continues disproportionately to affect gay men, and because up to one in five in some parts of London is infected, it is clear that a gay man having unsafe sex is at much greater risk of getting or giving HIV infection than anybody else having unsafe sex in the UK. (King 1993: ix)

Despite the impact of the epidemic on gay men, King continues, gay communities were not the primary benefactors of the resources dedicated to fighting the health crisis. The prioritisation of AIDS education efforts was not based on the statistical data that highlighted the growing health crisis within gay communities. Quite the opposite: those working professionally in HIV prevention within the structures of the National Health Service (NHS) or voluntary sector did not learn from the ways in which gay men responded to the epidemic – for instance, through inventing safer sex or using them to inform new initiatives designed to sustain those behaviour changes. At the same time, lesbian and gay groups often hesitated, avoiding becoming involved in the epidemic for fear of giving the

impression that AIDS was a ‘gay disease’. King reminds us that since the outbreak of the epidemic, the AIDS field has always relied largely on the work of gay men who recognise the epidemic as a key political issue for their community (1993: x). Other accounts suggest that at the early stage of the response to AIDS, when there was a considerable concern about AIDS and infectivity among healthcare professionals working in the epidemic, gay men became increasingly involved in nursing, pursuing their interest in determining a non-punitive response to AIDS (see Berridge 1996: 60). Yet, since the second half of the 1980s, the voluntary and statutory sectors became dominated by the idea that the epidemic was growing among heterosexuals. Consequently, King argues, many gay men involved in HIV/AIDS work have denied the significance of their own sexuality and rejected their commitment to the interests of other gay men. This, in turn, led to a sense of division between those gay men who remained dedicated to the ‘re-gaying’ of AIDS and other gay AIDS workers (King 1993: x).

Discourses around HIV and the sexuality of gay men

During the history of the HIV epidemic, gay men have experienced elevated homophobia, fuelled by the popular cultural representations of HIV in the media. These representations contributed to public panic and a misunderstanding of HIV infection by constructing ‘guilty’ versus ‘innocent victims’ and promoting the stigmatisation of gay men among others considered to be at a higher risk of infection (Patton 1990; Treichler 1987; Watney 1987). The link between the HIV/AIDS epidemic and the sexuality of gay men, their sexual practices and pleasures, has been well established since the beginning of the health crisis in the 1980s. Stereotypes underlying the understanding of the pandemic, reflected in labels such as ‘A gay plague’ or ‘the price paid for the sixties’, have been directly linked to sexual practices and desires. Treichler (1987) warned against dismissing the discourses built around HIV/AIDS as mere homophobic fantasies or irrational myths, arguing that they effectively influenced the foundations of the development of policies (Treichler 1987:

264-265). Correspondingly, Berridge (1996) writes that in the UK in 1985, each AIDS case made media headlines, contributing to a generalised sense of panic. Furthermore, Berridge argues that both the media and public opinion supported responses to the crisis based on assertions of 'family values' (Berridge 1996: 56-57). Berridge proposes that even though the media did not create AIDS as an issue, it played a key role in legitimating particular definitions and forms of policy response. The early reports on the 'gay plague' were more significant in representing and structuring the public response to AIDS than in policy-forming terms. Later, as journalists reported scientific breakthroughs, provided statistics of AIDS victims and noted famous people who died of AIDS, they acted as contemporary historians and played important roles in policy response[14] (1996: 285).

The response to the AIDS epidemic was largely characterised by the 'conflict between the containment of the epidemic and the moral sensibilities of the nation' (Berridge 1996: 193). Consequently, British gay communities experienced the translation of already existing homophobic sentiments into a political action when the Thatcher government created Clause 28 of the Local Government Act, making it illegal for local authorities to support anything that might promote homosexual relationships as a viable alternative to heterosexual 'family life'[15]. Clause

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[14] Importantly, even though media coverage of the AIDS epidemic played a role in promoting images of AIDS as a 'gay plague', Berridge reminds us that this was not the only significant media reaction. The media had also been used effectively by those who pressed the urgency of the issue on the government. Amongst these were members of the gay community, as well as doctors and scientists. They criticised the government for the initial lack of response. It is believed, Berridge continues, that television programmes that stressed the urgency of the AIDS issue merited a governmental response (1996: 103).

[15] Clause 28 reads as follows: 'A local authority shall not (a) promote homosexuality or publish material for the promotion of homosexuality; (b) promote the teaching in any maintained school of the acceptability of homosexuality as a pretended family relationship by the publication of such material or otherwise; and (c) give financial assistance to any person for either of the purposes referred to in paragraphs (a) and (b) above' (Crimp 1987: 270).

28 reflected and strengthened a climate in which homophobia reached new heights, fuelled by the AIDS panic, the misrepresentations of the epidemic in the press and the antagonistic response of the government. As reported in the 1986 Social Attitudes Survey, some 70% of Britons felt that homosexual relationships were mostly or almost always wrong (Kent 1999: 352). Watney (1989) explains the meaning and the impact of Clause 28:

> Section 28 is, of course, obliged to acknowledge that homosexuality exists, but can only explain its existence in terms of a crude conspiracy theory which regards lesbians and gay men as sinister predatory seducers, eagerly 'promoting' our perversions to the young and 'innocent'. It thus speaks from a long tradition of legal moralism, dedicated to the protection of the supposedly 'vulnerable'… It is the field of lesbian and gay culture that Section 28 targets, where our personal and collective identities and political confidence are formed and validated. (Watney 1989: 23)

Watney argues that from the point of view of Clause 28, gay relationships appear illegitimate and somewhat 'unreal'.

Here, it is useful to consider the discourses built around the sexuality of gay men in relation to the HIV/AIDS epidemic in a broader context. Michel Foucault (1990) argued that Western discourses on sexuality have been tied to political discourses, and have generated specific power relations. In *The History of Sexuality*, Foucault writes:

> But it appears to me that the essential thing is not this economic factor, but rather the existence in our era of a discourse in which sex, the revelation of truth, the overturning of global laws, the proclamation of a new day

> to come, and the promise of a certain felicity are linked together. Today it is sex that serves as a support for the ancient form – so familiar and important in the West – of preaching. (Foucault 1990: 7)

For Foucault, sexuality is thought of as a way of accessing the truth and is tied to regulations and power that operates within Western societies. For this reason, Foucault sees the importance of defining the regime of *'power-knowledge-pleasure'* that sustains the discourse on human sexuality. In other words, it is imperative that we question how sexuality has been discussed, what has been said about it and what the effects of the power generated by what was said have been. In other words, it is the way in which sex is 'put into discourse' that needs our scrutiny (1990: 11). Foucault argues that merely accepting sexuality as subjected to repression would be insufficient and potentially obscures more insidious social processes. Hence, efforts should be made to investigate the conditions for the emergence of the interplay between knowledge and pleasure (1990: 72-73). Furthermore, when Foucault links desire and power, he no longer considers power as a set of laws and prohibitions, but as something more elusive, complex and ubiquitous. Power comes from everywhere rather than emanating from any particular institution (1990: 92-93). Although the existence of power assumes the presence of resistance, this resistance is never in a position of exteriority in relation to power. To put it differently, while the dense network of power relations works through apparatuses and institutions, the omnipresent points of resistance traverse social stratifications and individuals. In other words, points of resistance are distributed irregularly over time and space, at times mobilising individuals or groups in definitive ways (1990: 95-96). Foucault offers a historical analysis to illustrate these processes, focusing on the emergence of the discourse on homosexuality in the nineteenth century. Undoubtedly, the series of discourses on homosexuality emerging in the domains of psychiatry, jurisprudence and literature advanced social controls into this area of 'perversity'. On the other hand, they also made possible the formation of a reverse discourse when homosexuality began

to demand its legitimacy or *'naturality'* be acknowledged, often using the same vocabulary and categories by which it was medically disqualified (1990: 101).

David M. Halperin (2009) argues that Foucault's decision to treat sexuality not as a biological or psychological drive, but as the product of modern systems of knowledge and power, offered a new vision of homosexuality and an opportunity for a significant shift in sexual politics practised by contemporary activist groups. Halperin goes on to discuss the significance of Foucault's shift from focusing on the workings of individual interiority and approaches locating sexuality at the core of the human subject in favour of a political understanding of sexuality that emphasised the impersonal operation of discourses, institutions and social practices (Halperin 2009: 4). Such a move, Halperin argues, proved to be useful in the times of the re-pathologising of homosexuality during the onset of the HIV/AIDS pandemic. As the topic of gay men's sexual risk-taking has opened a multitude of enquiries among scientists, journalists, community leaders and activists from the early 1980s onwards, nearly all of those enquiries have taken the form of psychological speculations about gay men's motives for engaging in risky sex. This led to a revival of medical reasoning, which distinguishes 'healthy' from 'unhealthy' behaviour, and starts from the normative premise that no sane person would ever put his life at risk to gain sexual pleasure (Halperin 2009: 11).

Critical research on the epidemic has shown that within the discourses on HIV prevention, gay men's sexual practices and desires have been framed as problematic and required to be changed if the epidemic was to be brought under control. In London at the beginning of the 1980s, what bound the gay male community[16] together was free-wheeling sexuality and

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[16] Throughout this thesis, I often refer to the 'gay community' in order to stress the scale of the impact of the epidemic and the value of the organised response to the crisis. Yet, it has to be acknowledged that the 'gay community' should not be seen as monolithic. Social research on HIV has underlined the fact that men's relationships to the gay community have been varied and complex (Holt 2011; Kippax *et al.* 1993). Instead, there has been a considerable variation in the degree of attachment to a gay community or in

a greater emphasis on the pursuit of sexual freedom and choice. The arrival of AIDS required a rethinking of the achievements of gay liberation that had brought a greater openness and democracy to the gay sexual scene in the second half of the twentieth century (Berridge 1996: 15). For the gay community, AIDS intersected with two issues: the efforts to de-medicalise homosexuality and the pursuit of gay liberation, and the growing importance of health issues among gay men in the 1970s and 1980s. It is worth mentioning that, as Berridge reports, there was a strategic division within gay organisations between those who preferred co-operation with the state aimed at doing whatever was possible to save gay men from AIDS and those who remained suspicious of the state's potential to undermine the hard-won gains of the gay sexual liberation period (1996: 19-20).

Watney argues that in the AIDS crisis, gay men were facing not only a threat to their health but also to their social identity. He continues by stating that in the 1970s, gay culture facilitated the emergence of a social identity that was detached from the pejorative and also the largely psychological/medical discourses of 'homosexuality'. On the other hand, representations surrounding the AIDS crisis threatened gay identity, which Watney viewed as being 'constructed through multiple encounters, shifts of sexual identification, actings out, cultural reinforcements, and a plurality of opportunity (at least in large urban areas) for de-sublimating the inherited sexual guilt of a grotesquely homophobic society' (1997: 18). Watney argues that, in this context, encouraging the de-sexualisation of gay culture was a significant threat to gay identity and community.

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their involvement in 'gay life'. In order to guard against the risk of assuming positive relationships between gay identity, attachment to a gay community and being receptive to HIV-prevention messages, research has shown how ageism, racism or classism prevented some gay men from relying on a gay community. Further, while some men embraced the social, sexual and political dimensions of gay life, others never became interested in gay politics (Dowsett 1996; Holt 2011).

Simultaneously, in the communities most directly affected by AIDS, it has been widely recognised that safer sex practices need to be adopted regardless of one's known or perceived HIV antibody status and have become established as a cultural practice among gay men in particular. Watney argued that for gay men to engage in safer sex, it had to be eroticised and made into something more than a mere technique – it had to connect with self-love, caring and gay pride. For that reason, explicit videos and magazines, as well as peer support played a major role in sustaining the culture of safer sex (1997: 147). Safer sex came to be perceived as an integral part of what it meant to be gay in the 1980s (King 1993: 53). Founded to support gay men and organised by them, the gay media treated AIDS with seriousness, regularly addressing the issue (in contrast to mainstream press reporting, which often sensationalised AIDS). It provided a forum for debates that made a positive contribution to the development of a culture among gay men, recognising the epidemic as a matter of great concern and legitimising safer sex as an essential strategy for gay men, rather than a restriction imposed from above. In the 1980s in London, the free weekly newspaper '*Capital Gay'* ran regular news stories, which turned into a weekly column dedicated to AIDS. The column provided reliable information on AIDS which included the latest findings published in medical journals, discussions around the social and psychological impact of the epidemic and debates around evolving safer sex recommendations. '*Capital Gay*' has been described as being the centre for much of the AIDS-related debate in London. Another example of an important gay publication is a weekly free newspaper titled '*Boyz*'. King explains that its significance for the gay community lay in its approach, which was characterised by 'light-hearted hedonism' as well as a 'uniquely mature, consolidatory response to the epidemic, in which safer sex, with all its attendant complexities, is a fact of late twentieth-century gay life' (1993: 58-59). Although gay men initially embraced the government strategy of emphasising the universality of the threat posed by AIDS as having the potential to avert the discrimination and blame which many of them feared (1993: 194), later, as the neglect of ongoing safer sex education among gay men became increasingly clear, the re-gaying of the

epidemic arose as an emergent issue (1993: 254). In 1991, it was found that only a third of agencies nationwide had engaged in HIV prevention activities of any kind for gay and bisexual men (1993: 257-258).

Theorists working with the epidemic worldwide have acknowledged that prevention efforts originating from high-risk groups successfully led to the decline of HIV rates and a remarkable modification of sexual and drug use practice in much of the developed world (see, for example, Kippax & Race 2003: 6). Importantly, it is often stressed that emerging safer sex practices offered an alternative to the guidelines proposed by many Western governments in the early years of the epidemic, which promoted family values, monogamy and heterosexuality and relied heavily on the stereotypical focus on gay male promiscuity. Safer sex practices came to be extensively accepted and easier to sustain, if adopted, than celibacy or abstinence. Furthermore, it has been argued that acknowledging the necessity to adjust sexual practices had the potential to generate positive feelings about gay identity and community (Patton 1985: 134-140).

AIDS activism: resisting normative discourses.

While the sexuality of gay men, their sexual practices and pleasures have been conceived in normative and medicalised discourses in ways that have given rise to specific and often unproductive HIV prevention strategies, they have also been an important site of resistance to those discourses. Openly expressed sexuality was crucial to early AIDS activism. The national, and later international, direct-action AIDS movement solidified under the name ACT UP in New York City in March 1987. Demonstrations, acts of civil disobedience, zaps and disruptions, die-ins and other forms of street theatre, as well as meetings with government and other officials organised by ACT UP in New York, intervened in every aspect of the epidemic with tremendous effect. The movement's profound effect on the course of the epidemic is evident in the long list of victories it secured, including forcing the Food and Drug Administration (FDA) to speed up the drug approval process and to adopt

policies that allowed people with life-threatening illnesses access to experimental drugs prior to their approval. Deborah B. Gould (2009) argues that the movement's efforts have also reconfigured scientific procedures, and thus scientific research itself, by securing the inclusion of people with HIV/AIDS in government and corporate AIDS decision-making organisations, allowing affected populations to have a say with regards to drug trial design and other aspects of drug research (Gould 2009: 4).

In addition to the many crucial triumphs that prolonged and saved lives, ACT UP's interventions posed a powerful challenge to conventional understandings of homosexuality and of sexuality more broadly. Gould writes:

> ACT UP's interventions posed a powerful challenge to conventional understandings of homosexuality and of sexuality more broadly. Indeed, ACT UP gave birth to a new queer generation that shook up straight and gay establishments with defiant, sex-radical politics. By reerotocizing and revalorizing all kinds of sex, ACT UP queers furnished a strong response to the sex-negative early years of the AIDS crisis. In many ways, ACT UP could be credited as well with the birth and explosion of queer theory in the academy; during the ACT UP years the separation between the streets and the academy was less pronounced than in other periods, and learning happened across these more typically segregated worlds. ACT UP also brought a renewed militancy to lesbian and gay activism – unsettling 'business as usual' in both straight and gay worlds. (1996: 5)

Gould argues that ACT UP inspired new politics and intervened in every aspect of the AIDS epidemic. Furthermore, the efficacy of confrontational direct-action politics that ACT UP helped co-ordinate, opened new political possibilities that had previously only comprised of voting, lobbying and the occasional national demonstration or protest march. In other words, Gould

advocates the idea that ACT UP opened up ways of being gay and of being political that had been barred by the more mainstream-oriented lesbian and gay establishment, ushering in the possibility of a new identity and political formations amongst those who found themselves outside of heteronormativity (Gould 2009: 5).

Articulate, defiant and non-compromising positions on questions of sexual expression emerged from the awareness of sexual freedom being a significant component of many gay men's self-identities, as well as from their determination to fight the equation of homosexuality with AIDS, which threatened to prove, in mainstream public perception, that gay sexual liberation was a mistake (Gould 2009: 78). ACT UP's sexual culture helped the movement to flourish. Gould quotes participants who remarked on ACT UP's vibrant sexual atmosphere, suggesting that its erotic climate played a powerful role in attracting people and sustaining their participation. The meetings were described as filled with 'a lot of sexual feeling and validation'. Challenging negative ideas about promiscuity, ACT UP seemed to be a place where a sex-radical ethos was thriving and where 'there were just a lot of hormones [in the air] at all times'. For many, Gould writes, ACT UP was almost the first place that gay men could celebrate sexuality after the beginning of the AIDS crisis, as ACT UP's self-identity entailed a celebration of gay sexual expression (Gould 2009: 192-193). Importantly, Gould points out that the connectedness of sex and politics in ACT UP meant that the movement challenged the standard dualism that suggests that the presence of supposedly private matters, like intimacies, threatens the supposed rationality of the political public sphere. Furthermore, for many participants, there was no distance between sex and politics. ACT UP's ethos made having sex, and lots of it, feel like a political act, and made those intimate contacts a form of civil disobedience, along with chants and propaganda – sexualised protests (2009: 195-196).

After it arrived on the UK scene in 1990, the activities of ACT UP became more limited. They included demonstrations across the country and small-

scale guerrilla actions, e.g., against the oil multinational Texaco, a company who pressured its employees to take HIV antibody tests and refused to employ those who tested positive (Berridge 1996: 270). In the UK, the organised gay response to AIDS was focused on self-help aimed at the community through raising awareness and providing available information that was being updated following scientific developments. For instance, in 1983, volunteers at the Lesbian and Gay Switchboard, established nine years earlier and initially dealing with an increased number of sexually transmitted diseases in the gay community, opened up a special line helping those who had questions regarding AIDS (1996: 17). The focus on self-help has been criticised by others who argued that instead of focusing solely on developing their own educational and support services within the gay community, AIDS activists should have adopted the US strategy of making clear demands for the provision of needed services within the statutory sector (Whitehead 1989: 107). Nevertheless, as I have argued here, eroticised strategies of self-help around the promotion of safer sex practices have contributed towards challenging the normative discourses of HIV and AIDS and generating positive feelings about gay identity and community. The dedication of many gay men to resisting the epidemic also helped to steer mainstream HIV/AIDS education in line with gay men's needs. For example, launched in 1992, Gay Men Fighting AIDS (GMFA) aimed at recreating the same type of community-level educational activities which had developed almost spontaneously at the beginning of the AIDS epidemic. GMFA succeeded in breaking away from professionalised models of HIV education, which were often constrained by the strict codes of conduct, and created explicit grass-roots support for safer sex through informal, peer education (King 1993: 264).

Shifting ideas about gay sexuality in relation to the epidemic was both an achievement of early AIDS activism and a vital part of strengthening community bonds among those affected. This celebration of sexuality outside of moral frameworks found its place in art. In the subversive style of queer, Jamie Dunbar's photograph *Positiv Sex Happens* depicts two

nude men embracing each other while one of them is connected to an intravenous drip. Marsha Rosengarten (2009) comments on the work:

> The two bodies in this image embrace in a manner that recasts medicine as having the capacity to be 'life serving', rather than 'life saving' or 'life preserving'. Viability is linked to sexual vitality, as if co-constitutive of each other and Posithiv comes to be enacted as both value and medical condition. Indeed, while bodies are here overtly linked to a 'life-sustaining medical technology' and overtly sexualized in their relation to this technology, it is sexualization of the medical technology that is most provocative. (Rosengarten 2009: 68-69)

Rosengarten suggests that Dunbar's work emphasises the connectedness of biomedicine and sex and recognises that medical technologies implemented in HIV/AIDS care possess life-serving qualities through allowing sexual vitality. Acknowledging the link between the biomedical and the sexual encourages the theoretical commitment, already stated here, of approaching sexuality as a site of embodied politics and creativity crucial to the communities in their efforts to challenge the normative discourses of epidemiology. It raises questions about HIV care and what the connection is between HIV treatments and sexual vitality in the current context. Today, we can read Dunbar's subversive art or Gould's account of early AIDS activism in the context of HIV normalisation, which, as I indicated in Chapter One, is a move towards treating HIV like any other chronic and manageable condition. The move towards HIV normalisation strips away the specificities of the HIV epidemic and of the experience of living with HIV. Discourses comparing HIV with other chronic conditions leave no room for considering the links between today's HIV specialised care and what is meaningful to patients who identify as gay men. On the other hand, the questions that can be raised are: is there a place for the vibrancy and sexual atmosphere described by Gould in HIV care today? Do they remain meaningful, and if so, how? Dunbar's sexualisation of the medical technology allowed its life-serving capacity to be seen. Can

acknowledging the link between today's HIV care and sexual vitality facilitate a different conceptualisation of HIV healthcare than that of the discourses of HIV normalisation?

Part Two

What is (good) care?

As I wrote at the beginning of this chapter, affected communities of gay men taught themselves epidemiological knowledge in order to take part in the fight against the epidemic. I have already detailed the victories won by AIDS activism in forcing the FDA to speed up the drug approval process and to adopt policies that allowed people living with HIV access to experimental drugs prior to their approval. Here, I turn to others who discuss the movement's effect on the forming of processes of care. Asking how HIV care is being formed and negotiated means becoming a part of a broader analysis of what constitutes (good) healthcare. Traditionally, physicians have always been required to uphold specific ethical standards. Today, the professional values, knowledge, skills and behaviours required of all doctors working in the UK are defined by the General Medical Council, which sets standards that cover fundamental aspects of a doctor's role, including working in partnership with patients and treating them with respect. *Good medical practice* provides guidance in a number of domains, such as implementations of knowledge and skills, safe practice, communication and teamwork and maintaining trust (General Medical Council 2017).

The British HIV Association (BHIVA), in partnership with care providers, professional associations, commissioners and people living with HIV, has produced a set of standards that provide a reference point against which to benchmark the quality of care of people with HIV in the UK. The standards focus on aspects that BHIVA identifies as having particular relevance for delivering equitable high-quality services that secure the best possible outcomes for people with HIV. Among them are standards

set for HIV testing and diagnosis; access and retention in care; access to care for complex co-morbidity; effective medicines management; psychological care; and sexual health services. BHIVA stresses that specialist HIV services should be provided in 'a non-judgemental environment in which people with HIV feel secure and where their confidentiality and autonomy is actively respected'. Furthermore, it is recommended that patients should have the opportunity to be actively involved in decisions about their healthcare, as well as the opportunity to be involved in the design, planning and delivery of the services they use (British HIV Association 2013).

In order to understand the complexities and specificities of HIV healthcare, we need to look back to the beginning of the epidemic and the process of the formation of relations between HIV/AIDS patients and the medical field. It has been argued that as a result, the boundaries between scientist insiders and lay outsiders were challenged and shifted. What has been a significant effect of AIDS, according to Steven Epstein (1996), is that the crisis and the ways in which biomedical technologies designed to hinder it were developed, encouraged an altered conception of the doctor-patient relationship that became linked explicitly to an emergent understanding of the appropriate researcher-subject relationship. In AIDS research, patients gained a participant's interest which extended beyond the mere protection of their rights as human subjects, and communities had a stake in the review of research protocols. The early years of the epidemic also precipitated new forms of critical engagement with biomedical practice and discourse. In their effort to advance medical treatments for the condition, AIDS activists subjected the procedures of biomedical and therapeutic authorities to critical pressure, with many becoming 'lay experts' (Epstein 1996: 346). They questioned the ways in which science's credibility is constructed and deconstructed, and gained enough of a voice in the scientific world to shape research to a significant extent. As a consequence, Epstein proposes that AIDS activism ushered in a new wave of democratisation struggles in the biomedical sciences and

healthcare (1996: 449). Correspondingly, Isabelle Stengers (1997) notes the specificity of HIV prevention:

> The 'AIDS event' is characterized by the choice of not yielding to the urgency of the strictly medical problem, of resisting demagogic and security-seeking temptations, in other words of trying to actually pose the problem clearly. This is why it has been decided to give a hearing not only to those whose expertise represents the virus and its paths of transmission but also to those who represent what we know about the manner in which individuals, groups, and societies invent themselves by way of rules, laws, and technical apparatuses. (Stengers 1997: 216)

That is, Stengers argues that the 'AIDS event' stands for a remarkable moment in rethinking the technologies of hindering the epidemic, as not only were doctors consulted but also others who might have been affected by the solutions that were being proposed. In other words, specialised HIV care emerged in a specific and complex entanglement of antiretroviral medicine and AIDS activism. As a consequence, it could be suggested that any analysis of how (*good*) HIV care can be understood needs to consider these complexities. For example, theorists analysing the history of the epidemic in the UK point to the tension between efforts to de-medicalise homosexuality and pursue gay liberation and the urgency of addressing health issues among gay men in the face of the growing AIDS crisis. Berridge (1996) notes that while clinical and scientific investigation and activism around AIDS were emerging in tandem, it was ironic that the defeat of the disease-based 'medical model' of gay sexuality witnessed the rise of health as a matter of concern in gay organisations (Berridge 1996: 18-19). In the altered-by-the-epidemic reality, gay men had powerful political and personal reasons for accepting the dominance of biomedicine: its potential ability to provide cures and vaccines and the scientific legitimation for the argument that it was not who you were but what you did, that caused AIDS. Consequently, 'lay experts' immersed themselves in information about the latest discoveries and treatment

possibilities, accepting medical premises rather than challenging them (1996: 53).

Epstein also identifies a number of difficulties interwoven with the processes of democratising science and building 'lay expertise'. Firstly, Epstein argues, due to a high level of specialisation among AIDS activists participating in scientific studies, they depend on each other and become essential to one another. Consequently, the democratisation of science is inseparable from the consolidation of new relationships of trust and authority. Secondly, Epstein suggests that there is a significant difference between the tactics adopted to ensure the activists' credibility before the research establishment and what is required to remain credible in the eyes of the communities that the movement seeks to represent. In short, Epstein insists that where activism and science meet, it introduces a wide range of effects upon the dynamics of a social movement. What is more, Epstein points out that knowledge hierarchies are rarely 'accidental' in their origins. Instead, they occur where social cleavages existed before, reinforcing them. They tend to be based on other markers of difference, such as class, formal education or race and often create a situation where the power of expert knowledge overlaps with other systems of hierarchy (Epstein 1996: 351-352). Yet, Epstein concludes, the genuine progress that has been made in order to democratise biomedicine should not be negated by the impossibility of realising it fully (1996: 353).

These processes of democratisation of doctor-patient relations in the context of the HIV/AIDS epidemic may be understood in the more general terms of biological citizenship, a concept proposed by Nikolas Rose and Carlos Novas (2005), who define it as resting on the biological understanding of the body and human existence, and the ways that this understanding links individuals and distinguishes them from others. Rose and Novas observe that particular biological presuppositions, explicitly or implicitly, have underlined numerous citizenship projects and have shaped conceptions of what it means to be a citizen. Even though continuous monitoring and optimisation of one's health through health promotion and

education constitute efforts to construct citizens from above, shaping the way they see their bodies and their responsibilities to themselves and to those around them, Rose and Novas note that it would be erroneous to merely focus upon strategies for 'making up citizens' that are imposed from above. Quite the opposite, as biological citizens actively engage in self-care, self-education and collectivising actions, demanding particular policies or actions or access to special resources (2005: 440-1). Rose and Novas draw on Paul Rabinow's forms of biosociality and new technologies that are being assembled around the proliferating categories of corporeal vulnerability, somatic suffering and genetic risk and susceptibility. They propose that biosocial collectives, formed around a biological conception of a shared identity, have a long history, which is linked to the medical activism of those who refused the status of mere 'patients' by seeking specialised scientific and medical knowledge of their condition and campaigning for better treatment or ending stigma (2005: 442). Rose and Novas propose the campaigning groups that arose around AIDS, particularly in the English-speaking world, as the templates for those forms of activism and collectives. It was through their identification as members of this community that those in 'high-risk' groups were recruited to take on responsibility as biological citizens, such as promoting and adhering to messages of safe(r) sex[17].

Adherence and the responsible patient

While arguments have been made for the significance of the involvement of gay men in the processes of democratisation of HIV care, other literature emphasises the role of biomedical discourses and practices in the emergence of a particular category of patienthood, one that remains concerned with the behaviours of individual patients and their ability to co-operate with physicians' recommendations. Traditionally, social scientific research into the problem of non-adherence, which first proliferated in the 1970s, focused on individual personality characteristics, such as: disliking the side effects of the drugs; having an unco-operative personality; being

[17] For a discussion on safer sex practices see Kippax and Race (2003).

unable to understand the physician's instructions; or lacking in motivation (Conrad 1985; Rosenstock 1974; Stimson 1974; Svarstad 1986). Although subsequent sociological research pointed to the importance of social and contextual constraints as supporting explanations for patients choosing not to follow medical instructions, non-adherence has often been investigated at the individual level, focusing exclusively on the patient or drawing attention to the potential impact of the healthcare provider role in patient behaviours and perceptions, despite the fact that employing conceptual ideal types of patients and doctors offers little contribution towards explaining how the processes of adherence and non-adherence might be done in lived practice (Lutfey 2005: 423-424).

Scholarly work exploring how biomedicine participates in the production of a patient that is considered individually responsible for failing his/her treatment, have been rooted in scholarship that acknowledges the relational nature of biomedicine and social processes. For example, Suzanne Fraser and Kate Seear's (2011) social account of hepatitis C, highlights the politicised role of medicine in (re)creating failed citizens. In *Making Disease, Making Citizens*, Fraser and Seear argue that treatment performs its subjects in familiar, often normative, ways by producing them as *ordered* and/or *chaotic*, as *successful* and/or *failed* (Fraser & Seear 2011: 111). For instance, overviews of hepatitis C treatment produce a specific order and shut down the possibility that things might be otherwise. In this sense, Fraser and Seear suggest that they create *'the centre'* and situate its relations to *'the periphery'* (2011: 112). Simultaneously, what counts as a centre and what counts as a periphery in hepatitis C treatment is moveable and constantly changing. Furthermore, Fraser and Seear argue that how these shifts occur, is always and inherently political. One example of this is found in the centrality of medicine to agency at times when treatment is successful and its retreat to the periphery when treatment fails – or, more precisely, 'the subject fails the treatment' (2011: 136). Fraser and Seear insist that as these movements are political, every shift equates to a politicisation of both medicine and the subject. Furthermore, medicine reproduces its subjects in ways that are already

familiar to us, by performing them as *chaotic* and *unstable* or *failing* and, at the same time, it produces itself as heroic and transformative. Consequently, it valorises certain subjective positions while making others less valuable and valid (2011: 137). The exploration of biomedical discourses around patienthood points to a certain politicisation of the user of medical technologies. This is an intriguing argument that may appear to contrast with the processes of democratisation of healthcare that I referred to earlier and, therefore, highlights the complexity that needs to be taken into account in the discussion of a patient's relation to medicine.

The responsible HIV patient

Research in HIV has suggested that the management of ART has been defined in large part by the responsibility resting with patients to engage with available medical technologies in the most efficient way (Race 2001; Rosengarten 2012, 2004). Although it has been noted more universally that the development of novel forms of biosociality and biological citizenship, such as medical self-help groups, have assigned to patients a greater responsibility for their well-being (Rose 2006: 20), it has been proposed that it is the specificity of the diagnostic tools employed in HIV diagnosis and treatment that allows for the emergence of an HIV patient who bears the responsibility for his own health. For example, Paul Flowers (2001) argues that the development of HIV antibody testing created a situation where 'each and every other body could be distinguished as a potential reservoir of infection'. In other words, the new technology had the potential to create a new typology – the untested, HIV-negative, HIV-positive – in which testing positive necessitated the greatest responsibility of risk management and, by introducing such division, it could divide the solidarity of gay men (Flowers 2001).

While the primary task of the viral load test is to measure the rate of viral replication in the peripheral blood of HIV-positive bodies (Bartlett & Finkbeiner 2007), the test also informs the extent to which a patient has followed the ART regimen and how likely an individual is to transmit the

virus[18]. Race (2001) argues that through this knowledge production, the viral load is capable of 'linking matters of sex and infectivity, lifestyle and medication adherence, and prognosis'. As the virus remains present in the body, its suppression – achieved through ART – may mean there's a possibility of returning to one's 'normal' life and creates the possibility of unprotected sex, as undetectable viral load is linked to infectivity[19]. Determining if the patient's viral load is undetectable is not the sole function of the test. Race suggests that in the clinic, viral load is believed to establish the 'truth' about a patient's state of health. Furthermore, this 'truth' may be in contrast to individuals' experiences and self-knowledge which may be seen as not accurate enough. Race proposes that the viral load test serves also as a tool for monitoring a patient's ability and/or will to adhere to the treatment. Consequently, replication of viral load is seen as a failure not only of the treatment but also of the patient who cannot or does not want to adhere. As such, the viral load test generates moralistic emotions around HIV treatments and carries the risk of patients being or feeling blamed for their ineffectiveness (Race 2001: 168). Subsequently, the HIV-positive individual emerges as the 'natural delegate of risk

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[18] Adherence to the treatment appears of great importance, as missing doses of drugs contributes to the development of viral resistance which indicates treatment failure and the necessity of altering ART. However, there are a limited number of combination options and the more treatment experienced one is, the fewer the options available (HIV i-Base 2013). In the contemporary HIV epidemic, antiretroviral treatments are increasingly considered so effective at viral suppression that they render people with HIV sexually non-infectious. Firstly, HTPN 052 trial results published in 2011 showed a remarkable reduction of 96% of transmission from the HIV-infected partner to the uninfected partner in couples who initiated ART very early after infection. The results encouraged the idea of using the treatment as prevention more widely than just to prevent mother-to-child transmission. It is noteworthy that the treatment guidelines published by WHO in July 2013 raised the treatment threshold (World Health Organization 2013). In 2014, initial results of the PARTNER study have also suggested that treatment as prevention works on someone with an undetectable viral load – gay or heterosexual – transmitting HIV in the first two years of the study (Collins 2014).

[19] Although results of the PARTNER study are extremely positive, pointing to the success of using HIV treatments as prevention, these results are not communicated to prove that it is safe to have sex without a condom when viral load is undetectable. It is believed that there are other factors affecting risk, including genetic predisposition to HIV infection and STIs (sexually transmitted infections) which could both make risks higher on an individual rather than a population-based level (Collins 2014).

management' responsible for adhering to ART, attending the clinic, monitoring levels of the virus in the blood and remaining undetectable and not infectious (2001: 179). In sum, Race reveals how the technologies of ART have led to the emergence of a very specific delegate of risk management: a patient whose adherence to the treatments can be monitored very closely by technologies believed to offer a better understanding of how effective the treatments are than the patient's self-knowledge and experiences. Race's account also suggests that HIV care emerges in an environment charged with responsibility and blame.

The inclusion of biomedical technologies in the sociological analysis of illness and medical care has challenged more traditional accounts of patients' non-adherence, understood in terms of individual personality characteristics, where blame was assigned in producing deviant behaviour in patients. Rosengarten (2012) argues that, in light of strong biomedical narratives, a user of medical technologies is always assessed according to whether he or she makes good use out of what is offered. In the context of HIV prevention, any failure is ascribed to a user's deficiency in the knowledge or understanding necessary for adopting safe practices, asymmetries in power and lack of access to services that help mitigate unsafe practices, for example: housing; food; education; safe forms of employment without discrimination; or a user's deficiency in taking responsibility causing her or him to be unable to act safely (Rosengarten 2012). In the case of HIV care, Rosengarten (2009) suggests that the lack of adherence that may cause viral resistance in a body is seen as the patient's failure when patients, knowledge, HIV and ART are imagined as stable and distinct. Yet, Rosengarten argues that as the practices involved in ART appear to be rarely straightforward, the adherence of the subjects of HIV care needs to be discussed in a way that encompasses the difficulties emerging from the features of medical technologies. Only then can we imagine a relation between patients' adherence and the difficulties of fitting dosing times into a schedule without disclosing one's seropositive status to those who may potentially stigmatise the patient, or between adherence and the size of medication which, if too large, may cause

difficulties in swallowing to the point of gagging or vomiting (Rosengarten 2009: 29-30). In other words, it can be suggested that HIV, patients, biomedical technologies and the knowledge they generate, are neither stable nor distinct. Rather, the technologies implicated in ART and the narratives they produce reconfigure the objectives of HIV treatment and care which, in turn, alter the subjectivities of patients and healthcare providers. In this process, a patient is conceived through measures generated by diagnostic tests and emerges as the *'delegate of risk management'*, responsible for making good use of the treatment and care that is offered. In other words, the emergence of HIV as a chronic condition requires a responsible patient.

To sum up, the literature on HIV specialist healthcare identifies a number of tensions in the way the HIV patient is conceptualised. On the one hand, gay men's engagement with biomedical developments at the beginning of the epidemic supported the processes of democratisation of relations between scientist insiders and those who initially occupied the position of lay outsiders. A more democratic model of healthcare was encouraged by, for example, including voices coming from communities of gay men in the rethinking of prevention technologies. Literature exploring the process of democratisation emphasises the role of gay communities and the role their assertiveness played in it, particularly, in the early years of the AIDS crisis. On the other hand, literature looking at the biomedical technologies implemented in HIV treatments has drawn attention to the responsibilisation of individuals and the individualisation of HIV treatment and care. It has been argued that, in light of strong biomedical narratives, a user of medical technologies tends to be assessed as an individual solely responsible for any potential failures of the treatments. The medicalisation of the epidemic that came with the development of effective biomedical treatments has led to the emergence of a responsible and disciplined patient, challenging the efforts of building a more democratic model of healthcare. Or, to put it differently, patient engagement, identified as a reason behind the victories in speeding up the drug approval of the life-saving medication, is now seen as a necessary element of biomedical

responsibility that is performed through adherence to ART and reducing the risks of other illnesses.

Yet, it would be reductive to see communities of gay men living with HIV as merely subjected to the practices and discourses of medicine. I began this chapter with a quote by Watney (2000), who describes a strong sense of solidarity among gay AIDS workers facing an outbreak of the epidemic, which became a motivating force to mobilise their actions against the crisis – to engage with the epidemiological knowledge and act on it to reduce the number of new infections and support those who were living with HIV. In other words, strengthened solidarity and assertiveness among gay communities were central to the first responses to the crisis. Further, it has been argued here that the sexuality of gay men, openly expressed, was crucial to AIDS activism. Sexual expression became a political act of protest against equating homosexuality with AIDS (Gould 2009) and eroticised strategies of promoting safer sex practices contributed towards generating positive feelings about identity and community (King 1993).

Conclusion

In order to provide context for later analysis, the literature reviewed in this chapter has foregrounded the significance of gay sexuality and the strategies centred around it that helped to build activism, challenged policies born out of normative and medicalised understandings of the epidemic and formed a community which could provide a safe haven for those facing the homophobic sentiments and stigma surrounding HIV and AIDS. I continue to argue for the importance of putting sexuality at the centre when we discuss aspects of the HIV epidemic. I consider approaching sexuality as a site of embodied politics and creativity crucial to the affected communities to be ethically and politically imperative for two reasons. It allows the researcher to partake in contesting normative and stigmatising discourses around the epidemic, which, as shown in this chapter, are often translated into policies regarding HIV prevention and treatment. Furthermore, the consequence of this mode of thinking about

gay sexuality, sexual practices and pleasures, is that it provides a way to conceive a potentially different understanding of the processes of care – one that reveals how non-judgmental and non-moralising doctor-patient relations form and how more democratic healthcare is achieved.

Furthermore, relying on understanding gay sexuality as an embodied site of politics draws attention to how those politics have formed throughout the epidemic. In other words, the politics of gay sexuality are historical phenomena, while potentially remaining meaningful in contemporary HIV care. Again, approaching the past as continuously re-imagined and potentially significant for how HIV care is being delivered and negotiated goes against the narratives focusing exclusively on the successes of anti-HIV treatments in managing the infection. In the following chapters, I ask how the strategies and values that were deemed meaningful and essential during the years of early AIDS activism are being renegotiated following the changes in the objectives of HIV care that are characterised by the responsibilisation of the individual patient for the success or failure of the treatments. In doing so, I explore the complex relationship between the past and the present. Rather than viewing the process of the individualisation of responsibilisation of an HIV patient merely in contradiction to the *'vibrant past'* of the early responses to the AIDS crisis, I ask about the potential continuities and disruptions that may result from them.

Chapter Three. Negotiating the social and the medical

In this chapter, I build a methodological approach to researching HIV care. While doing so, I will consider two main questions: what happens when a sociologist enters a medical setting and how can a sociologist research medical spaces and medical care? While proposing answers to these questions, I discuss the ethnographic approach to research taken in this thesis and present my enquiry into HIV healthcare as a case study.

This thesis has set out to investigate how HIV care is being delivered and negotiated in an outpatient specialist clinic. It offers an alternative angle to scientific medical expertise and epidemiological research that invests effort in ensuring that patients are satisfactorily and adequately engaged through a process of care engagements, from diagnosis to retention in treatment. Rather than defining and assessing HIV care in relation to the benchmark of viral suppression, as encouraged by the remedicalisation of the epidemic (Paparini & Rhodes 2016), this work seeks to discover more about how long-term survivors of the epidemic and their doctors negotiate processes of care.

In my research, I draw on ethnographic observations and semi-structured, in-depth interviews conducted with patients and healthcare professionals in a London outpatient HIV specialist clinic. In this chapter, I will reflect on how I developed this particular ethnographic approach and how it has informed my perspective on HIV care. I begin with an outline of the differences between various ethnographic approaches to data gathering and analysis within the social sciences, and a discussion about the usefulness of selected perspectives for conducting sociological research in a medical space. I offer an account of how the data for the thesis was gathered, noting how my theoretical commitments informed this process and the design of the interviews and later analysis. In the subsequent section, I discuss different understandings of interventions that social researchers form in the fields they study. I consider my position in relation

to the field and in the much wider debate about the relationship between the disciplines of the social and the medical sciences. Lastly, I discuss some of the assumptions embedded in the process of gaining ethical approval.

Negotiating the relationship between the disciplines of the social and the medical sciences

The process of acquiring access to the research site as well as conducting the research required me to negotiate challenges emerging from the meeting of the sociological and medical disciplines. This realisation came to me during one of my first meetings with Mark, with whom I negotiated access to the research site. As soon as we sat down, Mark asked me what it was that I specifically wanted to find out through my research. I admitted that I did not know yet but would appreciate it if he let me observe him during his work as an HIV consultant. I said I was hoping to find out what was significant for sociological research on HIV through my observations. I knew immediately that Mark was not satisfied with the answer I offered, and that he viewed it as an indication that I had not done sufficient preparation. Working in medical research, Mark might not have realised that the lack of hypothesis is part of a specific methodology embedded in ethnography (Denzin & Lincoln 1994). After leaving Mark's office that day, I wondered how the differences in our approaches to research would affect our working in the same space (Field Notes 15th October 2012). This anecdote can be seen as a snapshot of my relations with Mark: we are both motivated by a shared will to contribute to the field of HIV, but, coming from different perspectives rooted in two differing disciplines, we may have conflicting understandings of how to achieve such an ambition. It also provoked me to consider how I emerged as a certain agent in relation to the field and the wider debate about the relationship between the social and medical disciplines.

While for Mark, the fact that I didn't know what it was that I wanted to find out about HIV care seemed to be problematic, letting researchers refine

their initial interest or allowing it be transformed and enabling new questions to emerge from observations done in the field are the most important characteristics of an ethnography (Atkinson & Hammersley 2007). Permitting yourself to be influenced by the observed environment and interviewees is also, as I have learnt in my research process, a skill that requires the researcher to be patient and daring. I say that it requires being daring, because taking time to observe, without rushing to conclusions that fit with the literature that I read prior to the research, felt like taking a risk in relation to meeting the deadline set by the funding body. Doing ethnography demanded that I use the knowledge from other research done in the broader fields of HIV and medicine as a reference that could be challenged or abandoned at any time, as ethnographic research is interested in discovering new phenomena, gaining a better insight and seeking new interpretations rather than hypothesis testing (Denzin & Lincoln 1994). I treat Mark's lack of appreciation for an ethnographic approach as a manifestation of the tensions between sociological and medical research frameworks. In this chapter, I continue to identify and highlight those tensions after giving a more detailed explanation of what defines ethnography.

Ethnography: intricacies implicated in the definition

There have been significant differences in styles of data collection and analysis among sociologists who practice ethnography, and in this chapter, I draw attention to several of them. Yet, it can be argued that, in general terms, beginning with the work of The Chicago School in the first half of the twentieth century, ethnographers have been concerned with the relations between patterns of life and the environment in which people live (Hamersley & Atkinson 2007: 2). Some of the differences among ethnographers have been associated with the theoretical approaches they employ, as manifested in, for instance, the importance they attribute to the material and discursive components of data.

It has been largely accepted that ethnography does not have a 'standard, well-defined meaning' due to its complex history – it emerged originally from nineteenth-century anthropology – as well as its multidisciplinary character, since ethnography is now used in other disciplines such as psychology, geography and sociology, among others. Ethnography's multidisciplinary character and the fact that it has been influenced by a range of theoretical ideas have led to an ongoing reinterpretation and recontexualisation of its meaning (Hamersley & Atkinson 2007:2). However, the uncertainty of the definition of ethnography does not undermine its value as an approach, and considering the practicalities shared by those conducting ethnographic research it may bring us closer to what we, as ethnographers, do.

Providing an overview of most commonly recognised characteristics of ethnographic research, Atkinson and Hammersley (2007) focus on what sorts of data ethnographers collect and how they go about collecting it, what kind of analysis they deploy to handle that data and how theoretical ideas inform ethnographic practice. They continue by outlining features that most ethnographic work follows. First of all, Atkinson and Hammersley state that research takes place 'in the field', which means that people's actions and accounts are studied in everyday contexts rather than under conditions created by the researcher, such as highly structured interview situations. Secondly, data is gathered from a range of sources, but participant observation and/or conversations usually remain the main ones. Thirdly, data collection tends to be unstructured. It does not involve following a fixed and detailed research design specified at the start. The categories that are used for interpreting what people say or do are not built into the data collection process, observation schedules and questionnaires. Rather, as Atkinson and Hammersley argue, they are generated out of the process of data analysis. Moreover, the focus of ethnographic research rests on a few cases, which are generally fairly small scale – perhaps a single setting or group of people. Such conditions facilitate in-depth study. In addition, the analysis of data is understood as an interpretation of the meanings, functions and consequences of those

being studied, and how these are implicated in local as well as wider contexts. Finally, Atkinson and Hammersley propose that in an ethnographic practice it is expected that the initial interests and questions that motivated the research will be refined or transformed over the course of the research. In other words, research focus emerges from observation done in the field (Hamersley & Atkinson 2007: 3). Similarly, decisions about whom to interview, when and where, may be developed over time and the interviewing process typically has a relatively unstructured form (2007: 4). Margaret Diane LeCompte and Jean J. Schensul describe the process of conducting ethnographic research:

> However they begin the process, all ethnographers begin to collect, analyse, and interpret data with their first steps into the field, their first set of field notes and experiences, and the first set of guesses, hunches, or hypotheses they formulate about the phenomenon under study. Some of this kind of analysis is rather informal, but however it is done, the process continues recursively until a fully developed and well-supported interpretation of the entire cultural scene emerges, ready to be communicated to others. (LeCompte & Shensul 2010: 199)

To put it differently, in ethnographic research, the processes of collecting data and generating analysis are intertwined. Further, the unpredictability of the field means that apart from the straightforward following up of leads emerging from the field, ethnographic research may involve adapting to unforeseen contingencies and often redesigning research as a result (Crang & Cook 2007: 131).

Ethnography: stages of the fieldwork

As I pointed out earlier, ethnography takes place ‘in the field’ and data is gathered from a range of sources (Atkinson & Hammersley 2007). In practice, my ethnographic observation of an HIV outpatient clinic involved ensuring that I was present there whenever Mark was seeing his patients. I sat in the waiting areas where I would take notes of observed events and

sometimes have casual conversations with medical staff and patients. I was also present during consultations conducted by Mark and his colleagues when patients agreed. In addition, I attended one of the meetings the clinic organised to facilitate an open discussion between the staff of the clinic and patients. During the months of my ethnography, I made sure that I was up to date with developments in HIV treatments and research trials run by the clinic and that I read the materials on health issues available in the waiting area of the clinic.

It is advised that ethnographic fieldwork is done over a number of subsequent stages. Alan Barnard and Jonathan Spencer (2010) unpack the complexities embedded in the process of starting ethnographic fieldwork:

> As this initial stage of the ethnographic process develops, the fieldworker must constantly make decisions about where to be, whom to listen to, what events to follow, and what safely to ignore and leave out. These decisions are guided both by the significant theories prefiguring fieldwork, and by the theories of significance that arise in the field. These latter theories (hunches, hypotheses, ideas about connections and relationships) emerge as participant observation and listening to speech in action proceeds. They suggest what people and activities to focus upon, what places and events to attend, and what objects and their circulation to follow. (Barnard & Spencer 2010: 247)

Barnard and Spencer see the initial stage as nearly all-encompassing and serving the purpose of sharpening the aims of the research, crystallising the research design and finding out what is most interesting and significant to us and to the knowledge production. An important part of the ethnographic process, Barnard and Spencer continue, is taking field notes of observed events, objects and participants, their movements, associations and exchanges. The other side of ethnographic work involves

what Barnard and Spencer call ‘speech events’ in which the ethnographer may be a passive or an active participant. There are a number of identified speech events that are employed by ethnographers at different stages of their work. First of all, Barnard and Spencer propose, ethnographers engage with situated listening – they place themselves where the research participants are and observe them passively, focusing on using that experience to narrow the scope of the research. Later, researchers may start participating in the activities and conversations they have been witnessing, providing they start this process gently before making their first attempt to direct conversations by introducing questions and suggesting topics (Barnard & Spencer 2010: 247). Barnard and Spencer suggest that interviews with participants should begin no earlier than after a few months of the initial period of fieldwork, as they classify as disruptive speech events:

> Usually after some initial period of fieldwork (a few months perhaps), interviews may begin. This class of speech events is disruptive; the informant is removed from her or his turf, either to the ethnographer’s household or office, or by transforming an everyday location into a scene of ethnographer–informant dialogue (an activity that would otherwise not be occurring there). Typically the earliest of these deliberate breaks in time–place flow reserve topicality for the actor. In such open-ended (or discovery) interviews, the informant moves the conversation according to his or her own interests. (Barnard & Spencer 2010: 248)

Throughout the stage of interviewing participants, the ethnographer gradually begins to assert control over which topics are being introduced and, thus, gains more specific answers. Finally, the production of notes and transcription of interviews allows the ethnographer to move the ethnographic process towards its ultimate written product (Barnard & Spencer 2010: 248).

Barnard and Spencer (2010) provide a guide for social and cultural anthropologists. Despite this thesis being a sociological project, I find it useful for understanding the different stages of becoming familiar with the field. Yet, following Barnard and Spencer's instructions in a meticulous way was not possible, due to the nature of this project. As my research was conducted in an HIV clinic, I was given a limited time of a few months for both the initial stage of fieldwork and the interviews. This meant that I had to begin the interviews very early into my fieldwork. Furthermore, in order to secure patients' comfort and follow ethics guidelines, I did not take notes of patients' conversations in the waiting areas but only during their consultation visits to which I was invited.

Nevertheless, in a similar vein to the commonly recognised characteristics of ethnographic research, my research focus has been largely shaped by the field itself: what happened in the clinic and who agreed to participate in my study. The majority of my interviewees, gay men living with HIV for more than 10 years, belonged to a group that made up the majority of all patients attending the clinic. As a significant proportion of those men were in their 50s or older and long-term survivors, I saw the demographic of the clinic shaping the design of the research, as well as the topics of interest the study pursued, such as the negotiation of memories of the early AIDS crisis. As pointed out earlier, the processes of collecting data and generating analysis are intertwined in ethnography (Crang & Cook 2007). In the process of conducting my fieldwork, I was guided by my observations and the stories my interviewees shared with me that led me to think with new concepts and, particularly in the case of developing interview questions, by my knowledge of HIV research as well as my methodological commitments. Similarly, what I paid attention to and considered noteworthy was based on what I considered to be the object of my enquiry. For instance, my interest in how developments in HIV medicine have impacted the experience of living with HIV or conversations referring to the concept of HIV normalisation was sparked by literature I had read in the process of developing the research proposal. During that time, I was expected to identify the questions and problems I was going to

explore in my thesis and draft a timetable with deliverables. The strict timetable did not allow for gradual and extended time progressing from the initial stages of the fieldwork to interviews (Barnard & Spencer 2010). Thus, it may be concluded that the structures within academia and those imposed by the funding bodies exist in contravention of the rules of an ethnographic study.

Case study of an HIV clinic

This thesis presents a case study of an HIV clinic. Most commonly, a case study has been understood as an 'in-depth study of a single unit (a relatively bounded phenomenon) where the scholar's aim is to elucidate features of a larger class of similar phenomena' (Gerring 2004: 341). Case study methodology, it has been suggested, needs to be understood as a particular way of defining cases, rather than an analytical approach to studied objects or a way of modelling casual relations. As a method of enquiry, case studies often employ ethnography (Gerring 2004: 341-342). An ethnographic approach seems particularly useful, as case studies tend to investigate a process or a complex phenomenon in great depth (Noor 2008). It has been argued that choosing case studies as a method of enquiry allows for an engagement with the complexity of the researched case, which can be an event, an entity or another unit of analysis (Noor 2008; Yin 1989). Case studies focus on the particularities of an object of enquiry and the context within which it exists. They draw on multiple sources, providing an exhaustive and holistic account (Anderson 1993; Noor 2008). Noor argues:

> Case study is not intended as a study of the entire organization. Rather, is intended to focus on a particular issue, feature or unit of analysis. (Noor 2008: 1602)

The above discussion may reveal the tension that seems to arise around the question of the generalisability of a case study – its possibility and necessity. I will explore this in more detail in the sections below.

The aim of the analysis I will offer in the following chapters will be to build

an extensive account of HIV care in NW clinic, especially elements of it that are meaningful to those who identify as gay men and long-term survivors of the epidemic. There are certain attributes that make NW clinic an interesting and valuable site for a case study on HIV healthcare today. As I have mentioned here already, the clinic is attended by many long-term survivors and the healthcare professionals working there often began their medical careers during the early days of the AIDS epidemic. Investigating how care is being negotiated by those particular groups of doctors and patients may provide a better understanding of, for example, what it means to age with HIV – a subject matter that has not yet been widely explored, but is topical (Terrence Higgins Trust 2017). Furthermore, as I will show in Chapter Six, in many cases, a number of patients attending this particular clinic have known their doctors for many years and have often established friendly relationships with them. This means that NW clinic may be seen as a rather unique setting, possibly very different to other medical sites. In this thesis, I will show how what is unique about this specific HIV clinic and its patients offers an interesting and useful vantage point for debates on HIV care – in particular, how they allow for current ways of doing care to be situated within the history of the epidemic.

While case studies have been acknowledged to facilitate in-depth analysis, they have also been assumed by some to be lacking in scientific rigour and reliability. In particular, case studies have been criticised for insufficiently addressing the issue of generalisability (Noor 2008). Yet, such criticism has been countered with the argument that case studies allow generalisations when they can be replicated, meaning that research shows that multiple cases lead to similar findings (Noor 2008: 1603). For example, multiple case studies can be included in the same study when the researcher predicts that similar results will be achieved. It has been suggested that showing consistent findings over multiple cases may be assumed to be a robust finding, enhancing the accuracy, validity and reliability of the results (Yin in Noor 2008: 1604). In addition, it has been emphasised that even though the findings case studies generate may not

be generalisable, their value lies in helping to understand wider phenomena (Bowling 2009: 434). Lauren Berlant (2007) writes that the concept of the case opens up possibilities of thinking about and debating about the ways of negotiating singularity and generalisation in research design. Or, to put it slightly differently, the case study expresses a 'relation of expertise to a desire for shared knowledge'. It generates a form of expertise and an explanation that points to something greater than the case itself (Berlant 2007: 664-665).

Where does this thesis stand in relation to the discussion around the generalisability of case studies and the relationship between the local and the universal? Principally, a generalisation of findings is not the ambition this research is working towards. This thesis explores the specificities of HIV care. For this reason, the question of the generalisability of findings needs to be posed differently. Yet, I wish to argue also that the case study presented here does not have to be replicated in order to enhance its validity or usefulness. Quite the opposite: it is the focus on the geographical and historical context in which HIV care emerges in NW clinic that makes the research presented here useful for debates on HIV care. In Chapter One, I argued that engaging with HIV specialists working in the field of HIV medicine since the outbreak of the AIDS crisis, and with patients who identify as gay and long-term survivors of the epidemic, provides an important vantage point for approaching the debates on HIV care. Often having lived through the AIDS crisis and being the first generation to experience ageing with the HIV infection, long-term survivors occupy a unique position within the epidemic. Consequently, while I wish to avoid making universal and oversimplifying claims about HIV care, I suggest that a case study of how HIV care is delivered to and negotiated by long-term survivors offers insights that can help us to think about various aspects of HIV care and other stigmatising conditions in healthcare – for instance, curable sexually transmitted infections (STIs).

It could be argued that, in its position on the generalisability of findings, this thesis reflects the approaches of critical medical anthropology which

are characterised by an ‘effort to engage and extend the broader political economy of health tradition by marrying it to the microlevel understandings of on-the-ground behavior in local settings and socio-cultural insights’ (Singer 2004: 25). A critical approach to health and illness in medical anthropology, it has been suggested, requires both the scope and concern with the macro level and embedding the analysis in historical and political-economic contexts. This, in turn, allows for the knowledge generated through small-scale research to be extended to broader issues of, for instance, power, control and resistance (Morsy 1996; Singer 2004).

Ethnographic interview

I have already mentioned interviews as one of the tools ethnography uses in its pursuit of gaining knowledge about the researched field. I have also pointed out that interviews conducted as a part of ethnographic research reflect one of the distinctive features of the latter, by having a relatively unstructured form (Atkinson & Hammersley 2007: 4). Furthermore, it has been argued that the recognition of the significance of the accounts that studied subjects produce about themselves and their worlds has been central to ethnographic thinking. However, the meaning of conducting interviews has been interpreted differently over time and across different fields. Differences in view about the methodological function, and importance, of participants’ accounts have been generated by contradictory methodological philosophies and, generally speaking, have been expressed in the tension between approaches to the accounts of the people being studied as sources of information about themselves and the world they live in (Atkinson & Hammersley 2007: 97).

I believe that by making private stories public, researchers bring attention to marginalised stories and communicate their relevance. For that reason, I wish to argue that listening to these stories and bringing them to the readers, is an ethically and politically significant task. In other words, it is important to allow those stories to offer a context within which we can build the analysis of HIV care. Interestingly, my ethnographic practice has

shown that considering HIV care in the context of the epidemic's politics and history allows for a better understanding of the position of healthcare professionals and what constitutes *good* care in the specialist HIV clinic. The question that I had to ask while rethinking the purpose of an ethnographic interview was: how should I approach what my interviewees told me about their lives, the epidemic's history and the care in which they were engaging?

Exploring the complex relations between the data that is being produced, lived experience and biographies, Yasmin Gunaratnam (2009) suggests that what is told and retold is not necessarily lived experience. In other words, narratives are never transparent representations of experience but are shaped by the emotional and the social; they *do* things – they are a form of social action. Gunaratnam uses the example of 'thinking positive' as a narrative that has a function and consequences when it serves to minimise the interactional impact of difficult experiences and emotions, allowing the speaker to share their problems without the listener feeling a burden (Gunaratnam 2009: 56-57). While the accuracy of the stories in reflecting a speaker's lived experience is not the researcher's interest, Gunaratnam suggests that we can benefit from finding variations between the stories we collect. Gunaratnam argues that once there is sufficient information about why the variations occur, it is possible to start reading the different stories and to treat them individually. And, consequently, we can build an analytic understanding of a single story in its wider context. All in all, the process aims not so much at producing definitive answers, as refining the research methods and questions, connecting the particular to more general knowledge and bringing them closer to the unintelligible.

In light of Gunaratnam's theory of the relation between the data that is being produced, lived experience and biographies, an interviewer gains a specific position in the process of interviewing. He or she does not seek access to the experience of his or her participants, but rather seeks to understand the meanings of collected stories in a wider context (Gunaratnam 2009: 48). Gunaratnam writes:

> One of the most challenging, but vital skills for a narrative researcher/midwife is to 'go with the flow'; to allow the gestalt to emerge in its own way – and without interruptions – no matter how incoherent or 'off the point' certain accounts can feel. (Gunaratnam 2009: 50)

While acknowledging the importance of not interrupting the story being told, Gunaratnam sees an interviewer as playing a significant role in the process. She compares the role of the researcher to being a midwife, whose attentiveness skilfully helps or coaxes a narrative into the world by encouraging and supporting a deeper recall and 'being-there' experience (2009: 49). In other words, Gunaratnam suggests that an interviewer is not responsible for remaining in control of what is being said during the interview, but rather only for supporting interviewees who bring their narratives into being. Such a technique is feasible if the research does not aim at producing definite answers, but rather allows us to connect particular stories to more general knowledge while accepting incoherencies. Gunaratnam suggests later that our analysis should not 'drive towards the cleaning-up and pulling together impulses' in seeking out the unifying narrative. Instead of producing narrative coherence, we need to learn to work with its incompleteness and mysteries. Gunaratnam concludes that while 'not many of us would want practitioners who, full of angst about preserving multiplicity, avoid interpretation and become lost in our narrative complexity', the drive towards producing narrative coherence is no longer necessary. Instead, developments in narrative medicine are offering guidance on how to work with, rather than against, the incompleteness and the unknown of narrative experience (2009: 58).

Throughout the study, I interviewed 25 patients, 22 of whom can be described as long-term survivors. I also conducted interviews with 9 healthcare professionals. The average length of each interview was one hour. Interviews would take place in the clinic or outside, in a place designated by the patient to ensure his comfort. Firstly, I asked interviewed patients when they had been diagnosed with HIV. Their

answers allowed me to determine when the person was diagnosed with HIV. This information gave me an idea about their possible medical history, the context of their HIV diagnosis (as an untreatable condition before 1996 or a chronic illness after the introduction of ART[20]), as well as potential medications and side effects attributed to earlier or more advanced ART. Such knowledge ensured that I asked appropriate questions about their experiences with HIV care and remained sensitive to problems they might have been facing. Furthermore, I enquired about their journey of learning how to live with HIV and ART, and how to cope with side effects and other problems resulting from being HIV positive. Questions I asked during interviews with doctors and nurses mirrored questions I prepared for the patients. When interviewing the medical staff of NW clinic, I asked them when they had started working with HIV-positive people and how their practices had changed since then. I asked them how they had been keeping up with the developments in biomedicine and encouraged them to elaborate on ways in which they practiced care. For example, I enquired how decisions regarding changes in treatment regimens were made or how they dealt with low adherence or a patient's refusal to take the medications. In the case of both groups, questions were altered according to what I had learnt from observations and conversations that had happened prior to the interview.

The design of my interview questions may appear as imposing an order on the events and experiences that patients talked about. The questions I asked sought to organise issues and life events chronologically or according to different themes. Yet, looking at routines implied in HIV care

[20] I am aware that this statement oversimplifies the complex history of the HIV epidemic and of the development of HIV medicine. I use it here to illustrate the ways in which I was building an understanding of the stories which patients shared with me. As I explained in Chapter Two, AIDS started to become perceived as a 'chronic, long-term disease, capable of "treatment"' in the late 1980s when the focus on fears of dying from the infection was increasingly shifted to the issue of how to manage living with AIDS. This was due to the use of AZT (zidovudine, Retrovir) in palliative care and potentially even preventing the appearance of the full syndrome in those living with HIV (Berridge 1996: 182). On the other hand, in the clinic I also met patients who, even though they were diagnosed with HIV after the effective ART became a standard HIV treatment, carried vivid memories of the AIDS crisis and might have experienced the death of their friends and partners during the early years of the epidemic.

often exposed their ‘messiness’ and lack of coherence. Employing a methodology that does not seek to build a coherent, single narrative but to show all the inconsistencies and approach them as analytically significant, as explained above, my attention was frequently drawn to the ways in which the routines were broken when, for instance, patients missed their appointments or stopped the treatment. I was also exposed to the ways standardised patterns of care were being adapted to the needs of particular patients. Through our conversations, I found out about patients’ medical histories and prognoses, future plans and how their experiences of living with HIV had altered over the years. In this way, I attempted to extend accessible data beyond the contained space of the clinic at that specific moment in time. I argued in the previous sections that it is not necessarily beneficial to interpret what is told and retold in an interview as biographical individual stories but that instead, research can use them to build an analytical understanding of their wider context (Gunaratnam 2009). While the biographical stories I was told by the participants were expectedly located in specific periods of the history of the epidemic, I chose not to focus on the individual accounts, but used recorded narratives to think, for example, about how memories of the early AIDS crisis were featured in HIV care. Furthermore, the history of the epidemic provided me with the context in which I could understand elements of care in the clinic that occurred outside or at the margins of what is required by biomedical regimens.

Considering the past: history vs memory

Immersed in the analysis of narratives I collected through my interviews, I recalled a discussion that took place during one of the panels at the *2nd International Conference for the Social Sciences and Humanities in HIV* held in Paris in July 2013. In particular, I remembered two contrasting points that were raised by different social scientists working in the epidemic. One was a suggestion of the enduring value in looking back at the events of the AIDS crisis. The other point was an argument that there is not enough emphasis on current processes and the anticipation of

future developments. Being in the clinic, I often thought about the conflict between these two approaches to researching HIV: one that celebrates the achievements of the past (both of medicine and of communities affected by the epidemic) and one that asks to forget them, in an attempt to grasp the changing dynamics in the field. Yet, in my own work, I never thought of myself, and hence my research, as being caught between these two articulated focuses. Rather, very early into my fieldwork, the interviews I conducted with healthcare professionals and patients helped me to understand the relevance of the history of the outbreak of the epidemic, the shared memories and the development of HIV treatments. The awareness of the history of the epidemic, particularly its impact on gay communities, was vital in the development of this research. In particular, it was important to me that I familiarised myself with accounts written by gay men, which made me aware of what living through the epidemic meant to them.

The value of engaging with the past of the HIV epidemic was already recognised by Berridge (1996), ten years into the health crisis. Berridge argued then that the impact of the disease could not be assessed without knowing something of its history, as well as its pre-history (Berridge 1996). Berridge engages with the history by documenting the first decade of the epidemic as truthfully as possible, through recollections not yet 'too entrusted with the patinas of justification, mythology, even nostalgia' (1996: 13). Berridge is concerned with the ways in which the AIDS crisis underlined the nature of power in the British state, traditional modes of health policy-making and the input of gay groups and new clinical specialities into the building of an effective response to the epidemic.

Similar to Berridge's engagement with the history of the epidemic, I have invested effort into knowing the history of HIV/AIDS activism and the development of anti-HIV treatments and relate that knowledge to the understanding of HIV care today. On the other hand, while Berridge seemed to be occupied with 'hard facts', I was not bothered by the tone of accounts I encountered in the literature and in the clinic. What Berridge

might have identified as discolouration – for example, nostalgia – did not trouble me. Instead, I treated them as indicators of how gay men negotiate their relationships with the past. For that reason, it is perhaps more fitting for me to talk about memories rather than the history of the epidemic. The literature emphasises the situatedness, creativity and social character of memory. For instance, Maurice Halbwachs (1992) proposed the opposition between history and memory by conceiving the former as abstract, totalising and 'dead', and the latter as particular, meaningful and 'lived'. The dichotomy fed debates around the conception of memory as methodologically unregulated and identity-related versus a more 'scientific' perspective which was seemingly neutral and an objective historiography. On the other hand, Astrid Erll (2010) suggests replacing the binary with a notion of different modes of remembering. This approach proceeds from the assumption that the past is never given, but must be continually reconstructed and represented. It acknowledges that memories of past events, both individual and collective, can vary to a great degree and allows for a space for discussion on how events are remembered.

The concept of memory adopted by scholars in the humanities has been understood as contrary to a psychological model of scientific enquiry, which reduces memory to a faculty that is independent of the social order and thus stripped of all political and social implications. Humanities and social science research recognises memory as neither a substrate, in the sense of a remembering subject, nor a central organ of an operating memory, in the sense of a human brain. It pursues the assumption that social memory exclusively exists between subjects and not within them and that its form of existence consists of communication. Also, it has been argued that memory does not serve as storage for past experiences, but rather needs to be thought of as a catalyst for different elements of the past, which can then be combined by the involved person in such a way that it makes sense to them (Welzer 2010). In other words, social (or cultural) memory goes against the tradition of conceiving memory as an archived tradition, which until relatively recently continued to dominate both common-sense and academic understandings of the phenomenon

(Benton 2010). Furthermore, it acknowledges remembering and sharing memories as situated activities that are embedded in specific social and material environments. Consequently, the action of communicating past experiences is not driven by the mere transmission of narratives of the past, but also by a situated reconstruction of those experiences in the present, and depends on the goals and pragmatic needs of the social group engaged in the process (Bietti 2011).

When the argument was made during the conference debate I described above, about privileging the focus on current processes and the anticipation of future developments over looking back at the past AIDS epidemic, my impression was that the past seemed to be framed as fixed and somehow objectively known – it assumed we all referred to the same version of it. On the other hand, engaging with the past of the epidemic through memories allows the creativity of efforts of meaning-making by those who do the remembering to be seen. It creates an opportunity to appreciate how the past, continuously reworked, features in the HIV epidemic today.

Making interventions in the field

It has been argued that throughout the history of ethnographic research, studied objects have conventionally been represented as independent, both from the means by which the researcher gained access to and formed an understanding of them, and from the ways in which they were produced, reproduced and transformed (Cloke *et al.* 2004; Crang & Cook 2007; Duncan 1981). Yet, such a position has been heavily criticised for obscuring how researcher and researched are 'positioned, interconnected and involved in the changing social and cultural relations under study' (Crang & Cook 2007: 8). Consequently, research can be seen as an 'embodied activity' and what we learn from it depends not only on those studied but also on those who conduct the research (Crang & Cook 2007: 9). For this reason, it is always important to recognise that research is always being produced out of social relations that develop not only in the

researched field, but also between researchers and their ‘outside’ life (Clifford 1997; Cook 2001; Crang and Cook 2007; Katz 1994). In the context of this research, I had to acknowledge how my person affected the dynamic of the clinic and what kind of research it allowed. For instance, I could have easily been identified as an outsider by the men I interviewed because of my gender, age and even the fact that I am an immigrant. Throughout the fieldwork, I was wondering if that had an impact on the ways in which they were telling me about their lives. Was I invited to hear particular stories or did they perhaps feel the need to explain or emphasise those parts they might have assumed were unfamiliar to me? I was also wondering how my interests as a researcher or my training were influencing what I was paying attention to in the field.

Typically, the concept of reflexivity guards researchers against assuming their detachment from those they research. A basic definition of reflexivity in social research acknowledges that the orientations of researchers will be shaped by their socio-historical positions, including the values and interests these positions confer upon them. What reflexivity stands for is the rejection of the possibility of social research being carried out in a realm that is insulated from the wider society and from the biography of the researcher, in such a way that its findings can be unaffected by social processes and personal characteristics. Hammersley and Atkinson (2007) explain:

> There is no way in which we can escape the social world in order to study it; nor, fortunately, is that necessary. We cannot avoid relying on ‘common-sense’ knowledge nor, often, can we avoid having an effect on the social phenomena we study… we must work with what knowledge we have, while recognizing that it may be erroneous and subjecting it to systematic inquiry where doubt seems justified. Similarly, instead of treating reactivity merely as a source of bias, we can exploit it. (Hammersley & Atkinson 2007: 15)

In addition, Hammersley and Atkinson emphasise that the production of knowledge by researchers has consequences and, at the very least, the publication of research findings can shape the climate in which political and practical decisions are made, or actions are taken, leading to alterations in the situations under study (Atkinson & Hammersley 2007: 15).

Anim-Addo and Gunaratnam (2012) argue that narratives and stories are shaped by the social and the relationships between the narrator and the listener and, therefore, being a reflexive researcher requires us to investigate how we are a part of the production of narratives. Reflexivity necessitates remaining attentive to our critical stance, to research methods and to knowledge-making practices in order to make explicit how we produce what we come to know (Anim-Addo & Gunaratnam 2012). On the other hand, Law and Urry (2004) suggest that a researcher makes different kinds of intervention to produce different narratives. According to Law and Urry, research methods have effects and make differences. In other words, while social investigation aids bringing into being what it discovers, the presumption of the reality as pre-existing its own discovery loses validity. In fact, Law and Urry propose that reality is continuously being produced and sustained in diverse and contested socio-material interactions. As methods may overlap and interact with one another, multiple worlds become connected. Methodology design is always consequential, as different findings, coming from different intellectual traditions, produce different realities (Law & Urry 2004: 392-393). Law and Urry explain the implications of their argument:

> in some measure that which is socially real is made by, and through, the instruments of social analysis. If this is right, then the political grammar of social investigation undergoes an interesting shift. The issue is not simply how what is out there can be uncovered and brought to light, though this remains an important issue. It is also about what might be made in the relations of investigation,

> what might be brought into being. And indeed, it is about what should be brought into being. (2004: 392)

To put it differently, Law and Urry's proposition about what it is that we do as researcher places new responsibilities on us. What is necessary is the consideration of what realities the current methods of social science help to create or erode.

What I have briefly described here are different ways of conceiving the intervention that social research is capable of – one that gives rise to novel ways of thinking about the studied phenomena and that brings new phenomena into being. In order to pursue the debate on the lack of neutrality of the researcher's presence in the field, we may ask how ethnographers emerge as particular agents in relation to the field's narratives, other actors and the practices they employ. How do we negotiate our own presence and have our subjectivities altered? I began this chapter by suggesting the potential tensions between the disciplines of medicine and social science that arise from differing methodologies of conducting an enquiry, such as the necessity of having a hypothesis prior to the enquiry. In the next section, I begin to explore these tensions and the extent to which they can be argued to have shaped my research, but also I will show how I navigated them: how I found a way around them or even used them to my advantage. In the context of these tensions, I consider what happened when, as a sociologist, I entered the medicalised space of an HIV clinic.

Social enquiry into the medical

Ethnography of the medical and its proposed critical approach to science resonates with a debate about the relationship between social and medical disciplines in HIV research. The debate has given rise to online platforms critically assessing the position of the social sciences and humanities[21]. It

[21] See for example http://somatosphere.net.

has been placed at the heart of international conferences[22] and has featured in journal articles[23] (e.g., Mykhalovskiy & Rosengarten 2009; Nguyen *et al.* 2011). Nguyen and Hardon (2011) called on sociologists and other non-medical professionals to resist the dominance of biomedical understandings of the epidemic. They located the social within the context of today's remedicalised HIV pandemic and argued for the importance of social research for the development of a critical approach to emerging technologies and health policies designed to fight the crisis and their implications for individuals (Nguyen & Hardon 2011). Vinh-Kim Nguyen *et al.* (2011) have pointed to the threat of the remedicalisation of the HIV epidemic as a consequence of findings showing the benefits of using ART for prevention as well as treatment. The authors define remedicalisation as a shift in the battle against HIV and AIDS that signals a return to the early 1980s' view of the epidemic as 'a medical problem best addressed by purely technical, biomedical solutions whose management should be left to biomedical professionals and scientists' (Nguyen *et al.* 2011: 1). According to Nguyen *et al*., the growing emphasis on using treatment as prevention is occurring at the expense of non-medical prevention efforts, such as safe sex education or harm reduction strategies (2011: 1). In short, current reconfigurations of the HIV pandemic may hinder critical social enquiry concerning HIV infection.

On the other hand, there are other ways of conceiving the role of sociologists working in HIV. I was still doing my fieldwork when I heard a talk by Jane Anderson (2014), an HIV consultant physician regarded as a leader in the HIV sector, at the 'New Methodologies for Interdisciplinarity in HIV and Related Health Fields Symposium', who argued for the continuation of the development of social research on HIV. Anderson supported her argument by pointing out that the crisis is not yet over (Anderson 2014) and suggested that an interest in HIV research might

[22] See for example 'Reframing the social dimensions of HIV in a biomedicalised epidemic: the case of treatment as prevention', 5th March 2010 or 'New Methodologies for Interdisciplinarity in HIV and Related Health Fields', 25th June 2014.

[23] For example, Mykhalovskiy & Rosengarten (2009) or Nguyen *et al.* (2011).

only be validated if the epidemic were given the status of a medical crisis. Today, this would only be possible in the context of financial drought or the unmasking of a new layer of pathology. In other words, when medical solutions become insufficient to control the epidemic and, therefore, require the support of other disciplines. More importantly, what we learn from Anderson's argument is that social research in medicine and those who pursue it are considered in relation to medicine's inability to deal with a health problem. It appears to imply a disciplinary hierarchy, with medicine being superior to other areas of research and intervention. In other words, medicine has to fail first, deepening the health crisis, in order for social scientists to be required to act. Anderson appeared to advocate the position that has been criticised by Judith D. Auerbach (2010). Auerbach asserted that in the context of HIV/AIDS prevention, social research has primarily served as an adjunct or handmaiden to clinical trials. Auerbach writes that the main purpose of social science research in HIV has been to explain the likelihood that study participants in the first case, and the larger population afterwards, will take up a particular prevention tool. Auerbach suggests that while social research is required to assess the efficacy and eventual effectiveness of that tool, it is not allowed to fully investigate the complexity of people's practices in various social contexts. A question that must then be posed here is whether sociological work valued in some situations and under certain circumstances can potentially be conceived as unnecessary in other situations. Further, if sociological research in HIV is discussed as vital/dispensable, can it also be judged according to other criteria – for example, as disruptive or detrimental?

Making interventions and negotiating my position as a researcher

Over the course of my ethnography, I was also required to negotiate my position within the clinic and manage the tensions emerging from the meeting of the two disciplines: sociology and medicine. I have already mentioned the existing tensions between medical and social research on HIV, and the insistence of social scientists to continue efforts to build a

theoretical understanding of the epidemic (Nguyen & Hardon 2011). My experience of conducting an ethnography of an HIV outpatient clinic has suggested that the dynamics emerging from the meeting of the medical and the social and their disciplinary methodological implications have effects on the work of sociologists and the perception of our research.

On different occasions, I felt that my presence in the clinic was perceived as a little disruptive and, on other occasions, potentially supportive. While at the beginning of my fieldwork, I spent a significant amount of time explaining my research to nurses who expressed an interest in my project and stressed that they found it important for building an understanding of the epidemic, at one point I was questioned by one of the nurses who suspected that my research might not guarantee anonymity to the participants and that it might disrupt the work of the clinic. Yet, most of the time I felt that it might have been perceived as insignificant. Remembering Anderson's (2014) argument that an interest in HIV research might only be validated if the epidemic were given the status of a crisis, it could be suggested that the reason my research might have been perceived as insignificant was the fact that – as explained to me by the doctors – today's HIV treatment regimens are seen as straightforward. Even though Mark had known me for a couple of years, he sometimes introduced me to his patients as a psychologist. When I protested, saying I was a sociologist, he replied that *'we'*, psychologists and sociologists, belonged to the same *'psycho-bubble'* (Field Notes 21st July, 2014). In this astounding statement, I recognised myself as belonging to a larger group of agents assisting medical specialists. My guess is that Mark was more used to having psychologists working with him and, in essence, saw disciplinary boundaries among non-scientists as unimportant. Mark's obliviousness to the character of my work made me think that he attributed little significance to my work or my presence in the clinic. Although frustrating, this might have worked to my advantage as it meant that I was allowed to stay in the clinic for as long as I wished to and enquire about anything I found intriguing. After all, since the clinic had few difficulties with ensuring the effective treatment of its patients, sociological work might

have been perceived as unnecessary and the outcomes of my research were not meant to have any impact on the clinic's practice or its position.

On other occasions, my interest and my work were appreciated as potentially having substantial benefits for the HIV field. On my first visit to the clinic following a long break, Robert, a senior research nurse, hugged me and said how good it was to have me back since sociological research was beneficial for the clinic and necessary for learning about patients' experiences (Field Notes 30th June, 2014). Some of the patients I talked to thanked me for my work, stressing that they saw my work as having the potential to influence the ways in which people viewed HIV infection and those living with HIV. In these encounters, I was perceived and related to as a different agent – my work gained value by being imagined as a tool to reach wider audiences. Kelvin, one of the clinic's patients, told me that he hoped I could go 'out there' and 'tell people' that HIV was like any other chronic condition and did not deserve enduring stigmatisation (Field Notes 21st May, 2014). Not being certain how many people would engage with my work or if it would ever be read by healthcare professionals in the clinic, I had to consider whether I was going to fulfil Robert and Kelvin's expectations.

I mentioned earlier that the researcher's presence in the field is never neutral but, as ethnographers, we help to strengthen or erode certain realities. My experience of conducting fieldwork suggested that we also negotiate our own presence and have our subjectivities altered in the process. As a sociologist working in an HIV outpatient clinic, I emerged as an insignificant other or a supportive mediator between the community of people living with HIV and 'the outside world'. In both instances, I belonged partly to the clinic and the community of those involved in 'the work on HIV', while remaining something of an outsider – not a patient and not a medical specialist. The feeling of negotiating boundaries between otherness and belonging became familiar with time. I needed to negotiate those boundaries when one of the nurses questioned my presence in the clinic and I had to argue against his suspicion that I might disturb the

clinic's work. The negotiations also took place during interviews, when my curiosity as an outsider and my empathy as one familiar with the reality of living with HIV had to be sustained in order to ensure the comfort of the patient. On the one hand, I had to reassure interviewees that I was not making any assumptions about how they may find living with HIV. On the other hand, I had to remain aware of the problem they might have been facing and avoid framing questions in ways that could potentially cause upset. For example, I learnt it was important to avoid phrasing questions in a way that could suggest any presumptions about what it meant to be living with HIV. In spite of healthcare professionals and patients using the term 'HIV normalisation', I tried not to include it in my questions to patients as that could give the impression that I expected them to easily manage the infection. At the same time, I also avoided framing questions that could suggest that there was any presumption on my side that patients' lives were disadvantaged because of their HIV status.

I was not only present in the clinic as a social scientist but as someone who could potentially be thought of as an outsider. I wondered if patients I interviewed would see me as an outsider because of my gender or age or, arguably, more so because I did not have a contributory role in the clinic. Prior to my fieldwork, I was apprehensive about how being an outsider was going to affect my ability to recruit men to participate in my study. Surprisingly, from my first day in the clinic, I experienced positive rapport. I observed that patients were motivated by wanting to give back to the clinic by participating in the research or by a desire to share their stories. Consequently, my gender, role, or the fact that I was significantly younger than most of my interviewees, played a lesser role. On three occasions, patients sitting with me in a waiting area of the clinic guessed I was a researcher, explaining that the folders I carried with me gave away the purpose of my presence there. While I did not experience great difficulty in recruiting participants, I have no means of assessing how being an outsider impacted what my interviewees shared with me and how they narrated their stories. It is possible that, seeing me as a young woman, research participants felt they had to offer me a 'background story' and

thus, spent more time on telling me about the history of the early days of the AIDS crisis – something that I might not have remembered myself. For that reason, each time an interviewee started giving me what he perceived as a historical background, I would disclose that I had read about the history of the epidemic. In this way, I was not only building a relationship of trust through showing I had prepared thoroughly prior to my fieldwork but this also ensured that what patients discussed in the interviews was relevant and important to them, rather than serving educational purposes.

When considering the complex negotiations of my presence in the clinic, it was important to think about potential consequences. The pertinent question that then emerges is: what kinds of realities are strengthened by my research and which are eroded as a result? For instance, is it possible that my research practice enforced divisions, to which some of the patients referred, between the social world of the clinic where we shared a non-judgmental and empathetic understanding of living with HIV, and the outside world where this ideal had not been yet met? Does my research potentially reinforce or erode the boundary between the clinic and the 'outside'? Despite the fact that altering those relations was never the aim of my research, I was made to consider it as a potential outcome of the work I was doing. This highlights the unpredictability of the impact that the research may have on the researched worlds. In the following section, I discuss the process of gaining ethical approval and how guidelines on research ethics attempt to imagine the potential (often negative) impact of the research on the researched. Here, I have discussed other possible impacts which were not accounted for in the ethical guidelines.

Research ethics

Among the narratives a researcher encounters and negotiates before and during fieldwork is the issue of ethics. Ethics are meant to ensure that the goal of the research, which is the production of knowledge, is not pursued at all costs. While most ethical issues apply to social research generally, the particular characteristics of ethnography give them a distinctive

emphasis. For instance, in the context of ethnographic work, it is often difficult to meet the principle of informed consent. It is often insisted that people must consent to be researched in an unconstrained way, making their decision on the basis of comprehensive and accurate information about the research. Furthermore, participants should be free to withdraw from the research at any time. Yet, participant observation tends to be carried out by an ethnographer without most, or perhaps even all, of the other participants being aware that research is taking place. What is more, even when the fact that research is being carried out is made explicit, it is not uncommon for participants to quickly forget this once they come to know the ethnographer as a person. It is also rare that ethnographers tell all the people they are studying everything about the research, due to uncertainties resulting from the design of the study; for example, an ethnographer may not fully know what will be involved or/and what the consequences are likely to be. Finally, it is not always apparent what constitutes free consent, as it is unclear whether an attempt to persuade someone to be interviewed or observed constitutes a subtle form of coercion; that is, the judgment depends upon what sorts of arguments are used (Atkinson & Hammersley 2007: 210).

In addition, while ethnographic research has consequences, both for the people studied and for others, it may be considered potentially harmful. For instance, being researched can sometimes create anxiety or worsen it, and where people are already in stressful situations research may be judged unethical on these grounds alone (Atkinson & Hammersley 2007: 213). In the previous chapter, I wrote about the stigma that has surrounded those living with HIV and seen to be at a higher risk of infection (for instance, gay men, sex workers and intravenous drug users) since the beginning of the epidemic. I also argued that discussing living with HIV often involves touching on issues of intimacy. It could be expected that asking patients to share their personal life stories and events could bring forth painful memories and emotions, causing anxiety. In order to minimise the risk of that happening, I agreed with Mark that it was going to be he who would choose the patients for my research and

approach them first. As Mark had been caring for his patients for many years, I relied on his knowledge of their experiences and preferences regarding sharing personal stories. On the other hand, it has been argued that even in the democratised model of HIV healthcare, there are relationships of dependency and structures of hierarchy (Epstein 1996). For this reason, it may be expected that some patients may feel obliged to participate in the research if they are asked to do it by their doctors.

In her discussion about how data collectors are conceived in the debate around ethics, Patricia Kingori (2013) outlines an argument made by Paul Ricoeur who is critical about the almost exclusive focus on what actions are involved in the research and why they are being taken. Ricoeur does not dismiss the value of the *what and why* enquiry approach, but insists that they are insufficient without an understanding of *the who* – who is undertaking the action in question. Ricoeur suggests there is a need to consider the vital nature of the relationship between action and agent in the production of ethical practice and perspectives. From a Ricoeurian position, data collectors are not merely passive recipients of institutional priorities, but their values and how these are practised are integral to our understanding of bioethics in practice. Kingori explains Ricoeur's argument:

> if responding to this need means breaching institutional rules, then individuals will be less concerned with institutional ethics and more interested in the request presented to them. In this way, institutions do not hold complete power over 'the self' – individuals hold power in their everyday practices. He argues that for most individuals, their primary aim is to be 'good', to fulfil their self-esteem. (2013: 363)

According to Ricoeur, being confronted with the needs of the Other has the power to shape the ethical policies of institutions from below. It is in the face-to-face encounter with another person that we become responsible towards the 'Other' and motivated to do good deeds.

Therefore, the good in one situation is not the same good for all encounters (Ricoeur, cited in Kingori 2013: 361-362).

While this suggests the importance of giving sufficient attention to the researcher and his/her encounters with research subjects, processes of gaining ethical approval and informed consent have been dominated by the principle of autonomy. Yet, for data collectors, this principle may not be the most important marker of their ethical practice. There are several questions that emerge from these contradictions. What does this critique offer to the discussion on the ethnography of a medical space? What are the implications of a studied health condition for negotiating the ethical guidelines and practising ethical research? How can we come to a different notion of informed consent that takes into account relationships between different actors present in the field and the context in which they emerge? If we decide to consider the specificities of the researched condition – for example, patients' memories of the time they were diagnosed and their medical history – will we arrive at a more inclusive understanding of the relations between the researcher and the researched?

Negotiating ethics in an HIV clinic

Over the course of my research, I was required to negotiate my position as a sociologist of a medical space in relation to ethical propositions and discourses. Before I could begin my fieldwork, I had to familiarise myself with the British Sociological Association's Statement of Ethical Practice (2002) and the Code of Practice for Research (UK Research Integrity Office 2009) developed by the UK Research Integrity Office and followed by Goldsmiths College. Both documents assist researchers through advising on best practices of collecting, handling and storing of the data and disseminating results. They set standards which are aimed at ensuring confidentiality and security of the participants and their informed consent to taking part in the research. When tackling the topic of

relationships between the research participant and the researcher, the British Sociological Association asserts:

> Sociologists have a responsibility to ensure that the physical, social and psychological well-being of research participants is not adversely affected by the research. They should strive to protect the rights of those they study, their interests, sensitivities and privacy, while recognising the difficulty of balancing potentially conflicting interests. Because sociologists study the relatively powerless as well as those more powerful than themselves, research relationships are frequently characterised by disparities of power and status. Despite this, research relationships should be characterised, whenever possible, by trust and integrity. (British Sociological Association 2002: 5)

In this statement, the relationship between the research participant and the researcher is problematised through pointing to the disparities of power that it carries. The focus on power relations is understandable where the aim is to protect those who are vulnerable. On the other hand, being a solely instructive document, the Statement of Ethical Practice does not explore the elusiveness of those power relations or other aspects of the relationship between the researchers and their research participants. It also leaves the concepts of trust and honesty, as well as the ways in which those emerge in a research setting, unexplored. To some extent, the Goldsmiths ethics form (Goldsmiths, University of London 2017) unpacks the concept of researcher integrity present in the British Sociological Association's statement. It does so by encouraging researchers to anticipate possible ethical concerns that may emerge at different research stages. Undergoing the ethics process at Goldsmiths College required of me that I evaluate potential ethical issues emerging from the design of my research, such as possible adverse consequences on research participants and the use of deception in the recruitment process.

Before I could start my fieldwork, I attended a meeting with the NHS ethics committee during which, based on their interview with me, the committee was meant to decide whether they would grant me access to the research site. The National Research Ethics Service (NRES) describes its mandate as enabling and supporting ethical research in the NHS. Its aim is to protect the rights, safety, dignity and well-being of research participants. During the meeting, I was questioned whether my actions in the HIV outpatient clinic could cause potential harm to patients or disturb the work of medical staff. I was asked: 'Do you really believe that observing waiting areas and consultations is an ethical thing to do?' Members of the committee wanted to know in detail how I was going to approach doctors and patients, how much time I was going to grant them before signing the consent form and where exactly I was going to sit in the waiting area. I left with the impression that the committee took an exclusive interest in what action was going to be taken and why it was necessary. This made me recall Ricoeur's argument, that the 'what' and 'why' enquiry is never sufficient without acknowledging that ethical relations between the researcher and research participants emerge from and are shaped by their face-to-face encounters (Ricoeur, cited in Kingori 2013: 361-362). While the NHS committee's focus was placed on ensuring that I was not going to disrupt the work of the clinic, the process of gaining the ethical approval did not guarantee that I was prepared for the ethical dilemmas I was going to confront during my fieldwork. Yet, this is not an unusual experience among researchers and it has been acknowledged that the ethical difficulties researchers face are often specific and exclusive to their projects and that the universal rules of research ethics may fail researchers in some situations (Blee & Currier 2011: 407).

Later, when I was already conducting the ethnography, I was to experience the tensions between the ethics protocols and the way in which the relations built in the HIV outpatient clinic were formed. These tensions mainly related to or resulted from the unpredictable nature of ethnographic research. In the previous sections, I discussed how certain

characteristics of ethnography, e.g., lack of fixed questions or research focus, lead to difficulties in ensuring that all the people studied by an ethnographer receive comprehensive and accurate information about the study and provide informed consent for their participation (Atkinson & Hammersley 2007: 210). When I agreed with Mark that he would introduce me to patients who were likely to be willing to be interviewed, I began wondering how much of their willingness would result from the feeling of obligation patients may feel towards their doctors. For this reason, I decided that I would make more effort to ensure that patients did not feel they were expected to consent to the research. For instance, I put more emphasis on the fact that they could take as much time as needed to make the decision and they could withdraw their participation at any time with no further consequences. Furthermore, as I have already mentioned, the discussion on ethics is concerned with the fact that being researched can sometimes create anxiety or worsen it and, where people are already in stressful situations, research may be judged unethical on these grounds alone (Atkinson & Hammersley 2007: 213). My practice of interviewing required me to be sensitive to how patients felt about sharing often intimate details of living with HIV, as well as being constantly aware of how they reacted to particular questions. On numerous occasions, I found that the ethical guidelines provided insufficient advice on how to ensure that the patients were not adversely affected by the research and the power disparities embedded in our relations. This is unsurprising, as the richness and the messiness of relations between people – here the researcher and research participants – cannot be described and dealt with in a single guideline. With every encounter I had with a patient, I had to make a decision to continue or to bring the interview to an end when our conversation was evoking feelings of distress, anxiety or sadness. Interviewees' well-being, my integrity as a researcher and our mutual trust were being defined continuously in my encounters with the patients.

Furthermore, some of the assumptions made by the NHS committee were later opposed by Mark, who turned out to hold a contrasting idea about what could potentially cause distress to his patients. For instance, the

NHS committee told me that I should put a sign in the clinic informing patients about the research taking place, while Mark told me I shouldn't, because it would scare patients. When NHS guidelines for researchers consider the potential of research to create anxiety or worsen it, they do little to distinguish between different health conditions and the historical and social context in which care has emerged. Our discussion did not account for issues specific to HIV, such as patients being accustomed to sharing the same space with researchers. On the other hand, the sign proposed by the Committee could potentially disturb the familiar space of the clinic, being something unusual, as suggested by Mark. This particular situation reveals how, in the process of gaining access to the clinic and setting up the study, the ethical was negotiated between what I learnt from the guidelines, what was recommended by the NHS committee and what was suggested by Mark and his long-standing experience of caring for patients. This reflects what has been argued elsewhere: that the good in one situation is not the same good for all encounters (Ricoeur, cited in Kingori 2013: 361-362).

In comparison with other conditions – for instance, acute illnesses – there is a long history of collaboration between social science and those affected by HIV. This was reflected in the fact that patients were often familiar with the steps of the consenting process, patient information sheets and consent forms. A few read the information about the research quickly, and asked: 'Could I sign the consent form?' In these situations, when I felt guided by my interviewees, my position in the clinic was again renegotiated. This led me to conclude that the understanding of *the who* when referring to research participants in the NHS ethical guidelines, requires further discussion. It is not my aim to merely contrast the design of the NHS ethics approval process with what 'really' happened in the clinic, as such an evaluation could imply a far too simplistic assumption that the ethical and the functional exist in opposition. Instead, I wish to explore how ethical issues that emerge during fieldwork arise as a result of standardised regulations, what is thought to be functional, as well as the intuitive work performed by researchers and participants.

Conclusion

The who – research participants – are perhaps overlooked by the standardised definitions of the NHS ethical guidelines, leaving them seemingly passive in the research process. Similarly, within discourses around the epidemic, HIV patients have sometimes been framed as passive recipients of biomedical developments and wider processes that take place in HIV medicine and care. For instance, in the previous chapter, I presented the argument that patients are often seen merely as users of medical technologies who can only be assessed according to whether they make good use out of what is offered (Rosengarten 2012). Here, I have built a methodology that supports such theoretical commitment, through ensuring a wider understanding of the epidemic's history.

I explained in this chapter how doctors and patients possessed dissimilar understandings of what my research could achieve – for instance, generating knowledge about patients' experiences or educating wider audiences about what it means to live with HIV. At the same time, it was through rethinking how to approach HIV care and the stories that my interviewees shared with me, that I started to realise my sociological task: to contribute to research which recognises the unique position of gay men and long-term survivors within the epidemic, and their input into the formation of HIV care. In order to produce an analysis that accounts for that uniqueness, it is necessary to understand patients' voices within a more general knowledge of the epidemic and AIDS activism. Understanding these links allowed me to recognise what may seem to be uninteresting or accidental practices or events as unique and of significance to those in the clinic. Another important step in making '*the who*' matter in the analysis was to avoid attempting to build a single narrative. Gunaratnam (2009) argues that instead of producing narrative coherence, we need to learn to work with its incompleteness and mysteries. Inconsistencies, when approached analytically, provide an opportunity to see the complex contexts in which HIV care happens. In the

following chapters, I will show how multi-voiced accounts of care, understood in the context of the history of the epidemic and the involvement of gay communities in the formation of HIV/AIDS care, enable HIV patients and their physicians to be framed as not merely subjects of medical knowledge and guidelines. Rather, attention is drawn to the ways in which HIV care is negotiated and made to matter beyond its life-saving qualities.

Chapter Four. Camp culture: the uses of humour

The HIV clinic in which this research was conducted differed from medical spaces I was familiar with – such as General Practitioner (GP) services, Accident and Emergency (A&E), genitourinary medicine (GUM) clinics, or other specialist surgeries – in ways I had not anticipated. The first time I wrote field notes after a day spent at NW clinic, I commented on its lively atmosphere. In the following days, I started paying closer attention to the jokes that were exchanged in the corridors of waiting areas and during consultations. Humour seemed to be a consistent part of everyday interactions taking place in the clinic. I remember Mark welcoming an elderly patient who walked with noticeable difficulty by exclaiming: *'Hello young man!'* (Field Notes 1st July, 2014). On another occasion, Jo, a nurse working in the clinic, greeted a patient who arrived in an electric wheelchair: *'Oh, excuse me! We have a new toy!'* (Field Notes 16th July, 2014). At first, the use of humour by the clinic's practitioners suggested to me that health conditions, even if rigorously attended to in the medical sense, can still be treated with a dose of light-heartedness during interactions with patients. The clinic also employed a female volunteer who offered beverages and light snacks to waiting patients. I remember being surprised on my first day in the clinic, when I heard her offering patients, 'tea, coffee, or maybe gin?' Others in the waiting room answered with laughter and smiles that indicated familiarity with the volunteer and her jokes. I was aware that humour is widely used in medical settings and has received sociological attention. In medical settings, humour has been portrayed as supporting staff in dealing and coping with difficult complications, for comforting and reducing anxiety in patients, expressing frustration, relieving tensions, as well as enhancing their work satisfaction (Astedt & Liukkonen 1994; Bottorff et al. 1995; Lieber 1986; Mallet & Ahern 1996; Wender 1996; Yuels & Clair 1995). Humour may allow practitioners and patients to raise taboo topics that would be difficult to discuss in more serious discourse (Emerson 1973). Furthermore, humorous interactions have been recognised in HIV research for their anti-

stigmatising value and their potential to affect local social transformations in the way HIV is perceived (Black 2012). Yet, when I started conducting interviews with patients to collect their stories of living with HIV, I felt that common understandings of the uses of humour in medical care did not capture the character of the jokes and the particular playfulness I was party to. I was intrigued to explore what the humorous interactions, described above, did to the care provided by the HIV clinic specifically. In this chapter, I will show how I began to make sense of the uses of humour I was witnessing in NW clinic.

'I'm so camp!' Humour in self-narrative.

I spent weeks writing field notes in an attempt to understand the significance of the uses of humour I was observing, but it wasn't until I met Dave that I was able to begin to gain insights. Unlike other participants, Dave had not been referred to me by any of the clinicians. Before he approached me in the waiting room, we had seen each other every time I had been in the clinic. As I later learnt, Dave had undergone surgery to remove cancerous cells and had been asked to see a hospital nurse every day for aftercare. Dave caught my attention as I found him to be often tipsy and boisterous. His visits broke the monotony of the everyday. He was often late to his appointments and apologised profusely to the staff every time that happened. If he was too early, he would enquire if he had enough time to go to the pub and grab another beer. To me, Dave's visits felt like comedy acts (Field Notes 15th July, 2014). With time, we began to greet each other and one day Dave started chatting with me about my research. He was happy to sign a consent form but told me he didn't have time to sit down for an hour-long interview. We agreed that I could record audio or take notes of all our conversations. What I discuss here is the result of the many conversations we had over the final two weeks of my fieldwork.

From the beginning, I was interested in the contrast between the style of Dave's storytelling, often filled with jokes, and the difficulties and suffering

he was describing. Living with HIV for 20 years, Dave is a survivor of the AIDS epidemic. Since 1997, he has been battling reoccurring cancer. From our conversations, I learnt that Dave's experiences of homophobia made him deny his sexuality when he was in his twenties and led to his many attempts to reassure himself that he was a heterosexual man. For example, Dave told me that the desire to reassert his heterosexuality was behind his decision to join the British Army – Dave said that he believed that getting involved in activities conventionally associated with masculinity and conservative beliefs about gender roles would help him to 'become straight'. After coming out as homosexual, Dave lived in an abusive long-term relationship that further strained his mental well-being. Eventually, Dave escaped his violent partner and moved from Manchester to London. Soon after, he lost his beloved mother, whom he still seemed to mourn at the time of the interview, six years after her passing. Most of the time Dave told me about events in his life he found painful or distressing. Yet, our conversations were filled with chuckles and laughter loud enough to be heard by everyone sitting in the clinic's waiting room.

One day, Dave told me about a recent suicide attempt. He said that he had only been rescued because he had called an ambulance straight after overdosing on sleeping pills.

> I've tried suicide. Not so long ago actually. I thought I was having a nervous breakdown. But, I think it was more a cry for help. I wasn't getting any support within the community with all these cutbacks. And I don't know… I wasn't drunk. I only had one lager… […] and before I knew it, I had sleeping tablets in a drawer, I don't know… something just came over me […] And my friend Kevin came over: 'What you're doing?' 'Oh, I don't know, I want to get out of here. Get my clothes out of the cupboard'. There was only one sock there; they must've taken me naked. I said, 'You better go home and get me some clothes. And I'm telling you, don't you dare bring my

> clothes in a carrier bag'. I said, 'I have a leather bag. Don't you dare show up here with a carrier bag!' I'm in intensive care and the only thing I was concerned about was him not bringing my clothes in a carrier bag. I'm so camp! (Interview with Dave)

While listening to Dave, I started to come to a realisation that he had shared with me the story of how he tried to take his own life, in a way in which one might tell a funny anecdote. Dave's exaggerated gestures and alternating vocal tones almost created the illusion that I was witnessing a show written for the purpose of mere entertainment. We both laughed as he made his outrage at the possibility of his friend carrying his clothes in an ordinary carrier bag the centre of the story. I say that Dave *almost* created an illusion that the story was an anecdote because I never felt the story might have been untrue or less than horrifying.

After that conversation, 'camp', the term Dave used to describe himself, became one of my keywords for searching for research on the epidemic. I found that camp culture can be traced to the beginning of the eighteenth century when homosexuality emerged as a non-identity – as 'unspeakable' or 'offstage' - and was assigned traits such as arbitrariness, excessiveness and social impotency. Thomas A. King (1994) argues that what was most problematic about newly visible modern male homosexual identity was that it inhabited this 'no-place' within an increasingly normative society (1994: 40). As a consequence, the concept of homosexuality became associated with excessiveness and nothingness simultaneously and the homosexual's flamboyance and narcissism became understood as a compensation for the latter. Importantly, King acknowledges and emphasises the political significance of camp. He sees the potential of camp in numerous ways: it reasserts the primacy of performance beyond the privileging of the real; it allows for understanding gestural practices beyond their rereading as merely or too theatrical; and it rejects the naturalness of psychoanalytic discourses that have inscribed excess and nothingness as the 'content of homosexual psyches' (1994:

46). In short, King demonstrates how, in an increasingly normative society, camp became culturally and politically subversive through the adoption of effeminacy and boastfulness. Camp became a means of challenging and displacing social norms and dominant codes of identity.

By describing himself as 'camp', Dave nudged me towards reviewing a new body of literature and, as a consequence, to a new and clearer understanding of the events I observed in NW clinic and its lively atmosphere. I found the concept of camp as proposed by Halperin (2012), particularly useful when analysing my conversation with Dave. Halperin (2012) offers an account of how camp has been employed in the times of the AIDS crisis. In particular, Halperin is interested in how camp use of humour 'works to drain suffering of the pain that it also does not deny'. When one makes fun of one's own suffering, laughing at situations that are horrifying or tragic does not mean that one does not feel the horror of them; rather, one laughs precisely because of such feelings of horror. It is laughter that suppresses crying and self-pity. Yet, the pain does not cease with the laughter – on the contrary, it becomes sharper and more precise. But now, Halperin continues, pain has an acknowledged place, a specific social and emotional location. Hence, it is no longer incapacitating or isolating. The effect is not to evade the reality of pain, but to transfer it in order to share it and, thus, to cope with it. In this way, Halperin argues, human tragedies such as the HIV/AIDS epidemic could become 'vehicles of parody without the slightest implication of cruelty, distance, or disavowal' (Halperin 2012: 186).

By making fun of his own suffering at, possibly, one of the most terrifying moments in his life, Dave acknowledged and shared his pain and fears, without lapsing into what could be perceived as self-pity. The anecdotal style of his story may have made it easier to share it with me and, therefore, in the process, Dave's pain became less isolating and incapacitating. Before I was able to understand and locate Dave's humour in a broader context, it continued to surprise me, like when Dave laughed while telling me: 'I don't know, I just find the strength to carry on. You have

to, really […] But you can't complain, can you?' (Interview with Dave). The lightness with which Dave spoke about the difficulties he encountered was striking throughout our conversations. This was evident when Dave described to me the time when he was receiving chemotherapy:

> When you're stuck in a proper cancer hospital, it does open your eyes to everything, you know…The children, women with breast cancer, kids with chemo… you just say to yourself, whoa, somewhere somebody is suffering ten times more than what I am. (Interview with Dave)

Dave's words recall what Halperin (2012) identified as a part of the practice of camp: the implication that no tragedy should claim so much worth as to presume unquestionable entitlement to be taken completely seriously in a world where some people's suffering is routinely discounted. Halperin continues:

> Unlike the kind of mockery that fortifies you in an illusory sense of immunity to what other people are going through, that insulates you from their suffering, the sort of trivialization that is involved in this kind of humour is not an exercise in denial. For despite its outrageous impertinence, it has an egalitarian, inclusive thrust: it implies that no tragedy, not even yours, can or should claim so much worth as to presume an unquestionable entitlement to be taken completely seriously—that is, to be taken straight—in a world where some people's sufferings are routinely discounted. (Halperin 2012: 187)

Halperin rests his arguments on what he describes as a gay male perspective, from which *'every thing in the social world is also a performance'*. Halperin continues that, if seriousness is a performance and if seeing something as an act is not to take it seriously, then gay male culture is permitted to convert the serious into the trivial and humorous. We read:

> And indeed, what could possibly be more appropriate, more realistic to take unseriously, to laugh at, than the hostile and unalterable realities of the social world, even or especially when they are horrifying or tragic, when they are matters of life and death – and when they are happening to you? Camp, after all, is 'a form of self-defense'. … If that is what 'trivializing' your own or someone else's feelings means, if it means not taking them literally or unironically, then to trivialize them is hardly to devalue or cheapen them. On the contrary, it is the very mode of claiming them and, if you're lucky surviving in spite of them. (2012: 200)

Halperin explains how camp offers gay men a way of dealing with personal and collective tragedies, one that does not devalue suffering but also refuses to dignify that suffering.

In short, camp humour is inclusive and functions as an expression of solidarity with others who experience pain and suffering. My interview with Dave took place in the HIV clinic, which he compared to 'a proper cancer hospital'. Shifting the focus of our conversation, Dave expressed that he recognised others' experiences with illness as more painful than his own. When I asked Dave about what it felt like to have to manage his own health condition, he emphasised the ways in which he had learnt how to cope with living with HIV and cancer:

> I've always coped with it myself […] OK, you may spend a couple of days feeling sorry for yourself, bit down, don't get me wrong… I deal with the illness, the physical side of it really well. The mental side of it – that's the hardest thing. Going to bed, you know, not being able to sleep. Thoughts going through your head: am I going to wake up in the morning? Or, I just wish, you know… I just wish… It's a long time to be suffering. And you wake up the next day and it's totally different: oh, great day, you know… but

> that's life for everybody. Everybody gets things thrown at them. So, yeah… I think I'm a very lucky man to be here. I wouldn't change anything. No way. I wouldn't change one single thing. And I tell you why. It's because it made me the person I am today. Yeah, it builds you. It builds your character. You become stronger. And at times you think you can't face things. You do. You find inner strength from somewhere. God knows where it comes from but you do […] I come across as strong when I'm out. I do my crying indoors. I cry myself to sleep actually. (Interview with Dave)

Dave shared with me, with equal attention, his feelings of resignation and hopelessness and his resistance to giving in to those feelings. He strongly resisted portraying himself as a victim by stressing that he considered himself 'lucky' and by pointing out the positive outcomes of battling an illness, such as building character. Again, by referring back to Halperin's (2012) account of how camp has been employed by gay men in the times of the epidemic, we can observe how Dave does two, potentially seemingly opposite, things here: he acknowledges the pain he has been going through by suppressing what could be perceived as self-pity. Yet, Halperin argues, the resistance to surrender to victimisation, does not, at any point, erase the pain. Although Dave repeatedly stressed that his suffering was no different, or even sometimes insignificant, when compared with others, the quote above shows us that it was his deteriorating mental health that he found most challenging to cope with.

I had already finished recording Dave's story when one day he asked me if I could accompany him during his consultation with Mark, as he was about to find out if new cancerous cells had been found in his body. He told me he felt scared and would feel reassured if I was there with him. Inside the consultation room, we found out that the most recent scan did not show any cancerous changes and Dave's mood changed rapidly. He jokingly asked Mark: 'I'm not suicidal anymore; can I have some sleeping pills?' He

then exclaimed, pointing at my feet: 'Oh, I like your nails! Pretty!' and insisted that Mark did not notice because, unlike him, he could not 'appreciate a beautiful woman' (Field Notes 15th July, 2014). Being in the consultation room with Dave allowed me to see how he used laughter as a tool to face horrifying situations, how he joked about his suicide attempt and how he made fun of the adopted cultural performance of being a gay man, that might involve exhibiting a lack of appreciation for women's looks.

I mentioned earlier that at the beginning, I was not able to view Dave's humour or the lively atmosphere of NW clinic in a broader context. Reflecting on my research process, I argue here that building a better understanding of my initial observations made in the clinic involved carefully listening to how patients like Dave self-narrated their lives, and identifying and following clues from recorded stories, such as the word 'camp'. It was important for my analysis to engage with a historical perspective on the uses of camp. By doing so, I began to understand patients' uses of humour not as isolated phenomena, but as a part of the culture in which gay men have been engaging in particular ways since the outbreak of the epidemic. Acknowledging camp humour as a strategy of coping with the AIDS crisis brought me closer to the current significance of camp culture. On the other hand, while other theorists look at the uses of camp in non-medical settings, camp became important to me as one of the elements of HIV care employed in NW clinic. What is more, employing the concept of camp as an analytical tool shows the specificity of the kind of humour that I found in NW clinic by relating it to the aesthetic sensibility that is historically anchored in strategic performances of the intersection of sexuality and gender within gay male culture. In this way, it exposes the value of putting gay sexuality at the centre of the discussion about HIV care – how it allows one to build a potentially richer understanding of the role and significance of laughter in an HIV clinic and for gay men living with HIV. In NW clinic, camp humour plays an additional role to those identified by Halperin. It allows for a distancing of oneself from the idea of a responsible patient – one that, as I discussed at length in Chapter Two,

produces an HIV patient as a mere user of medical technologies, who is then assessed according to whether he or she makes good use out of what is offered. In other words, today, camp humour disrupts expectations that follow biomedical narratives by refusing to take anything literally or unironically.

After meeting Dave and undertaking a review of the literature on the culture of camp, I began to recognise camp humour as one of the vital elements of care in which both patients and doctors participate. Camp humour seemed to me to be vital for avoiding any potential victimisation of the HIV patient. Through using camp humour, long-term survivors are able to share their painful experiences or negotiate care following a suicide attempt without occupying the position of a victim with assumed docility. Quite the opposite: the use of camp humour in self-narration reveals the creativity of those who narrate their lives and their refusal to surrender to self-pity. Here, I wish to show how patient's self-narrated stories of living with HIV, understood in the broader context of the epidemic, allowed me to ascertain elements of care that are not necessarily obvious at first, and grasp their meanings and significance for those involved in them.

'How dare you call me normal?!' The use of camp humour against normative standards and self-pity

Returning to Dave once again, our conversations about his mental wellbeing offered an interesting insight into the possibilities offered by camp culture. Following his suicide attempt and persisting mental health issues, Dave was advised to make an appointment with a psychiatrist. Dave continued to amuse me with his sense of humour when telling me about his visit:

> I thought I was going nuts. One minute I will be extremely high and the next minute I'll be extremely low. There's no in between. So I thought maybe I was having a nervous breakdown. Or suffering with bipolar. Or maybe, you don't know, AIDS dementia. But anyway, he came back and

> said I'm not mad. I was really disappointed. Normal?! How dare you call me normal?! He said, 'You need to see a psychologist'. He asked me if I drink. 'No, not at all'. Still stinking of alcohol. (Interview with Dave)

Following the understanding of camp as a cultural performance, I choose to read Dave's expressed disappointment at being called 'normal', not as an expression of dissatisfaction but as possessing a different function. Dave laughed again while telling me this story. His laughter and mock disappointment at being told he did not require psychiatric treatment can be seen as both unexpected and lacking in the kind of seriousness and consideration commonly associated with those discussing mental health issues. On the other hand, the concept of camp humour allows us to see it as a purposeful strategy. Dave's joke, it seemed to me, ridiculed the idea of being 'normal' and the premise of medicine that being diagnosed as 'normal' should be desirable. As stated by Halperin (2012), camp humour constitutes a challenge to normativity. Halperin proposes that camp works against the heterosexual and heteronormative cultural standard, which measures the sincerity of public sentiments by how seriously they are intended to be taken. The purpose of laughing at one's own suffering is to escape being seen as merely pathetic, while at the same time exposing the insistent earnestness of heterosexual theatrics which confuse compulsory social roles with essences and refuse to recognise personal authenticity as a cultural performance. Halperin points out that, when viewed from a mainstream, heteronormative perspective, the tactic of presenting one's own suffering as a performance of suffering can only undercut that suffering's authenticity and its dignity (Halperin 2012: 187-188).

In the story he shared with me, Dave mocked the compulsory social role of a patient who is supposed to appreciate a good prognosis and the assumed desire to be diagnosed as not requiring psychiatric care. At the same time, Dave played with the idea of personal authenticity, offering me what felt like a performance rather than a straightforward answer to my

interview questions. By this, I do not mean to suggest that I felt that the interview lacked honesty. Acknowledging camp as an imaginative and purposeful practice allows us to see that presenting one's suffering as a performance can never undercut that suffering's authenticity and dignity. Furthermore, it appeared to me that every time Dave made fun of his own suffering by turning it into a parody, he anticipated and pre-empted the potential of others to devalue it: such as the psychiatrist who made the assessment, or me, who interviewed him about his painful experiences. As a researcher, drawing attention to the culture of camp allowed me to engage with patients and share their stories without constructing them as victims. The playfulness and humour with which Dave interacted with me brought the imaginative ways he shared his experiences to the forefront of this analysis. But I also found Dave's humour and his 'performance-like' interviews troubling. I remembered the effort it took for me to understand them as significant to Dave as a gay man living with HIV and in the broader context of the strategies that gay men used to cope in the times of the epidemic. It meant that others, those who did not participate in camp culture, might have formed their own and very different understandings of Dave. I have already argued that camp culture has the potential to disrupt the idea of a responsible patient. What I was also wondering about were the risks that came with employing camp culture so visibly to an audience who were not necessarily familiar with the historical and political significance of it. How would they perceive those disruptions?

Camping up HIV treatments

At the beginning of this chapter, I described humorous exchanges between patients and healthcare professionals. I wish to argue that, considering popular narratives around HIV that have historically had a rather moralising character – leaving little space for any humorousness[24] –

[24] As I wrote in Chapter Two, critical research on the epidemic has shown that, within the discourses on HIV prevention, gay men's sexual practices and desires have been framed as problematic and were required to be changed if the epidemic was to be brought under control. Consequently, mainstream prevention strategies focused on behavioural interventions lacked engagement with gay communities and aimed to evoke emotions of fear (see for example, McGrath 1993).

using jokes in the context of the waiting room may be viewed as culturally subversive. While early ACT UP campaigns were known to use humour as a strategy to mobilise the movement and engage the public with their demands (Gould 2009), jokes shared in the confined space of the clinic lack that impact. Rather, they seem to have become a vital part of HIV care. In their everyday lives, patients may also use humour when facing difficulties that come with being on HIV treatment. When I interviewed Nick and Jim, a couple who were both HIV positive and had lived with the infection for over 10 years, they told me about their complex ART regimens. At that time, Nick was taking 12 tablets in the morning, which included anti-HIV drugs, medicines preventing adverse effects of ART and vitamins. His partner disclosed that he often joked that Nick 'rattles when you shake him' (Interview with Nick and Jim). I recognise in this utterance an awareness of having a body or seeing a body that is heavily medicated. That awareness persists, even if HIV does not produce any visible symptoms, drawing attention to the invisible yet significant features of living with HIV. Yet, Jim's joke can also be seen as a way of dealing with the condition and ART regimens that require a lot of planning, dedication and tackling of side effects.

As argued by Race (2009), humour offers a degree of ironic distance from the negative experiences and difficulties resulting from being HIV positive while, simultaneously, being attentive to the embodied specificity of living with the infection – such as, in the case of Nick, having to consume a large number of pills. Race recognises camp as a strategy that provides a way to conceive of a potentially different understanding of the epidemic in the era of ART. In *Pleasure consuming medicine: the queer politics of drugs*, Race (2009) looks at an event entitled the *Wheel of Misfortune,* set up to deliver 'clear and accessible information around [AIDS] treatment side effects'. The event aimed to be an educative intervention, as well as to provide peer support and a good night out filled with camp humour. It was led by Nurse Nancy who, dressed in a crisp, white nurse's uniform, approached members of the audience to participate in her 'community survey'. Race explains that the character of Nurse Nancy was created as

a response to the widespread practice of surveying that had been taking place during gay events in Australia since the early 1990s. It was not uncommon for gay men attending various events to be asked to fill in lengthy questionnaires about the most intimate details of their lives. Nurse Nancy was seen for the first time at dance parties in 1996, administering mock surveys. She was also present at the *Wheel of Misfortune* (2009: 128). Race describes the event as follows:

> At the forum I attended, Nurse Nancy canvassed participants with questions like: 'What are you on tonight?' 'What's your favourite side effect?' 'How are you being 'serviced' locally?' As well as muddling moral distinctions between the licit and the illicit, pleasure and discomfort, this encourages a level of humorous discussion around topics not generally subject of polite social or easy clinical discourse. From the recreational use of drugs, to tensions in local service provision, it creates a zone of permission and encourages a level of impudence among participants that is entirely necessary for contending with the debilitating conditions of privacy produced around HIV-positive experience. (Race 2009: 129-130)

Race draws our attention to the style of the event, derived from the queer cultural practice of camp. Participants at the event used parody and irreverent humour to bring into public consciousness and elaborate on issues around the subjectivity, difficult treatments, embarrassment and isolation of HIV-positive life in ways that often conventional medical narratives do not highlight (2009: 131).

I have written here about the revival of medical reasoning, which distinguishes 'healthy' from 'unhealthy' behaviour, the subsequent individualisation of the interventions taken to manage the epidemic and their harmful impact on those defined as 'deviant'. Here, Race proposes that, in the context of HIV treatments, camp can be understood as a form of active consumption that allows for a re-contextualisation of the

meanings and effects of medical discourse. He ascribes to camp the potential to contest some of the forms of privatisation and individualisation that he sees as inherent in the medical discourses around antiretroviral treatments. Race argues that camp responses can potentially resist medicine's role that contributes to the isolation that can characterise HIV-positive experiences. Camp style also enables articulated responses to topics which are pertinent to HIV care – such as the experience of side effects, recreational drug use or sex – in such a way that they are no longer a matter of illegitimacy (Race 2009: 129). Race argues that camp can potentially place an entertainment value on the incongruity between the subjective experience of living with HIV and medical ideals or expectations of how being on HIV treatments should be experienced (2009: 131). As a result, the use of camp enables the voicing of a consumer perspective on the experience of medicine and provides novel avenues for demanding better drugs and better strategies (2009: 133). Race suggests that this helps to create a more comfortable setting within which decisions about bodily experience and well-being might be made, and in which diverse priorities around the body are more openly raised and contested. For Race, this brings hope that a more responsive form of care that is more dynamic and, at the same time, attentive to embodied experiences of living with HIV and being on ART, can emerge (2009: 135-136).

The concept of camp, as used by Race, allows us to understand how jokes made among people living with HIV simultaneously operate within a broader context. On the other hand, what I have already begun to reveal is the way in which the uses of camp in NW clinic often involve an audience of those who do not actively participate in queer culture. In Chapter One, I described patients excluded from my analysis – heterosexual men and women – as 'silent witnesses'. Being a witness to camp culture means that one has a function in that culture. Jokes that are made by doctors and nurses can be heard by all patients in the waiting areas, amongst them heterosexual men and women, gay men who do not take part in these exchanges and, occasionally, researchers like me. During our

conversations, Dave often raised his voice, allowing others sitting around us to listen to his story. It could be argued that by witnessing camp culture at work, we were included to some extent in it as, according to the existing analysis of camp, the cultural practices of camp emerged and are employed in relation to heteronormative standards and to challenge intended audiences – for example, the FDA, which was reluctant to adopt policies that allowed people with HIV access to experimental drugs prior to their approval (Gould 2009). Another difference between what Race described in the *Wheel of Misfortune* event and what I observed in NW clinic, was that for the patients I spoke to, camp humour seemed to offer what I read as only a momentary relief. It did not contest the meanings or effects of their medical treatment regimens. A joke about the burden of being on ART may be a moment when it is no longer just a private matter – the experience is shared. It may make it easier to talk about how one's subjective experience of living with HIV and on ART differs from expectations of how being on HIV treatments should be experienced today. Yet, what I observed did not allow me to see how camp culture helps in instigating the possibility of creating new avenues for demanding better drugs and better treatment regimens.

Conclusion

This chapter foregrounds the argument that gay sexuality needs to be thought of as crucial to the analysis of HIV care in research that focuses on gay men attending the clinic. I argued here that gay sexuality, being at the centre of camp culture and articulated through that culture, is the vital element in how patients share their experiences of living with HIV and receiving ART. In doing so, I spoke to the commitment expressed earlier: to approach sexuality as a site of politics and creativity, allowing patients to share their painful experiences and negotiate their position by refusing what could be perceived as self-pity. Furthermore, pointing out how camp culture is being employed by HIV patients is a means of ensuring that those patients are not assumed to be passive and escapes the risk of their victimisation. As I have already argued in Chapter Three, this is important,

as it poses a challenge to the normative, medicalised discourses around the epidemic, which have been prevalent since the beginning of the health crisis.

In Chapter Three, I discussed the methodology employed in this study and highlighted the need for building a larger analytical framework by including the historical context within which patients, illnesses and care are located. Engaging with the camp style of care became possible only through analysing the vibrant atmosphere of NW clinic in the context of the history of the cultural practice of camp and, in particular, its role in the HIV/AIDS epidemic. In other words, by employing a historical perspective on camp, it was possible for me to understand patients' uses of humour not as isolated phenomena, but as a part of the culture in which gay men have been engaging in various ways since the outbreak of the epidemic. Such an analysis has been enabled through a focus on patients who identify as gay and can be described as long-term survivors. The stories of living through the epidemic which they shared with me steered me towards acknowledging the links between the role of camp culture in the past and its presence today.

Chapter Five. Air kisses and hugs in the HIV clinic

I wrote in Chapter Two about how guidelines proposed by many Western governments in the early years of the epidemic promoted family values, monogamy and heterosexuality and relied heavily on the stereotypical focus on gay male promiscuity. Since the beginning of the AIDS crisis, one very common response to the epidemic was based on the assumption that HIV transmission could be stopped only at the expense of sexual pleasures (Halperin 2009; King 1993; Race 2009; Watney 1997, 1989). On the other hand, on many occasions, I felt that NW clinic was not a place where the sexuality of patients or doctors would be denied or subjected to moralising discourses which, as I have shown in Part One of Chapter Two, have prevailed elsewhere in the epidemic. In fact, most of the time, I was under the impression that sexual energy was very apparent in the clinic, and intimacy and closeness among doctors and patients were openly celebrated. Mark often greeted his patients in the waiting room with air kisses and hugs. Once, in a playful mood, he gave a long hug to a patient in order to – as he later admitted – evoke jealousy in the patient's boyfriend, who was standing behind (Field Notes 3rd September, 2014). During one of the consultations I observed, Mark did not stop at noting the patient's weight in kilograms, but he grabbed his waist to check if he had any excess fat (Field Notes 1st April, 2014). Other doctors also tended to maintain physical closeness between their patients and themselves. Shaun would gently pat the knees of the patients in the waiting area as he walked past them. Patients responded to doctors in a similar touchy and flirtatious way, as I witnessed on a few occasions. For example, I remember when Alexander, noticing that Mark was looking stressed, offered him a massage (Field Notes 2nd April, 2014). Here, I will build my own understanding of the role of the sexual energy that I observed in NW clinic in the delivery of HIV care.

The clinic against policing desires

On my last day of conducting the fieldwork, I was approached by two men: Stewart, who was a patient at NW clinic, and his friend. They said they guessed I was a researcher as I had a notebook and a folder with me. That, perhaps, made me look similar to other researchers they had met in the clinic before. As they sat next to me, Stewart said that they had decided to *'entertain me'* as I looked like *'I didn't have much to do'.* We had a short conversation about my purpose of being in the clinic before Stewart decided that he did not want to talk about his health condition, but wanted to show me pictures of his cat instead. After I eagerly agreed, he took his phone out of his pocket and started with the most recent ones. As he was sliding through the pictures looking for older photos, he stopped at one of a semi-naked man. Stewart explained to me that this was his former boyfriend and congratulated himself on his good taste in men. He then started showing me more pictures of different men, friends and former boyfriends, most of them half-naked. When Stewart was called to the consultation room, I left the clinic and typed field notes about how I had spent the last half an hour of my fieldwork looking at and commenting on semi-nude photos on Stewart's phone (Field Notes 3rd September, 2014). As a researcher who spent a significant amount of time in the waiting areas of the clinic, I was invited into and included in the sex-positive culture where sexual desires and practices where openly discussed and valued. I felt that Stewart's invitation to be a part of it was a realisation of one of the most significant functions of camp: to reach out to those outside of the gay culture, to challenge them and to affect them.

As I wrote in Chapter Two, sexual expression has played a big part in forming and sustaining early AIDS activism. One of the stances of the movement was acknowledging sexual freedom as a significant component of many gay men's self-identity, and the determination to fight the equation of homosexuality with AIDS which would prove that gay sexual liberation was a mistake. Organisations such as ACT UP were determined to challenge negative ideas about promiscuity (Gould 2009). In London, the free newsletter '*Boyz*' was described as being able to successfully

combine hedonism and a consistently mature response to the epidemic that recognised and engaged with the complexities of gay life rather than trying to 'fix' the sexual behaviours of gay men (King 1993: 58-59). On more than one occasion, I was able to observe connections between Gould's description of the AIDS movement and the happenings in the HIV clinic. I recall a day when Bruno came to the clinic with his boyfriend, who told Mark that Bruno had caught gonorrhoea. The exchange took place in the waiting area where, even though the clinic was quiet that day, I was sitting with two patients. Mark seemed not to mind our presence and raised his voice: *'Could you stop getting STDs?!'* They all laughed – even Bruno, who looked only slightly embarrassed (Field Notes 21st July, 2014). The teasing tone of Mark's comment suggested to me that he did not give in to the moralising rhetoric concerning the sexual practices and sexual desires of gay men. In this interaction, an HIV-positive person admitting to unprotected sex was not met with judgment or condemnation. Mark's light-hearted joke suggested an understanding or a certain degree of acceptance of the possibility of his patients engaging in unprotected sex. The fact that the situation took place in the waiting room where others could witness it, reminded me of another important strategy employed by ACT UP: disturbance of the boundary between the private and the public, especially through the expression of sexuality (as noted in Gould 2009). When patients' sexual health is discussed in the waiting area and not behind the closed doors of a consultation room, this can be seen as a continuation of strategies that threaten the dualism between what is public and what is supposed to remain intimate and private.

The context of the event was not political in the way that ACT UP's protests were when they were reaching wider audiences and challenging policies around the HIV pandemic. Yet, to me, this situation could be understood as a moment of challenging the more normative idea that any discussion about unprotected sex not directly aimed at correcting 'risky behaviours' threatens the 'rationality' of medical care. Although less spectacularly than in the *Wheel of Misfortune* evening discussed in the previous chapter, on which Race (2009) builds his analysis, when Mark

teased Bruno about his tendency to be ‘forgetful’ about safe sex practices, he also opened up the matter of safe/unsafe sex for public consideration and concern, as everyone sharing the space of the waiting room became a participant in the event. While what happened in NW clinic might have been considered as a breach of the patient’s privacy, the concept of camp, as we learn from Race (2009), allows for reading of that situation which transforms it into a moment of defying the isolation that can characterise HIV-positive experiences**.** Interestingly, my observations of the HIV clinic suggest that healthcare professionals take an active part in camp culture. Such observation bears significance for the debates around HIV care, as well as the critique of the remedicalisation of the epidemic. Acknowledging how doctors and nurses engage with camp culture reveals it as an appreciated element of care, despite not being explicitly included in the guidelines. Recognising how healthcare professionals employ camp humour and sexual expression draws attention to the limits of remedicalisation which, as argued by Nguyen *et al.* (2011) and Kippax and Stephenson (2012), following the successes of ART in not only treating HIV infection but also preventing new infections, encourages a narrow understanding of care in relation to the benchmark of viral suppression. On the other hand, I argue that the presence of camp culture reveals how the remedicalised idea of HIV care is being resisted by those who deliver it, as well as those on the receiving end of care.

On another day, when observing Mark’s consultations, I heard his young male patient disclosing that he practised unprotected anal sex with his HIV-negative partner. He and the partner had decided not to use condoms after reading findings that undetectable viral load suppression means the risk of HIV transmission is 'at most' 4% during anal sex (World Health Organization 2013)[25]. Mark’s reply lacked definitiveness. While he

[25] This research was concluded before the ‘Consensus Statement’ was published in July 2016 and was endorsed by over 550 major organisations in the HIV field from 71 countries. The document equals undetectable viral load with negligible to non-existent infectiousness: ‘There is now evidence-based confirmation that the risk of HIV transmission from a person living with HIV (PLHIV), who is on Antiretroviral Therapy (ART) and has achieved an undetectable viral load in their blood for at least 6 months is

expressed an understanding of the patient's decision, he also said that, as his doctor, he could not encourage the practice, as unprotected sexual intercourse always carries a risk of seroconversion (Field Notes 7th April, 2014). In this situation, Mark again avoided the judgmental or moralising rhetoric which, as I have shown in Chapter Two, has often been employed in discourses around gay men's sex in the context of the HIV/AIDS epidemic, particularly in popular cultural representations in mainstream media. Instead, he chose to acknowledge the patient's right not to align his sexual desire and sexual practices with the medical advice. In Chapter Two, I referred to Dunbar's photograph *Posithiv Sex Happens*, which Rosengarten (2009) interpreted as a recognition of the medical technologies implemented in HIV/AIDS care as possessing life-serving qualities through allowing sexual vitality (Rosengarten 2009: 68-69). To me, the ease of acceptance of the fact that patients may be 'forgetful' about safe sex measures also indicates an appreciation of HIV medicine for its life-serving qualities and enhancing of sexual experiences. In the two situations described above, we can see elements of the practice of camp attributed by Race (2009) as having the potential to defy medicine's appearance as a measure of social morality, ensuring that topics pertinent to HIV care, such as the experience of practising safe sex and protecting oneself and/or a partner's health, are not a matter of illegitimacy, and that pleasure suffuses knowledge practices rather than being extraneous to the knowledge relation. In contrast to Race, however, I am interested in what elements of camp culture did to the negotiations of HIV care in the clinic and, specifically, how they challenged standardised doctor-patient relationships.

Making sense of the playful

The interactions I was observing in NW clinic continued to surprise me and I often thought about how they existed in relation to standardising care protocols. The General Medical Council that sets standards which cover the fundamental aspects of a doctor's role, do not account for the

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negligible to non-existent. (Negligible is defined as: so small or unimportant as to be not worth considering; insignificant.)' (Prevention Access Campaign 2017).

character or history of specific conditions. On the other hand, as I argued in Chapter Three following Ricoeur (Ricoeur, cited in Kingori 2013), debates on research ethics which almost exclusively focus on what actions are taken and why they are being taken, are insufficient without an understanding of *the who* – who is undertaking the action in question. Indeed, Ricoeur suggests that there is a need to consider the vital nature of the relationship between action and agent in the production of ethical practices and perspectives. From a Ricoeurian position, it is in a face-to-face encounter with another person that we become responsible towards the 'Other' and motivated to do good deeds. Therefore, the good in one situation is not the same good for all encounters (Ricoeur, cited in Kingori 2013: 361-362). When applied to the analysis HIV care, Ricoeur's arguments suggest that it is more useful to look at the relations between patients and their healthcare providers in the context of their personal stories of living with HIV/caring for HIV patients, rather than exclusively in comparison with standardised guidelines for medical professionals. Evoking jealousy in a patient's partner, grabbing a patient's waist to check his excessive fat or discussing a patient's unsafe sex practices in front of others in the clinic, could be seen as breaching a patient's privacy or disturbing the professional boundaries that are required to be maintained between doctors and patients. Yet, as I have shown and will continue to argue, personal stories of long-term survivors living with HIV, analysed in the context of the broader culture of camp, offers a framework for understanding the relations between doctors and their patients. In this light, the use of playfulness and flirtatious jokes can be seen as an inheritance from the early responses of gay men to homophobic sentiments. It could be argued that while sexual expression was a big part of forming and sustaining early AIDS activism, today it can be a component of HIV care and relations between long-term survivors and their doctors and nurses.

Furthermore, being present during patients' consultations allowed me to observe a certain style of communicating medical information employed by doctors and often also patients themselves and the affectionate language

used by healthcare professionals. Mark would tell his patients that they were 'perfect' or 'wonderful' if their test results were satisfactory and showed undetectable viral load and a good level of CD4 count (Field Notes 7th April, 2014). Once, I heard him addressing his patient, 'Sweetie, you're doing quite well', when the patient expressed worries about his health (Field Notes 4th April, 2014). In those instances, medical information was not conveyed in the direct way that a reading of the latest results would offer but was communicated through caring language that contributed to the affectionate nature of care.

It seemed to me that, through physical closeness, cheeky humour and flamboyance, both doctors and patients were participating in the tradition of camp, evoking its cultural subversiveness and similarly the sex-positive culture that helped AIDS activism to flourish. While physical closeness seems to be a part of how care is delivered in NW clinic, it instantaneously creates a flirtatious and playful atmosphere. What is more, considering that both Mark and Shaun, as well as many of their patients, remember the times when the fear surrounding the emerging epidemic of HIV prevented such closeness, and continue to experience persisting stigmatisation which stops those living with HIV from having intimate relationships, caring through physical closeness becomes significant for its anti-stigmatising value. It is a political statement that celebrates sexuality outside of moral frameworks. This may be crucial to the long-term survivors who, reportedly, are largely affected by stigmatisation and discrimination from peers who might be less aware of the advances in HIV medicine. It has been argued that this can lead to, for instance, social isolation and poorer well-being (*The Lancet* HIV 2017). The extent to which an ageing population suffers from isolation and stigmatisation has been highlighted by the Terrence Higgins Trust's report, which states that a third of interviewed people with HIV aged 50 or older reported being socially isolated, 82% had experienced moderate to high levels of loneliness, and 58% reported HIV self-stigma (Terrence Higgins Trust 2017).

It could be argued that physical closeness with HIV-positive patients has been used more widely as a way of defying the stigma surrounding the infection. For instance, images of Princess Diana holding the hand of a man dying of AIDS during her visit to Lighthouse, then London's AIDS hospice at the height of the epidemic, were circulated for that purpose. Yet, I would like to argue that what I observed in NW clinic was not just physical closeness as an expression of the caring nature of the doctor-patient relation, but that the flirtatious character of the interactions between them made it into something different, which could be better understood through the concept of camp. On the other hand, the way in which camp is employed today in the HIV clinic differs from how it was employed by ACT UP. The aim is not to shock and/or challenge the public. Instead, camp has become incorporated into affectionate ways of delivering care. What is more, it seems to me that those affectionate ways of doing care are possible because of a shared understanding of the significance of provocative and flirtatious jokes or openly expressed sexual desires. To put it differently, the particular atmosphere of NW clinic and the inclusion of elements of camp culture in providing and negotiating care are possible as the space of the clinic is shared by a large number of patients who identify as gay and are long-term survivors. They belong to the communities most affected by both the AIDS crisis and homophobia and are accustomed to strategies of defying them.

Camp culture and negotiating stereotypes

It has to be considered what it means that those men who choose to participate in camp culture become visible to others. Those who are not a part of camp culture become audiences to exchanges of affection, exaggerated gestures and jokes about sexually transmitted infections that could be seen as inappropriate. Such visibility carries a risk of camp culture feeding into homophobic discourses around HIV. As I explained in Chapter Two, popular cultural representations of HIV in the media contributed to public panic and a misunderstanding of HIV infection by constructing 'guilty' versus 'innocent victims' and promoting the

stigmatisation of gay men among others considered to be at a higher risk of infection (Patton 1990; Treichler 1987; Watney 1987). Whilst the link between the HIV/AIDS epidemic and the sexuality of gay men, their sexual practices and pleasures has been well established since the beginning of the epidemic, it shaped particular definitions and forms of policy response favouring assertions of 'family values' (Berridge 1996: 56-57). In the previous chapter, I described a sense of uneasiness that I had felt when interviewing Dave. On the one hand, I appreciated his use of humour as a creative response to his experiences of living throughout the epidemic as a gay man. On the other hand, I wondered how others, who were not a part of camp culture, would perceive his jokes. Would he be seen, for example, as an irresponsible patient?

What I have also argued earlier in this thesis, drawing on Foucault (1990), is that, although the existence of power assumes the presence of resistance, this resistance is never in a position of exteriority in relation to power (Foucault 1990: 101). In the HIV clinic, while camp culture may subvert one's sense of victimhood or serve as means of distancing from moralising discourses around sexual risks, it simultaneously uses the same categories of oversexualised and irresponsible gay men who now may be blamed for the outbreak of the epidemic. In other words, employing camp culture in HIV care, especially in ways visible to those who are not partaking in it, or are even unfamiliar with its long-standing political significance, may enforce existing stereotypes of gay men and give them more power. Further, as a researcher, the way I portray my research participants may potentially strengthen those categories. Despite seeing the significance of camp culture in ways of care delivery, I initially felt somewhat uncomfortable with describing patients and healthcare professionals as camp. In order to minimise what I identified as a risk of further stereotyping of gay men, it became important for me to learn about and then present camp culture as historically and contemporarily politically meaningful. I believe that, in this way, I was able to show how camp culture features in HIV care without the risk of presenting what could be read as inappropriate affection and jokes as feeding into stereotypes of

frivolous and irresponsible gay men who could then be seen as ‘guilty’ for the outbreak of the epidemic.

I felt that my doubts were reflected in much broader debates around the visibility of gay men within the HIV/AIDS epidemic. I wrote in Chapter Two that despite the disproportionate impact of the epidemic on gay men and the AIDS field relying heavily on the work of gay men who recognised the epidemic as a key political issue for their community, lesbian and gay groups often hesitated to become involved in the epidemic for fear of giving the impression that AIDS was a ‘gay disease’. As a consequence, gay communities were not the primary benefactors of the resources dedicated to fighting the health crisis and the NHS or voluntary sector was hesitant to learn from the ways in which gay men responded to the epidemic, for instance through inventing safer sex, or using them to inform new initiatives designed to sustain those behaviour changes (King 1993: x). At the same time, a number of gay activists stressed the need for a ‘re-gaying’ of the epidemic: increasing safer sex education among gay men; eroticising safer sex to make it into something more than a mere technique through connecting it with self-love, caring and gay pride; and recognising the importance of sex within gay communities where it replaces ‘often hostile family bonds and shapes politics’ (Watney 1997: 12-13). To put it differently, it has been recognised that there is a value or even necessity in making gay sexuality visible and at the centre of the epidemic, even if this risks enforcing certain stereotypes. In an HIV clinic, it may mean that the benefits of employing camp culture in delivering care may be recognised as outweighing the potential risks.

Conclusion

In the previous chapter, I described the process of making sense of the uses of humour through placing them within a broader context of how gay men have been dealing with the tragic events of the HIV/AIDS epidemic. Here, I have built on the knowledge of camp culture, showing how it features in the affectionate and playful interactions between healthcare

professionals and their patients. Importantly, exploring camp culture in NW clinic allowed me to start building an analytical framework for studying doctor-patient relationships that does not rest on the disparities between the power and knowledge the two groups are believed to hold. Instead of relying on more traditional approaches to doctor-patient relationships, I drew attention to the humour and physical closeness shared by patients and physicians, and how doctors too employed camp humour to avoid complying with, for example, the normative ideas about safe sex practices. By engaging with camp culture in an analytical way, I painted a picture that reveals HIV care as consisting of much more than the management and implementation of medical knowledge and technologies. The case study presented here suggests that physical closeness between patients and HIV physicians and the use of camp humour reveal HIV care practices to be affective and collaborative efforts that are situated within the broader context of the epidemic and the communities affected by the health crisis. In other words, HIV care may extend beyond monitoring the infection and it may require being attentive to how the lives of patients have been affected by being at the epicentre of the epidemic.

Chapter Six. Camp culture and the doctor-patient relationship: being-with-friends

Spending time conversing with nurses throughout my fieldwork allowed me to understand how NW clinic operated: what clinical pathways the patients took and how responsibilities were redistributed among the staff. I learnt that in most cases, clinicians prescribe and monitor the treatment. They are supported by research nurses who care for patients enrolled on clinical trials, which includes trials of new antivirals, novel combinations of therapies and treatment at different stages of HIV. The responsibilities of research nurses differ little from those shared by consultants, although research nurses possess less autonomy. The clinic also employs nurses who attend to patients before and/or after their consultations with the physicians – they check patients' blood pressure, weight and take blood for routine monitoring tests (Field Notes 21st April, 2014). Because of the layout of NW clinic, with the nurses' station being set in the waiting area, nurses were likely to engage with patients before and after their appointments. At the same time, it was not uncommon for clinicians to stop and greet their patients in a way – as I explained in the previous chapter – that could fill the clinic with vibrant and sexual energy.

Before I joined Mark in his consultation room where I continued to conduct my observations, I expected to witness a dynamic that would suggest the democratic character of decision-making processes that actively involved patients. I anticipated seeing the consequences of the process of shifting the power dynamic that took place early on in the epidemic and which I described in Chapter Two. Yet, I was surprised by what was waiting for me in Mark's consultation room. In fact, Mark kept the medical matters to a minimum. What I observed in the consultation room were friendly and informal exchanges, often concluded with hugs or Mark saying 'bugger off now'. In this chapter, I will explore that informality and think about what facilitates what I identified as friendly relations between patients and their healthcare providers.

'The doctor was straight and the patient was gay', or how sexuality matters for relations formed in the clinic

In the previous chapter, I highlighted that NW clinic can be thought of as a non-judgmental space where doctors do not give in to the moralising rhetoric which permeates discourses around HIV and concerning the sexual practices of gay men. I argued that although patients receive comprehensive guidance concerning safe sex, there seems to be a shared acknowledgement of the patients' right not to align their desires and practices with medical advice. Interviews I conducted with healthcare professionals working in the clinic shed more light on how the non-judgmental environment of the clinic is created and sustained. Exploring this particular aspect of HIV care, allowed me to deepen my understanding of how camp culture is present in NW clinic and what this presence means for those who participate in it.

Jonathan, now an HIV research nurse, has been working in the field of HIV medicine since 1991. He told me that one of the reasons he moved from general medicine to HIV nursing was his sense of injustice evoked by seeing people living with and affected by HIV being judged and blamed for the epidemic. At that time, Jonathan felt he wanted to support those who lived with the infection and contribute to fighting the stigma around HIV. Jonathan saw that stigma as making HIV and AIDS distinctive from other health conditions. In particular, as he told me, stigmatised routes of infection – injection of drugs or (often gay) sex – means that those who are diagnosed with HIV have not been receiving as much social support as patients diagnosed with, for instance, cancer. Working for many years in in-patient as well as out-patient HIV care, Jonathan seemed to be one of the clinic's most experienced healthcare professionals. In our interview, he emphasised the need for effective communication between healthcare professionals and patients:

> the communication is the main one with the patient, to be able to be there, to support the patient […] We need, as

> nurses, to have an open and direct communication with the patient. Be honest, be frank. Be completely non-judgmental. We can talk to patients about anything. But we need to be able to turn the subject around to anything. I would have no reservation about going to a patient and asking some intimate question. Very personal questions but in a non-judgmental way. (Interview with Jonathan)

Jonathan stressed honesty and lack of judgment as the main factors that allow doctors and nurses to support patients. Contrary to other chronic conditions, HIV treatments are always closely tied to the intimate spheres of patients' sexual lives. This is because, for example, through lowering viral load to an undetectable level, HIV treatments have the capacity to create the possibility of unprotected sex, as undetectable viral load is linked to infectivity (Thompson *et al.* 2012: 3). The proximity of HIV treatments and sex requires doctors and nurses to discuss patients' sexual practices and sexual desires. Consequently, as Jonathan told me, healthcare professionals need to know how to talk to patients about the most intimate issues.

Later on in our interview, Jonathan listed obstacles to open and direct communication and, interestingly, one of them was a situation where 'the doctor was straight and the patient was gay' (Interview with Jonathan). Jonathan explained that sharing the same sexual orientation allows for a better understanding of issues related to sexual practices and lifestyle more generally. It also creates more room for honesty about one's fears and needs. I understand Jonathan's argument as suggesting that situations in which both patient and doctor identify as gay men may allow for a different HIV care. Jonathan was not alone in this view. I remember when Mark encouraged one of the patients to visit his GP by saying he remembered the GP to be 'quite nice, quite gay' (Field Notes 22nd April, 2014). This highlights that the value of having a doctor who is gay or 'quite gay' is openly recognised and communicated in NW clinic.

Following the methodology set out in this research, I explore the openness of communication between a doctor and patient who both identify as gay by putting gay sexuality, understood as a political and historical formation, at the centre of the analysis. Earlier in this thesis, I discussed the damaging effects of homophobic sentiments that have fuelled popular cultural representations of HIV and, consequently, contributed to public panic and a misunderstanding of HIV infection by constructing 'guilty' versus 'innocent victims', and promoting the stigmatisation of gay men amongst others considered to be at a higher risk of infection (Patton 1990; Treichler 1987; Watney 1987). Furthermore, the same sentiments effectively influenced the premises of developed policies, such as Clause 28 of the Local Government Act, as well as HIV prevention discourses in which gay men's sexual practices and desires have been framed as problematic and dangerous. What I wish to propose here, is that, while the non-judgmental approach and refusal to give in to a stigmatising, moralising framework and acknowledging and celebrating gay men's sexuality were achievements of gay communities and movements originating from those communities, having a doctor who is gay seems to allow for a safe space, where understanding and trust can be developed to become a part of the delivery of care.

Being in the consultation room allowed me to see that it is not only sex that may be easier to discuss with a physician who identifies as gay. I recall a consultation during which Mark and his patient discussed Christmas plans. The patient said he was going to visit his family but was hoping to lock himself in his bedroom and sleep. They both laughed and Mark said he had 'the same policy with family'. The conversation could be understood as a mutual agreement on preferring to stay away from family and, in the context of the presented discussion, perhaps more heteronormative ideas of spending the festive time. One of the most memorable things Mark told me when I first met him, was that the clinic operates in such a way that gay men tend to be treated by physicians who also identify as gay. Mark explained to me that, according to him, this was reasonable, as it was easier for him to spot and understand worrying

symptoms in another gay man (Field Notes 22nd April, 2011). This reminds me of Annemarie Mol's (2006) description of elements of medical care that are affective and may be omitted in textbooks. Mol concludes that *good* care is not a matter of making well-argued individual choices, but is something that grows out of collaborative and continuing attempts to attune knowledge and technologies to diseased bodies and complex lives. Studying the day-to-day practices of caring through which diabetes is managed, Mol emphasises the relationality of care: care arises from negotiations between patients, medical professionals, patients' families and, in an equal manner, medical tests and technologies. She draws attention to the incoherencies and breaks in these negotiations, and also describes the elements of care that are affective and may be hidden in textbooks. For instance, Mol writes how clinicians may 'diagnose with their senses' through noticing sadness in a patient's voice or the signs of impaired breathing (2006: 39). Similarly, Mark's rationale for gay patients being treated by clinicians who identify as gay, also pinpoints elements of care that are affective and extend beyond the implementation of HIV medicine. On the other hand, Mol identifies doctors' empathy as a basis of her argument about affective care. What I found out was that, perhaps, empathy would not be sufficient if the doctors did not share sexuality with their patients.

HIV care as a mode of being-with-friends.

The healthcare professionals whom I interviewed and followed in their work had been working in the field of HIV medicine since the early years of the epidemic. For this reason, as I learnt early into my fieldwork, they tended to have established long-term relations with their patients. For instance, a significant number of patients followed Mark when he moved to NW clinic from a different clinic earlier in his career. Mark and other clinicians who have treated HIV and AIDS patients since the epidemic's outbreak witnessed first-hand the impact of the early epidemic on the community of gay men and the positive changes that came with the introduction ART. At the time of my fieldwork, Mark was providing care to

over 600 patients. Many of them were his long-term patients whom Mark had been caring for since their diagnosis. He referred to the patients he had been treating since the early years of the epidemic as people with whom he had grown old with (Interview with Mark).

In Chapter One, I made a remark about Mark being a much respected HIV specialist who was surrounded by ‘legends’, based on the knowledge of his achievements in the field of HIV science but emerging as something that was more elusive. Mark was a very confident and charismatic man. Just because of those characteristics, it was easy for me to empathise with patients who, in interviews, shared an unquestioned admiration for him. Having a huge number of patients and research responsibilities in the clinic, Mark was often rushing around and sometimes I would only catch a glimpse of him. Yet, he was generous with his time, let me follow him around the clinic and accompany him during his cigarette breaks, which were sometimes the only moments we could have a conversation. What was striking and somehow surprising about Mark, was his appearance. Most of the time, Mark wore a t-shirt, tracksuit bottoms and trainers. He seemed rather unbothered about wearing casual outfits, not only to the clinic but also to conferences and restaurants. Sometimes, his trainers would be covered in mud, which I explained by his love for gardening. Mark’s appearance seemed significant to me, as I saw it as partly a sign of his confidence – Mark did not need to assert himself as professional. Before I met Mark for the first time, I heard about his many achievements as a scientist and a care provider. His casual style made me less anxious about working with him.

Every morning I would go with Mark through the list of patients he was meant to see that day. Despite the large numbers he had enrolled in his care, Mark was often able to tell me how many years each of his patients had been living with HIV, what the patient did and how likely he was to engage with my research. In our interview, Mark reflected on his relationships with the long-term patients:

> On the whole, it means that they are willing to tell you everything. Whereas, I think, that often patients will edit what they say to a doctor depending on their relationship. And also that means that they have the comfort of knowing that they don't have to repeat the same story endlessly. So if an old patient is seeing a new doctor, he spends an hour telling him all about the history. Now, some of that is relevant and some isn't. So having that long-term relations means not having to decide what's important and what isn't. (Interview with Mark)

When observing Mark's consultations, I was often reminded of this description. The consultations tended to be very short, under ten minutes in most cases. Frequently, Mark would just briefly mention a patient's last medical results and spend more time chatting with him about issues not related to HIV treatments, such as preferred holiday destinations or cultural events they had attended. Mark often seemed to know where his patients worked and what relationships they had with their families and partners. The design of the consultation rooms facilitated the informal character of patients' visits. In every room, the patient's chair was positioned in a way that it was possible for a patient to look at the doctor's screen should they wish to do so. In most cases, there was no physical barrier separating the patient and the doctor, such as a desk positioned in between them. In addition, the pathway that patients followed after entering the clinic and before seeing their consultants helped to free time during the consultations to have casual chats, often unrelated to their healthcare and touching on their hobbies, holidays or careers instead. Before the consultation, patients would check their weight on a scale placed in a corner in the waiting room. After, they would sit down and wait for a nurse to note down their weight, ask about their general well-being and check their blood pressure. The notes were then delivered to the right consultation room. It was explained to me that this was done in order to reduce the time patients had to spend in the consultation room (Field Notes 21st April, 2014).

Given that Mark knew his patients for many years, it could be expected that their relations would be relaxed and friendly. Yet, as I also wrote in Chapter Two, in 'the AIDS event', specialised HIV care emerged in a complex entanglement of antiretroviral medicine and AIDS activism (Stengers 1997) and, for that reason, HIV care has to be discussed and understood in relation to those complexities. Following this lead, I would like to revisit the friendliness of Mark's relationships with his patients in the context of HIV care. At the same time, observations which I presented in the previous chapter showed how patients and doctors participate in camp culture, potentially disrupting in this way normative discourses of medicine. I became interested in whether the friendliness in NW clinic was only a result of the process of democratisation that was identified at the beginning of the epidemic as a result of gay men living with HIV becoming informed about available anti-HIV treatments and contributing to decision-making. The literature on camp culture made it possible for me to propose a new angle.

Eve Kosofsky Sedgwick (2008) proposes that camp requires a willingness to participate in cultural subversion. Sedgwick (2008) argues that the ability to identify a particular object as camp and to induce others to share that perception thereby creates a basis for community – a common fellowship of shared recognition and anti-social aesthetic practice. Furthermore, David Caron suggests that camp simultaneously produces and is produced by a community of equals. Caron argues that camp is a 'mode of being-with-friends'. It is a collective friendship, which exists only through its own performance. Importantly, it goes nowhere and produces nothing other than itself, being a social critique of other models of socialisation – for instance, the couple or the bearing of children. In other words, camp is a critique that does not aim to correct and improve, but to question, to undercut and to destabilise. What is more, being a potential source of collective strength and by seizing that opportunity, camp endows its anti-social aesthetics with a political dimension (Caron, cited in Halperin 2012: 190-191).

In previous chapters, I illustrated how both patients and healthcare professionals can participate in camp culture. Here, evoking Sedgwick and Caron's arguments, I propose that Mark's friendship with his patients may also be seen as rooted in camp culture and engaging with a social critique of other models of socialisation. Yet, in contrast to Caron, I see the fellowship of a doctor and a patient as productive, as it participates in the production of HIV care. Furthermore, the 'mode of being-with-friends' produces what complies with the definition of *good* care – care that is based on honesty and the patient's comfort (General Medical Council 2017). The importance of good relations between doctors and patients has been emphasised by research that suggests its crucial role in patients' adherence to ART and retention in care (Garcia *et al.* 2005). On the other hand, I do not wish to propose that Mark's friendship or the good relations he has with his patients are motivated exclusively by his wish to encourage patients' good ART adherence. Rather, I acknowledge both the roots of friendships formed in the clinic in camp culture and the productivity of those relations. Further, the act of ensuring good HIV care for gay men can be seen as an act of subversion and resistance when gay men living with HIV continue to face elevated homophobia often fuelled by HIV-related stigmatisation. I wrote in Chapter Two that the early efforts towards saving lives were taking place amongst public panic and a misunderstanding of the epidemic that was frequently represented as a 'gay plague' (Patton 1990; Treichler 1987; Watney 1987). Mark's relations with his patients and his work ethic could be thought of as being formed in opposition to those discourses and the discriminatory policies that followed them, e.g. Clause 28 of the Local Government Act. In such a context, the productivity of HIV care doesn't have to be necessarily read as solely a compliance with medical guidelines and medical ethics. It can simultaneously be radical.

'As a gay man, I interface with HIV on every level': blurring of the professional and the personal.

In short, what I was observing in NW clinic were often not just relationships between healthcare professionals and patients but, equally significantly, between friends who 'have grown old together'. During my fieldwork, I also interviewed Shaun who had been providing care to HIV/AIDS patients since 1991. Similar to Mark, Shaun made an impression as a charismatic man. Unlike Mark, he seemed to always stand out in the clinic because of his unique yet stylish sense of fashion.

Initially, I felt intimidated by Shaun's presence. This was because of his apparent annoyance, the source of which I was not sure. As a researcher, I feared he was going to be reluctant to open up in our interview. I was mistaken. Our conversation, which I describe below, sheds light on the reasons behind Shaun's ostensible irritation.

Shaun told me that being gay and at the epicentre of the epidemic, meant that he shared similar experiences to his patients. According to Shaun, it was for that reason that, over time, patients became his family and friends (Interview with Shaun). While observing Mark practising care allowed me to acknowledge how the 'mode of being-with-friends' could produce *good* care, my conversation with Shaun shed new light on the relations between doctors and patients in NW clinic. Shaun described the close relations he had with his patients:

> and now, you know, I'm sitting in the clinic with people who go to the same restaurants as me, do the same things, you have the same life issues – and patients who don't. But now I've known some of these patients and see some of those patients more than I see my family and friends. So they've become friends. They've become family. And my social life became very interwoven with my patients' lives. Among all human beings and in all human interactions, you find people that you like; you're just naturally drawn to people. And you get on really well and

> after a couple of years, you go for a drink together, for dinner together. So they mean more to you than just a patient. (Interview with Shaun)

Shaun recognised that being a part of the community of gay men allowed him to form friendships with his patients based on shared life experiences, located outside of the clinic and beyond the conventional doctor-patient framework. It could be suggested that even though Shaun retained his professional role through maintaining control over decisions made with regards to patients' treatment regimens, being a part of the gay community encouraged a 'mode of being-with-friends'. Or, in other words, the boundaries between being a doctor and being a friend became blurred over time, and as a result of sharing similar life experiences and London's cultural and leisure spaces.

Shaun continued to tell me about his experience of being gay and an HIV practitioner:

> My problem is also, as an HIV physician, is that, as a gay man who interfaces with HIV on every level, probably in every moment of my life because I work with it and when I leave I'm going to my personal life I have to deal with it too. I have to deal with friends who are HIV positive, lovers who are HIV positive, potential partners who may be HIV positive. And so I can never let go. When your average heterosexual doctor leaves the building, they go to bringing up their children and you know, going to a theatre, shopping and saving for school fees… whatever it is that they're doing in their lives. I can't switch off. So I've had all of this for 20-odd years plus and, not to sound defeatist or let down or disappointed or anything, it's like as I said: 'copers' cope; I obviously cope. (Interview with Shaun)

Shaun's description of how his personal life had been intertwined with his medical practice draws attention to the consequences of being always in close proximity to the pandemic. Shaun's words that his friends and partners live with HIV or are at risk of HIV infection, could be referenced with statistical data upholding the assumption that the prevalence of HIV remains higher among men who have sex with men compared to other populations (How common is HIV? 2017). For Shaun, that means that he continues to be immersed in the complexities of the epidemic outside of the clinic 'probably in every moment' of his life.

In the previous chapter, I argued that those in NW clinic who do not engage with camp culture directly may still participate in it to some extent by witnessing it. This role has been seen as important by theorists such as Gould (2009), who argued that the cultural practices of camp were produced and employed not only for the community but also as a response to those intended as an audience. On the other hand, Shaun pointed to the differences between himself and doctors who identify as heterosexual. Being gay and an HIV practitioner caring for other gay men, does not only mean a potentially shared critique of heteronormativity but, for Shaun, it means that he continues to provide care outside of the clinic. It has been argued that gay men who are HIV negative remain in close proximity to the epidemic, with their intimate lives often intertwined with their awareness and knowledge of HIV. Shaun's description of what it means to him to be an HIV clinician and gay man reminds me of Dowsett's (2009) claim that for many gay men, the epidemic is not about a job or career, or even a community commitment. Dowsett argues that gay men who are HIV negative occupy a liminal space where there is always the possibility of becoming seropositive. Further, gay men fighting the epidemic invest in an ongoing interest in behaviour, experience and the circumstances of sex in the epidemic that is driven by their reflexivity (Dowsett 2009: 219). Correspondingly, Race (2003) discusses a 'homosexually and scientifically active' man who, having access to scientific knowledge of the epidemic, incorporates that knowledge into his

sexual risk negotiation and decision-making (Race 2003; Race in Dowsett 2009).

On the other hand, here, the intersection of being gay and an HIV practitioner influences how Shaun provides care and how he experiences his professional role. Shaun believes that for those healthcare professionals who identify as heterosexual, it is easier to separate one's personal from one's professional life. Importantly, Shaun expressed upset at not being able to *'let it go'*. Listening to Shaun's story, I thought about how similar it seemed to the patients' self-narratives I heard in NW clinic. I see these similarities in his willingness to share painful or distressing experiences without positioning himself as a victim. Camp culture offers an interesting angle from which we can look at doctor-patient relations. While the differences in knowledge and negotiations over disparities between the lay and the professional perspectives have provided a starting point for many of the debates on doctor-patient relations in sociology, camp elements of care draw attention to the similarities rather than the differences between healthcare professionals and HIV patients. As shown above, exploring elements of camp culture in NW clinic offers specificities of the relations formed in HIV healthcare that are vital for both groups, revealing issues that may escape an analysis that begins with lay/professional perspectives.

During our conversation, Shaun continued to tell me about the complexities of HIV care:

> There is no modelling medicine that really trains you to be a doctor who looks after patients as complex as those living with HIV for long periods of time […] When I started, there were no books to tell me how to be as a doctor when everybody was dying. As a youngster, I was 26 years old when I started looking after people who were HIV positive – no training; I was thrown into the deep end and I had to be kind and compassionate and look after

> people who were like me who were dying. I'm not a saint, but I did it. (Interview with Shaun)

While Shaun used to find it demanding when providing care for AIDS patients during the pre-treatment era, the introduction of effective ART brought its own challenges:

> A lot of doctors in my situation gave up HIV medicine a long time ago because they couldn't cope with the transition. They didn't want to cope with this transition. And, you know, I never really saw it as an issue then. But now in retrospective, I realise that there's always been an issue. And perhaps I might have been more sensible and protected my career and my own psychological well-being in the workplace a long time ago. So a lot of my frustration, irritation and inability to cope with the pathetic patient is based on that feeling of like, you know, 'Well if I have to cope with it, you can too'. And maybe you would argue that, as a professional, you are supposed to stand back – you know, psychiatrists stand back and barriers, barriers. Psychologists stand back and barriers, barriers. We were never taught barriers. As a caring doctor, you're not supposed to have barriers. You are supposed to just give and be kind and just give yourself and be empathetic and sympathetic and do everything. And maybe I am unusual and I think I am, and I have a great capacity to do those things and give. And I am kind. (Interview with Shaun)

It is important to remind the reader that Shaun's situation bears its own specificities within HIV care, as he started caring for HIV patients at the beginning of the epidemic – when there were fewer guidelines for HIV care – and he witnessed the changes to the technologies, treatments and objectives of care that took place after 1996. Two points emerge from Shaun's description of what it means to be an HIV consultant. Firstly,

Shaun states that he wants his patients to be able to cope with the transitions in HIV care the way he does. He admits to being impatient with those who have difficulty with accepting their seropositive diagnosis. Hearing Shaun expressing his frustration made me rethink the idea of HIV care as a 'mode of being-with-friends'. The equalising potential of camp culture may mean that in the context of HIV care, patients may be expected to share the same understanding of what an HIV diagnosis means with their doctors. In other words, the perceived proximity of the experiences of gay HIV patients and gay HIV physicians may be expected to smooth out any differences. Secondly, just as Shaun sees himself as different from HIV doctors who identify as heterosexual, he also emphasises the difference he sees between being an HIV consultant and being a medical professional in other fields. Shaun argued that, working in HIV care, he was never encouraged to distance himself from the care he was delivering to patients. Simultaneously, Shaun focused on the ways in which he had been coping with the difficulties he had been encountering as an HIV physician. In doing so, he reminded me of a camp culture that allows for the acknowledgement of suffering while resisting the urge to surrender to victimisation.

Analysing Shaun and Mark's stories about what it means to be an HIV clinician made me rethink the term 'long-term survivors'. I see the possibility and the need for redefining the concept in the context of this research, in a way that it becomes inclusive, not just of those living with HIV, but others who have been living with and surviving the HIV/AIDS epidemic. Such a claim, it should be stated, does not aim at equating the experiences of patients with HIV healthcare professionals, but rather pointing to shared politics. In other words, the identity of a 'long-term survivor of the epidemic' does not have to depend on the HIV residing in one's body. It may mean that one engages with practices that have an equalising potential and can act subversively against normative discourses around the epidemic. The term I wish to propose is 'alliances of long-term survivors'. Alliance is defined as 'a union or association formed for mutual benefit, especially between countries or organizations' or 'a relationship

based on similarity of interests, nature, or qualities' (Oxford Dictionaries 2017). Correspondingly, my analysis shows that through engaging with camp culture – its equalising and subversive potential – both patients and healthcare professionals engage with shared politics, which, as one of the benefits, produce HIV care. Alliances that I have identified in NW clinic could be thought of as a continuation of those, which, as Berridge (1996) argues, emerged in the first half of the 1980s – times she describes as of 'incoherence, of absence of knowledge, of "groping in the dark"'. Berridge observes that alliances were formed among the gay community and also among clinicians and scientists. She stresses that those alliances were often established where none had previously existed; for instance, between gay activists, public health doctors, clinicians and scientists. Berridge suggests that the alliances reflected the fact that, for both gays and clinicians, the very early days of the epidemic were a period of 'self-help', where responses to the crisis were being formed in a 'bottom-up' rather than a 'top-down' way (Berridge 1996: 13). It could be argued that the alliances of long-term survivors of the epidemic have retained these qualities, as 'self-help' remains an important need in the face of the changing reality of what it means to live with HIV and what it entails to care for HIV positive patients[26]. For instance, while the current move towards HIV normalisation may potentially reintroduce more standardised HIV care, alliances of long-term survivors allow for a space where normative constraints typically attached to doctor-patient relations are being continuously challenged. Yet, it has to be stressed that the alliances I was observing in NW clinic differ from those identified by Berridge. As HIV medicine has evolved, providing more certainty, the alliances today are not motivated by 'groping in the dark'. They are facilitated by shared experiences of living through the epidemic and, often by friendships developed over the years.

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[26] Furthermore, Let's Kick ASS, a grass-roots movement to empower, engage and unify HIV long-term survivors, recognises 'HIV-Negative Long-Term Survivors', among whom they list lovers, caretakers and frontline healthcare workers who also suffered enormous losses during the AIDS crisis (Anderson 2017). This may suggest that the community of long-term survivors recognises that the term may be used more broadly than just in relation to those living with the infection.

'I like swearing. It's very good'. What is a good HIV care?

Just as when talking to Dave, at times I felt that what he was offering me was a performance rather than a straightforward answer, Shaun's interview gave me a similar impression. Again, rather than suggesting that I felt that his answers lacked honesty, I wish to explore what his 'performance' did. Halperin (2012) argues that treating everything as a performance opens a crucial gap between actor and role, between identity and essence[27] and, hence, camp irony makes it possible to gain some distance from one's self and the self that society has labelled one with, as its authentic nature. Camp undoes the seriousness and authenticity of the naturalised identities and hierarchies of values that degrade gay men. For example, embracing the stigma of homosexuality is a tactic for overcoming it only when those who embrace it also refuse to recognise themselves as definitively described by it. In other words, converting serious social meanings into triviality is a foundation of a political strategy of social contestation and defiance (Halperin 2012: 195).

On the other hand, I did not read Shaun's 'performance' as an attempt to contest homophobia and its consequences. Rather, I felt that Shaun was challenging the social meanings attached to the medical profession. Towards the end of our conversation, Shaun told me:

> I like swearing. It's very good. To say, 'fuck'. 'Fuck off' to a patient when they're getting on my nerves. It's very good to say: 'What the fuck are you doing with your pills? If you don't take them properly, I'll kick your fucking head in. What are you doing?' I do it. They love it. If I sit here and say, you know, 'It's imperative that you take your zidovudine and lamivudine at the same time every day and compliance is of utmost importance', most people will

[27] Halperin (2012) argues that manipulating appearances and social forms in mastering style and passing for normal is necessary for gay men. Hence, gay men tend to perceive masculinity as a social form rather than as a natural phenomenon (Halperin 2012: 196-197).

> just look at you and think 'You're a twat'. 'So, these fucking pills are going to keep you alive for the next 20 years. You do what I say, take them properly. If you have problems, let me know and I will change them, but if you don't do it properly, actually fuck off and go and see another doctor and don't waste my time'. That's not an approach we were supposed to have, but you know what? I have a job to do. And I'm going to do it the best way I can. And if they don't like the word fuck, they can fuck off… that's what I think. (Interview with Shaun)

Shaun decided to introduce swearing into the consultation room as a tool he sees as necessary for his communication with patients, a tool that, he thinks, may encourage their adherence. Similar to how I earlier approached the flirtatious jokes, hugging and air kisses that are a part of the interactions between patients and doctors, I view swearing as subversive and embedded in the camp culture present in NW clinic[28]. In what could be seen as camp style, through swearing, Shaun mocks the compulsory social role of a healthcare professional, who is expected refrain from using 'inappropriate' language. To put it differently, Shaun's swearing reveals the social role of a medical professional as a form of a cultural performance rather than an authentic self. To argue, as Shaun

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[28] The use of swearing by medical professionals seems to be a controversial but widespread issue (Palazzo & Warner 1999). It has been reported that some doctors believe that swearing can support building relationships with patients and that, in some situations, it may be 'appropriate'. On the other hand, swearing can also result in an investigation into allegations of unprofessional behaviour and it may be thought of as putting public confidence in the medical profession at risk (Davis 2015; Zimmerman & Stern 2010). The literature suggests that using words which are considered to be outside the confines of polite doctor-patient interactions needs to be always seen in the context of those interactions. For example, swearwords may help to convey a message where professional language fails to communicate the powerful emotions evoked in certain situations (Maier & Miller 1993). Moreover, swearwords may help express empathy and encourage patients to show their feelings (Zimmerman & Stern 2010). Yet, a great deal of research has linked swearing to verbal aggression, anger and other negative emotions, suggesting the unacceptability of its use (Stone *et al.* 2015). Here, in agreement with the premise of this thesis to engage with camp culture as centred around gay sexuality, I will approach swearing as a part of it and as carrying a subversive potential similar to other elements of camp culture described in this thesis.

does, that swearing helps him in delivering care, is to suggest that disrupting the social meanings attached to the medical profession has its uses in HIV care in NW clinic.

Camp culture as a facilitator of solidarity and resistance

Throughout Chapters Four and Five, I pointed out how camp humour and the celebration of gay sexuality works against discourses policing sexual practices and desires or is a way of engaging with painful experiences without presenting oneself as a victim and pre-empting the potential of others to devalue those experiences. In this chapter, I focused on how participation in camp culture can facilitate solidarity among patients and doctors. I wish to argue here that the forms of resistance that camp culture supports and solidarity in the HIV clinic are interlinked, allowing for HIV care that is not only affectionate but also political and strategic.

To remind the reader, research shows that the ageing population with HIV infection is greatly affected by feelings of social isolation, loneliness and self-stigmatisation (Terrence Higgins Trust 2017). Further, gay men living with HIV continue to be subjected to homophobia, with one in five gay men (19%) experiencing a hate crime or incident in 2017 because of their sexual orientation (Bachmann & Gooch 2017). In this context, fostering solidarity among gay men in an HIV clinic can be perceived as a strategic act of resistance against the homophobia gay men continue to experience. For gay men living with HIV, seeing an HIV clinician who also identifies as gay may generate feelings of being understood and even safeguarded against any homophobic sentiments potentially persisting elsewhere.

Further, to think about an ‘alliance of long-term survivors’ rather than ‘patients’ and ‘healthcare professionals’ as distinct groups, can suggest that what I observed in the clinic was also a resistance to the discourses and processes of the remedicalisation of the epidemic. To reiterate: Vinh-Kim Nguyen et al. (2011) have seen the remedicalisation of the HIV epidemic as a shift in the battle against HIV and AIDS that signals a

reinforcement of a view of the epidemic as ‘a medical problem best addressed by purely technical, biomedical solutions whose management should be left to biomedical professionals and scientists’ (Nguyen et al. 2011:1). It has also been asserted that HIV remedicalisation encourages a narrow understanding of HIV care in relation to the benchmark of viral suppression (Kippax & Stephenson 2012). It appears to me that the debates on the remedicalisation of the epidemic leave little room for understanding the nuances of the relationship between healthcare professionals and biomedicine. As a result, HIV doctors and nurses may easily be seen as agents of remedicalisation. On the other hand, what my research has shown by defining the elements of camp culture in HIV care is the doctor’s engagement with aspects of care that extend beyond monitoring treatments. In my discussion on the inclusion of camp humour and the equalising qualities of camp culture, I have shown how HIV remedicalisation is being resisted by those who deliver HIV care and administer ART. To put it differently, my research has suggested that health professionals may recognise that administering treatments is not sufficient for providing care to HIV patients and, therefore, their relationship with biomedicine is more nuanced than assumed in criticisms of HIV remedicalisation. Yet, rather than leaning towards denying HIV remedicalisation, I wish to argue that revealing these complexities may offer a new angle to the debate, by showing the importance of a pervasive sexuality that has contributed towards the forming of HIV care and relations in the clinic.

Conclusion

Foregrounding gay sexuality in my analysis led me to acknowledge how both patients and healthcare professionals can be equally invested in participating in camp culture. I was steered towards thinking about alliances of long-term survivors – a concept that can include both patients and medical professionals. In this way, in this chapter, I arrived at an analysis of HIV care and doctor-patient relations that did not use negotiations of the power relation between doctors and patients as its

starting point. Instead of looking at the differences in knowledge of HIV and HIV treatments between medical professionals and HIV patients and what those differences may mean, I focused on the shared camp aesthetic and the shared history of living through the epidemic as gay men and how they form specific relations in NW clinic. This is significant, as a great deal of research done by sociologists of medicine has revolved around questions of a patient's agency, the asymmetry embedded in doctor-patient relations and patients' adherence to medical prescriptions (see, for example, Gil et al. 2010; Maseide 1991; Segall & Roberts 1980). Similarly, the arguments suggesting that AIDS activism, which ushered in the democratisation of HIV healthcare, relied on the renegotiating of power relations in medical settings (Epstein 1996). While it cannot be assumed that all patients have been able and/or willing to participate in negotiations over HIV treatments to the same extent, the subversive and equalising qualities of camp culture offer an alternative way of acknowledging the uniqueness of relations between gay men who are long-term survivors and their carers. The HIV care which I have depicted in this thesis does not always come with the greater involvement of patients in decision-making. It may be attached to the physical closeness between patients and doctors or the use of camp humour that comes from being sensitive to patients' experiences of being at the epicentre of the epidemic.

Chapter Seven. Negotiating the past of the epidemic

The way in which I have shown how sexuality has political and ethical importance for gay men in the delivery of care contextualises my arguments within the broader history of negotiations of gay sexuality throughout the epidemic. I have focused on those elements of HIV care that seemed to be imbued with a history crucial to those who identify as gay and are long-term survivors. In my research, I assessed the significance of camp culture in HIV care through looking at how camp has been present and useful in gay communities in the past – how it has been embedded in specific political, social and historical practices. At the same time, while using my knowledge of historical accounts of the epidemic centred around gay men, I remain aware that the past is never given, but must be continually reconstructed and re-presented by both individuals and collectively (Erll 2010).

The men I met and interviewed in NW clinic recalled frequently the early days of the epidemic and the change that came with effective ART becoming available. They often described the 'pre-treatment' era in similar terms to Jack Halberstam (Halberstam, cited in Kafer 2013) who proposed that in the early years of the AIDS epidemic, the crisis forced gay communities to focus on 'the here, the present, the now'. The interviews with patients and healthcare professionals as well as my observations conducted in consultation rooms made me think about how the urgency to act, fuelled by the uncertainty of the future resulting from being diagnosed with an untreatable infection, has been since replaced by the necessity to consistently adhere to the long-term treatment of life-saving ART. Simultaneously, the frequent remembering of the outbreak of the epidemic and the AIDS crisis that I witnessed in the clinic left me under the impression that the past continued to matter to the men I engaged with through my research.

The shift from 'then' to 'now'

Robert, who was the most senior among the nurses, shared with me what the shift from *'then'* to *'now'* meant to him. At the time of my research, Robert had been working as a research nurse in the HIV clinic for 33 years. He gave the impression of a calm and warm person. I was particularly grateful to him for always trying to include me in the conversations that were taking place in the waiting rooms and explaining any in-jokes that were shared. I enjoyed our interview, as Robert seemed to care about making sure that I was getting enough information from him and that he was answering my questions in the right manner. Even after I explained that there are no right or wrong answers, Robert would check with me from time to time if what he was telling me was useful to me. It was probably the most relaxing interview in my research. Other staff members seemed to trust Robert's skills in making things right, as he would be called every time there was a disagreement, confusion or a complaint from a patient. As Robert had worked in the HIV field from the beginning of the AIDS crisis, he frequently referred to those early days in our conversation, explaining how the memories he has, help him in his work today. He referred to the changes in the field of HIV medicine throughout our interview, shedding light on what they might have meant for an HIV healthcare professional. This is how he described these changes:

> Changes came in the mid-90s with the introduction of antiretroviral therapies. So when I first started, we never had an effective antiretroviral therapy. We still used therapy, but we could never sustain it for very long. […] And I doubted it. Until I see the evidence, I don't quite believe it. If I don't see it for myself… So when I started to see people turn their health around, people who were really, really sick started to get better and get better still. That really transformed my experience of nursing in this area. (Interview with Robert)

Robert explained to me that now, he is confident about the benefits of ART for patients' health, and that this confidence came from witnessing a large number of patients who started regaining their health after starting ART. This suggests that the change in HIV care might not have been experienced as a fixed point in time, but rather as years of increasing confidence in the scientific evidence and experiences of witnessing patients' progression in getting healthier and feeling better. The question that emerges then is: what was required for the shift from *'then'* to *'now'* to take place? Furthermore, what happens to the knowledge accumulated in the pre-treatment era? How is the past of the epidemic negotiated in an HIV clinic today?

The old guard: the value of experience and the necessity of unremembering

The majority of the medical staff I met and interviewed for this case study began their careers in the HIV field during the early years of the HIV/AIDS epidemic. With the objectives of care changing over time, I began to think about the role of the knowledge that doctors and nurses have accumulated over the years, especially during the pre-treatment era when care often had a palliative function. Is it useful today? If so, how is it useful?

Among other healthcare professionals, I interviewed Lauren. Despite the fact that she did not identify as a part of the group I was focusing on, I was interested in her story, knowing she had been working in the HIV field since the outbreak of the epidemic. Lauren seemed to be close to Mark and Shaun – they often stopped to chat in the clinic's corridors. Lauren had a strong presence in the clinic. She attracted my attention, wearing elegant clothes and always greeting her patients from a distance. She seemed affectionate and often held patients' hands while they were having casual chats in the waiting area (Field Notes 9th June, 2014). The interview with Lauren shed light on what it means to her to have worked through the epidemic since its emergence:

> It's a question of strategy. I think what young people need to understand is that you have to have a strategy with each patient […] and I think that's the old guard, like us – Mark, Shaun and myself – who know because we've gone through all those ARVs [antiretroviral drugs] one after the other. So we've seen all different types of drugs. So we have a historical view. We forget that the rest of the people don't have it. Because we've been there since the beginning which is such a rare thing. In the history of diseases, who has seen the beginning of tuberculosis? This was probably before Jesus Christ so, you know, nobody is around and for other diseases it's the same probably. So that makes the generation of HIV experts quite amazing. That people have seen it from the beginning. (Interview with Lauren)

Lauren points to the exceptionality of the situation of HIV doctors who cared for HIV and AIDS patients early in the epidemic, and suggests that the years they spent being involved in providing care from early in the epidemic, are a source of knowledge from which she benefits in her everyday practice. Lauren calls it a 'historical view'. To me, that utterance signalled that the past continues to play a role in the forming of care today. Or, to put it differently, knowledge does not simply disappear, being replaced following biomedical developments. It continues to be relevant and, therefore, the question that needs to be posed is: what does it do? How does this knowledge continue to be negotiated?

Throughout our interview, Shaun, whom I interviewed in the previous chapter, remained focused on what he saw as the challenges of his profession. When I asked him about the difference between working with HIV patients *'then'* and *'now'*, he told me:

> as a doctor who's worked in the field when everybody was going to die and then you had to change the whole way of thinking and looking after people in the long-term with

> very little issue about dying is quite difficult I think. I was very good at what I did then and I had to almost review the way in which I look at the HIV medicine. You know, you can't be blasé and just say 'This patient doesn't matter, they are going to die'. Every decision that you make now, in the modern HIV medicine, may have an impact on their ability to live, their expectancy to live.

Later he added:

> I think that the changes in the field have had quite a significant impact on me, but as a 'coper' I just get on with it. I shut up and get on with it. (Interview with Shaun)

Shaun described to me the changes that came with HIV becoming a treatable and chronic condition as altering the way in which patients' futures are imagined and acted upon. What is interesting about this particular quote is that Shaun points out the difficulties that the introduction of effective ART brought to him as an HIV practitioner. The implementation of ART as a routine treatment for HIV tends to be discussed in terms of its life-saving impact. This may mean that the complexity of what is required to implement ART can be overlooked. I do not wish to dismiss how ART has dramatically changed the lives of those living with the infection, allowing them to regain their health. What I wish to explore here, are the intricacies that came with the most radical change in HIV medicine and care. Shaun's story suggested to me that the introduction of ART did not merely mean absorbing new medical guidelines, but it required a holistic change to the way he viewed his work and his capability to provide good care. It required adapting and coping with the shift and the new reality of HIV care.

Shaun told me that, while he felt confident about delivering care to the fatally ill AIDS patients, he had to make an effort to review the objectives of care and relearn HIV care. Turning to the literature on the negotiating of the past within gay communities helped me to broaden my understanding

of Shaun's experiences. It has been theorised that gay men used to negotiate the past of the AIDS epidemic in particular ways, through which they dealt with the immense loss of lives and the damaging discourses and policies that perpetuated homophobic sentiments and HIV/AIDS stigma. It has been proposed that, for gays, one of the strategies for managing the shared past in the times of the epidemic was unremembering. Christopher Castiglia and Christopher Reed (2012) explain that, following the AIDS crisis, gay memory needed *'cleaned-up'* versions of the past, as substitutes for more challenging memories of social struggle. They argue that practices of unremembering sought to undo the historical basis for gay communities that once seemed to offer radically new forms of social and sexual engagement. Castiglia and Reed argue that the AIDS crisis became an occasion for a powerful concentration of cultural forces that have been wiping out memories, not only of everything that came before, but also the remarkably vibrant and imaginative ways that gay communities responded to the epidemic (Castiglia & Reed 2012: 2-3). The concept of unremembering made me think about the tension that I saw in NW clinic between using the experiences gained through working in the AIDS epidemic pointed out by Lauren and the need to forget the practices initially adopted, referred to by Shaun. While Castiglia and Reed see unremembering as a perpetual process, not a once-and-for-all occurrence of forgetting (2012: 10), Shaun pointed out the effort that was required of him to learn how to become an HIV clinician who treats HIV chronic infection. At the same time, Shaun's experiences seemed to me somewhat different to what Castiglia and Reed's concept of unremembering assumes. Unremembering in the times of the epidemic was an attempt by gay communities to distance themselves from the supposedly excessive generational past in exchange for promises of 'acceptance' in mainstream institutions (2012: 9). By contrast, I was under the impression that Shaun experienced his distancing from the past in isolation. When he said he 'shut up and got on with it', I saw it as a solitary process. It reminded me of the arguments suggesting – in relation to HIV patients – that, in the medicalisation of the epidemic that came with the development of effective biomedical

treatments, a user of medical technologies tends to be assessed as an individual, solely responsible for any potential failure of the treatments (Race 2001; Rosengarten 2012). While listening to Shaun, I wondered how the individualisation of responsibilities affected HIV specialists at the time when it was required for them to change their medical practices.

Remembering to adhere

Patients' adherence to ART has been one of the most debated objectives of HIV care and treatment since the biomedical breakthrough in 1996. The literature has argued for the importance of patients' adherence for the success of ART and has listed factors that may impact on it, such as good physician-patient relations (Garcia *et al.* 2005; Lutfey 2005). When I asked Shaun how he approached patients who have adherence problems, he suggested that referencing the past AIDS crisis could encourage regular dosing of medications:

> Sometimes I think we need to put up pictures of people with AIDS-defining complications, up all around, to remind them of what this disease is capable of doing, to remind them that if they don't take their medications properly and appreciate how lucky they are to have those medications, it can all go horribly wrong. (Interview with Shaun)

I interpret Shaun's statement as a recognition of the power that remembering the past of the epidemic holds. In Chapter Three, I wrote that the action of communicating past experiences is never driven solely by the transmission of narratives of the past, but also by a situated reconstruction of those experiences in the present, and depends on the goals and pragmatic needs of the social group engaged in the process (Bietti 2011). For Shaun, the memories of the AIDS crisis resulting from the lack of ART may support the emergence of the adhering HIV patient, who is responsible for making good use of available treatments, not only to hinder the progression to AIDS but also to prevent history from repeating itself. Shaun's idea resonates with Ross Poole's (2008) discussion on a collective memory in which he draws on philosophers

Maurice Halbwachs and Friedrich Nietzsche, in order to argue that it is through the process of remembering that a past action creates a present commitment and we learn to act knowing that our future selves will be held responsible for what we have done (Poole 2008: 154). Shaun recognised that pictures of AIDS victims would have the potential to mobilise memories of the past health crisis in a way that would generate a commitment to avert a similar tragedy in the future. Visualisations of AIDS complications, according to Shaun, would also remind patients that the chronicity of HIV infection is not given, but requires the effort of adherence. There are no pictures of people with AIDS symptoms in NW clinic, but Shaun told me that he warns his patients about the possible consequences of missing doses of anti-HIV drugs by reminding them about what the HIV infection leads to without ART. In other words, Shaun incorporates memories in the ways in which he provides HIV care. Or, to put it differently, remembering the HIV crisis is embedded in HIV care.

According to Robert, whom I introduced earlier in this chapter, many of the newly diagnosed patients still see HIV as a 'death sentence'. He explains his role as 'taking those patients on a journey', through explaining how things were before antiretroviral drugs were available and how current therapies prolong life. On the other hand, those patients who seem knowledgeable about the treatment may 'mess around' with the therapy. These are also people who need to be brought to treatment through agreeing on a single understanding of HIV as a life-threatening virus which needs to be continuously kept at bay with ART (Interview with Robert). Robert presented me with two different situations of care, with the first one requiring an effort to detach HIV infection from its association with the pre-treatment era of the AIDS crisis and assert HIV as a chronic condition. In the second instance, Robert needs to remind the patient that the chronicity of HIV infection is not to be taken as given and may put the patient's life at risk. Telling me about different strategies he uses to encourage adherence and help patients in sustaining the chronicity of HIV, Robert illustrated how physicians may draw on the past as well as the imagined future of the epidemic. In doing so, Robert drew my attention to how the past and the

future are mobilised when delivering HIV care and sustaining the chronicity of HIV.

Again, turning to the literature on the ways in which gay communities have been negotiating their relationship with the past throughout the epidemic helped me to build a greater understanding of what Robert and Shaun shared with me. As Watney (1996) puts it, the times before AIDS – of gay liberation and sexual freedom – became a threat to the lives of individuals. The livelihood of the gay community became like 'a prelapsarian dream, impossibly distant', while gay men remained aware of what their lives might have been like if the epidemic had not happened (Watney, cited in Berridge 1996: 15). In 1990, John Clum wrote that in the face of the AIDS epidemic, remembering became a central act in gay culture. AIDS literature, art and film exposed memory intertwined with desire and forged new links to the past (Clum 1990: 648). In the context of the AIDS epidemic and for the generation most affected by it, remembering was not just answering a desire to memorialise the dead and honour their lives. It also became a means of recalling the vanished past of a drastically changed society, by remembering the 'orgiastic time before AIDS' (1990: 653). Celebrating past pleasures – as opposed to lamenting sexual promiscuity – made it possible to come to terms with one's past without giving in to feelings of guilt or regret. It often affirmed the present, which meant dealing with memories of the past and facing an uncertain future (1990: 657).

Similar to Castiglia and Reed's concept of unremembering, remembering has been recognised as an act that engages communities of gay men. Further, remembering in art production has the potential to attract the attention of broader audiences of outsiders. Probably the most famous act of memorialising and honouring those who lost their lives to the epidemic was initiated by Cleve Jones in the NAMES Project AIDS memorial Quilt. It has been argued that the Quilt created a wall of memory that exposed both private loss and public indifference (Hawkins 1993: 756). It strengthened the sense of community and turned what was perceived to

be a ‘gay disease’ into a shared national tragedy (1993: 757). The Quilt brought mourning from the margin to the centre of everyone’s attention, offering a way to suffer intimate losses in the most public space in America (1993: 760). The Quilt as a way of remembering was simultaneously private and public, as it did more than simply sustain a memory of the dead by raising social awareness of the AIDS tragedy and confronting homophobia. The memorial gave voice to relationships and stories which had not been anticipated before and emerged as a vital tool for AIDS prevention education (Stull 2001: 86-87).

On the other hand, the remembering I observed in my research had a very different character. In NW clinic, the tragic events of the AIDS epidemic were remembered in a different manner. Memories seemed to serve a different purpose. Instead of being a means of strengthening the community or being an act of activism, my case study reveals that the remembering that was adopted in care in the clinic could take the form of warnings to which patients are exposed as individuals, often during one-to-one consultations with their physicians. The memories of the past AIDS crisis did not aim to bring the community of long-term survivors closer in a way that the Quilt did. Rather, they enforced the sense of individualisation through making one feel exclusively responsible for one’s health and for the success of HIV medicine in hindering the epidemic.

Conclusion

The arrival of AIDS changed the relationship with the past that gay men had (Watney in Berridge 1996: 15). Here, I have shown how the transformation of HIV into a chronic disease that need not reduce longevity or quality of life, has created the necessity for long-term survivors to rework their relationship with the past again. In my case study of HIV care, I observed how, as the AIDS crisis ‘became the past’, long-term survivors negotiate their relationship with it through acts of remembering and unremembering, which are largely aimed at supporting the success of ART. The ways in which the past AIDS crisis is being

remembered and unremembered in the clinic today seems to reinforce the sense of individualisation, through making one feel exclusively responsible for one's (or one's patient's) health, and for the success of HIV medicine in hindering the epidemic. Yet, as I have shown in the previous chapters, the long-term survivors of the epidemic, both patients and healthcare professionals, seem to continue to engage with what constituted the 'vibrant past' of the early responses to the AIDS crisis: a celebration of queer sexuality and a willingness to be subversive and to reveal the social roles of a doctor or a patient as cultural performances. What I am proposing in this case study is an account of HIV care that is imbued with a history crucial to those who identify as gay and long-term survivors of the epidemic. Acknowledging the epidemic's history and the history of gay communities underlines the potential continuities and disruptions within which *good* care and what is necessary for *good* care is renegotiated. It can be argued that in the past, HIV care was a site of exception and experimentation that facilitated the emergence of doctor-patient relations that could be described as relatively free of the normative constraints that tend to define medical spaces – for example, the constraints that specifically and explicitly exclude considerations of desire and a consideration of the body in aesthetic or erotic terms. Through that relative freedom, it became possible for HIV doctors and their patients to experiment with how good *care* could be practised.

Chapter Eight. Conclusion

Bringing sexuality to the forefront of the analysis

A few months before completing this text, I watched *Angels in America*, an HBO series based on a play by Tony Kushner in which he depicts the effects of the AIDS crisis on gay communities in New York. There is a scene in *Angels in America* where we can see one of the characters, Prior, in a hospital room, already suffering from AIDS symptoms. The room looks exactly how we expect it to be: it is filled with medical equipment and there is a bland-looking hospital meal next to Prior's bed. The atmosphere changes suddenly when Prior is visited by Belize, his friend and former lover. Belize wears a brightly coloured outfit with a feather boa around his neck. His extravagant and glamorous style is striking against the backdrop of the hospital room. Entering the room, Belize showers it with glitter and embraces Prior before addressing him: 'You look like shit!' Behind Belize, we can see a nurse who stopped in the corridor to watch this 'spectacle'. It is the beginning of the epidemic and my guess is that the nurse had not seen anything like this before.

Describing this particular scene from *Angels in America* seems an appropriate way to conclude, as it captures what has been the object of enquiry throughout this thesis: the ways in which sexuality matters when HIV care is provided for and negotiated by men who identify as gay. Or, to put it differently, what engaging in certain sexual cultures allows for in HIV healthcare. Belize's performance-like aesthetic and the excessiveness of his outfit represent the subversiveness of camp culture in relation to the seriousness of medicine and medical spaces. Very early into my research, I recognised sexuality as a site of embodied politics and creativity that has been crucial to the affected communities' efforts to challenge normative discourses of epidemiology and biomedicine. Yet, on the first day in the clinic, I probably looked like the surprised nurse who watched Belize in the scene described from *Angels in America*. Just like him, I had little awareness of camp culture, never expecting to find it in a medical space.

One of the things this thesis has offered is a story of my journey of discovering the role that sexuality plays in HIV care today. My focus on patients who identify as gay and can be described as long-term survivors, enabled me to identify specific elements of care, and notably the mode of what I term ‘camp culture’. Guided by patients, doctors and nurses in NW clinic, I reflected on the humour and flirtatious atmosphere that formed a vital contribution to the care practised. On the basis of my observations and interviews, I have sought to convey the contributory role played by this culture in the delivery of care to those who chose to participate in it. With that in mind, I will now draw out some of the implications of my work in relation to the processes and discourses of HIV normalisation – in particular, the shift of HIV treatment into the setting of general medical practice proposed by the UK health authority.

Recently, I was describing my findings to a clinician working in HIV and sexual health. While expressing fascination with my observations of HIV care, he asked me immediately how I saw my research making an impact on how HIV care is delivered. He wanted to know if it was going to contribute to, for example, designing new policies. Yet, I remain reluctant to assess the significance of my findings in the ways that sociologists working in medicine and healthcare are often required to do, e.g. in terms of what interventions we can help design to improve the outcomes of care. My reluctance comes from the realisation that the care I observed and described here emerged organically under conditions that cannot be replicated, outside or even contrary to official guidelines. To put it differently, such care cannot be ‘designed’ as an ‘intervention’. Yet, knowledge generated in this research invites new ways of thinking about HIV care. Looking at how sexuality matters in care delivery shows new possibilities for conceptualising HIV care in alternative ways to how it began to be understood with the introduction of antiretroviral drug treatments, i.e. in relation to biomedical responses to the epidemic and their efficacy. It contributes towards building a critical approach to HIV healthcare, health policies and their implications for individuals – a task that, as discussed in Chapter Three, Vinh-Kim Nguyen *et al.* (2011)

identified as increasingly difficult within the context of today's remedicalised HIV pandemic, which encourages a view that the epidemic should be addressed as purely a medical problem with knowledge and technologies provided by biomedical professionals and scientists (Nguyen *et al.* 2011:1).

Rethinking HIV exceptionalism and normalisation

Putting sexuality at the centre of my analysis led me to rethink the definition of HIV exceptionalism, particularly in relation to the current efforts to reorganise the distribution of HIV healthcare which are one of the visible consequences of the discourse of normalisation. Since the outbreak of the epidemic, there has been a tendency for HIV physicians to provide holistic care to their patients, which addresses both HIV-related and non-HIV-related health conditions, and many patients have indicated that this is preferable (Hutchinson et al. 2016; Weatherburn et al. 2013). During the consultations I observed, patients would often seek advice regarding their general health in addition to discussing their HIV treatment. Yet, I also noticed that patients were routinely asked to agree for their GPs to be notified of their seropositive status and were encouraged to visit their GPs for advice on non-HIV related problems. More recently, there has been a shift, reflecting national recommendations (British HIV Association 2011) which encourage the increased involvement of GPs in providing primary care to HIV patients (Desai *et al.* 2011; Hutchinson *et al*. 2016). It has been reported that it is becoming increasingly difficult for HIV specialists to prescribe medication for conditions that could be managed in primary care – for example, hypertension. Simultaneously, the shift in care distribution remains controversial and is sometimes framed as a sign of moving away from exceptionalism, understood in terms of increased confidentiality and patients' autonomy (Hutchinson *et al.* 2016).

What I would like to propose is that for the gay men I describe in my research as long-term survivors, both patients and healthcare professionals, HIV exceptionalism exceeds its standard definition that, as

discussed in Chapter One, focuses on the patient's autonomy and increased caution around issues of consent and confidentiality (De Cock & Johnson 1998). The case study I offer suggests that HIV exceptionalism is also manifested in the non-judgmental approach to what medicine has constructed as unsafe sex practices, the physical closeness between patients and healthcare professionals, and humour that is used in NW clinic. It is a style of response to the epidemic and to another gay man's seropositive status that reminds me of the one portrayed by Belize's character in *Angels in America*. HIV exceptionalism, defined by these aspects, can be secured if both patients and doctors share a particular sexual culture. Its value seems to be acknowledged in situations such as the one where, for example, Mark reassured his patient about going to his GP by saying that the GP seemed 'quite gay'. While elsewhere, concerns about stigmatisation or a perceived lack of confidentiality in primary care settings were one of the main reasons patients did not wish to disclose their seropositive status (Weatherburn et *al.* 2013), in my case study, I have shown how the prevalence of camp culture in NW clinic was an important facilitator of honest discussions about patients' sexual health and the sexual risks they may take. I wish to propose that, while the move towards HIV normalisation may reintroduce normative constraints on doctor-patient relationships, it is worth investigating what can be learnt about what the era of HIV exceptionalism enabled in terms of defining and practising *good* HIV care.

Caught between the past and the future

The scene from *Angels in America* that I described earlier captures a moment in history: the outbreak of the epidemic, the inability of medicine to hinder the progression to AIDS in those living with HIV and the response of gay men to the crisis. Understanding the significance of that historical event for how HIV healthcare is being delivered in NW clinic was one of the themes in my research. In Chapter Three, I described being a witness to a debate during which two contrasting points were raised by different social scientists working in the epidemic: one suggested the

enduring value in looking back at the events of the AIDS crisis and the other argued that there is not enough emphasis on current processes and the anticipation of future developments. Yet, in my research practice, I found the choice between focusing on the past of the epidemic and HIV care or patients' individual life histories and analysing the current state of HIV medicine and predictions of future developments, to be a deceptive dichotomy. Rather, very early into my fieldwork, I realised that the ways in which patients related to the past were continuously negotiated. In NW clinic, they also mattered to doctors who considered the past events in the process of making decisions regarding the provision of care. Consequently, I argued here that the past has a performative function in HIV care.

In other words, my research suggests that, as social scientists working in HIV, we may consider it important not to distance ourselves from the 'past'. Doing research that acknowledges the history of a disease and of biomedicine may be seen as part of a larger project of resisting the dominance of biomedical discourse. Reflecting on the past may be seen as one of the strategies for building an approach to what matters in HIV healthcare that is inclusive of elements of care that occur outside or on the margins of what is required by biomedical treatment regimens. It may allow for a richer picture of what happens in the clinic. In this thesis, I have shown how HIV is a condition that *has* a history and how that history matters for how HIV care is being delivered and negotiated – for instance, how it forms doctor-patient relationships and how it features in strategies employed to encourage patients' adherence to the treatments. Rather than being omitted from the analysis, in the case study of NW clinic presented here, the past emerged as an object of interest in its own right and as means to understand the observed ways of practising care.

Furthermore, the memories that patients and doctors shared with me allowed me to counter the medicalised discourses of the epidemic within which patients, and to some extent doctors, are merely subjects in relation to biomedical technologies and biomedical progress. In other words, by

understanding the phenomena I was observing in NW clinic as resulting from complex longstanding negotiations and by engaging with the social and historical contexts that remained significant to those I wrote about, provided me with an opportunity to challenge the post-treatment discourse within which the HIV patient has been reconfigured as a responsible individual contributing to the success of hindering the epidemic through the correct use of ART. Within such discourse, the HIV patient remains a mere subject in relation to biomedicine – he or she is seen, understood and judged in relation to biomedical progress. On the other hand, I have highlighted how particular elements of care that reveal creativity outside of standard treatment practices, can be characterised as subversive to medical discourses and often engage healthcare professionals or other patients. To put it differently, looking at ways of delivering HIV care which are shared and subversive, allowed me to move away from discussing the individualised responsibility of the patient who is understood as a mere user of medical technologies.

Lastly, I mentioned in Chapter Two that in the UK, the organised gay response to the AIDS epidemic, such as efforts to provide self-help aimed at the community, raising awareness and providing available scientific information, used the existing structures formed many years before the outbreak of the epidemic in the 1980s. For instance, the Lesbian and Gay Switchboard established nine years earlier and initially dealing with an increased number of sexually transmitted diseases in the gay community, opened up a special line helping those who had questions regarding AIDS (Berridge 1996: 17). Considering the ‘pre-history’ of the AIDS epidemic underlines the continuity of knowledge and structures within the gay communities. Perhaps we may also draw continuity between HIV and other sexually transmitted infections. While infection with HIV has been considered as the prime health issue for gay and bisexual men, it is known that other infectious diseases also affect this population. For example, men who have sex with men (MSM) are at increased risk of acquiring hepatitis A virus (HAV) and hepatitis B virus (HBV) through sexual exposure (Kahn 2002). In June 2017, it was reported that new cases of

HAV cases soared in Western Europe as a result of an epidemic in gay and bisexual men. Europe's health body, The European Centre for Disease Prevention and Control (ECDC), has called for increasing prevention measures targeting MSM and for ensuring a timely monitoring of this new outbreak that would allow the rapid detection of critical developments, such as the spread of the epidemic into other populations (European Centre for Disease Prevention and Control 2017). At the same time, building and preserving the knowledge of the ways in which gay men were responding to the epidemic that was endangering their health and lives in the past may enhance our understanding of the possibilities for and barriers to resisting current and future outbreaks. In other words, I wish to argue that remembering and scrutinising the past may be a useful tool for experts working in sexual health. While it has been observed that social research has primarily served as an adjunct to clinical trials in the context of HIV/AIDS prevention (Auerbach 2010), social scientists and others recognising and working with these continuities of knowledge and structures, e.g. historians, could play a central and instructive role in public health.

Thinking beyond NW clinic

While working on the completion of this text, I took on employment as a researcher in sexual health. This experience has provided a valuable contrast to what I observed in NW clinic. I include it here in order to discuss the potential implications of the findings presented in this thesis for thinking about healthcare for other stigmatised sexually transmitted infections (STIs), especially in relation to the recent and ongoing reorganisation of sexual health services in London.

The research required spending a significant portion of time in sexual health clinics in different parts of London, interviewing patients and healthcare professionals. My observations confirmed and expanded my understanding of how the provision of sexual health services that had been initially structured in response to HIV was going to be drastically

changed. A new collaborative commissioning model for sexual health services in London that has been implemented since April 2017, called the London Sexual Health Services Transformation Programme, aims at increasing access to the services through the internet. Effectively, patients are being discouraged from attending a clinic. At the same time, the programme promises to improve the patient experience and sexual health outcomes, provide cost-effective delivery of services across the capital and reduce the incidence of STIs, HIV and teenage pregnancies (London Sexual Health Transformation Programme 2017).

Concurrently, my work in the clinics exposed me to the growing concern about drug-resistant STIs – in particular, gonorrhoea[29]. While effective control of gonorrhoea relies on appropriate treatment with antimicrobials, antimicrobial resistance (AMR) has emerged for essentially all antimicrobials following their introduction into clinical practice[30]. Health experts increasingly describe gonorrhoea as becoming an 'untreatable superbug' (see for example Ohnishi 2011; Unemo & Nicholas 2012; WHO 2012). Among strategies suggested as necessary to tackle the public health challenge that multidrug-resistant gonorrhoea is posing are: prevention efforts, including greater STI screening coverage and easy access to sexual health services; sustained and continued focus on the groups at highest risk; health promotion and education increasing public awareness and encouraging safer sexual behaviour (Savage 2011).

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[29] Gonorrhoea is among the most common STIs and countries with good surveillance have reported increases in cases of gonorrhoea – for example, an 11% rise between 2014 and 2015 in the United Kingdom, which is believed to reflect longer-term trends (Alirol 2017). For public health worldwide, gonorrhoea, including its severe complications, remains a major health concern which now requires new strategies and treatments.

[30] At the moment, the only first-line options for antimicrobial monotherapy in most settings worldwide are the third generation, extended-spectrum cephalosporins (ESC), ceftriaxone (injectable) and cefixime (oral). However, during the last decade, susceptibility to these antibiotics has been reported to have significantly decreased and clinical treatment failures with these ESCs have been verified in multiple settings internationally. Furthermore, cases of gonorrhoeae strains with high-level resistance to the last remaining option for empiric antimicrobial monotherapy were also reported (Unemo *et al.* 2013). The WHO Gonococcal Antimicrobial Surveillance Programme (GASP) suggests that resistance is spreading, especially in Asia, North America, Europe, Latin America and the Caribbean, and Australia, with large data gaps in Africa and Central Asia (Alirol 2017).

One of the things that my case study has revealed is that challenging the stigma around sexual health and increasing the openness of conversations about sexual lives and sexual risks may require employing humour in care delivery and defying hierarchies that commonly characterise relations in medical settings. In the light of my findings, limiting patients' access to services and, consequently, to relationships with healthcare professionals, may hinder strategies that have been identified as crucial to stopping gonorrhoea from becoming an 'untreatable superbug'. At the same time, as the move to online care seems unavoidable, it is important that social scientists remain engaged in research on how different sexual cultures are being articulated in online spaces and how they become significant to their users.

Bibliography

Aliouat-Denis, C-M.; et al. 2008, '*Pneumocystis*species, co-evolution and pathogenic power', *Infection, Genetics and Evolution*, vol. 8, no. 5, pp. 708–726.

Alirol, E, Wi, TE, Bala, M, Bazzo, ML, Chen, X, Deal, C, Dillon, JR, Kularatne, R, Heim, J, Hooft van Huijsduijnen, R, Hook, EW, Lahra, MM, Lewis, DA & Balasegaram, M 2017, 'Multidrug-resistant gonorrhea: A research and development roadmap to discover new medicines', *PLoS Medicine*, vol. 14, no. 7.

Anderson, G 1993, Fundamentals of Educational Research, Falmer Press, London.

Anderson, J 2014, Paper presented at the *New methodologies for Interdisciplinarity in HIV and related health fields*, Goldsmiths University of London, London.

Anderson, T 2017, *HIV Long-Term Survivors Declaration: A Vision for Our Future 2017.* Available from: <https://letskickass.hiv/with-courage-and-compassion-long-term-survivors-of-hiv-strive-not-only-to-survive-but-also-to-ee056d372994>. [27 June 2017].

Anderson, T n.d., *What is AIDS Survivor Syndrome and Why Do You Need to Know?*. Available from: < http://letskickass.org/aids-survivor-syndrome>. [2 June 2017].

Anim-Addo, J & Gunaratnam, Y 2012, 'Secrets and lies: Narrative methods at the limits of research', *Journal of Writing in Creative Practice*, vol. 5, no. 3, pp. 387–400.

Astedt-Kurki, P & Liukkonen A 1994, ‘A humour in nursing care’, *Journal of Advanced Nursing*, vol. 20, no. 1, pp. 183–188.

Atkinson, P & Hammersley, M 2007, *Ethnography: principles in practice*, Routledge, London & New York.

Auerbach, JD 2010, ‘Not Just a Handmaiden: The Critical Role of Social Science in Microbicides and Other Prevention Research’. Paper presented at the *International Microbicides 2010 Conference*, Pittsburgh, PA, USA.

Bachmann, CL, Gooch B 2017, LGBT in Britain. Hate crime and discrimination, Stonewall.

Barnard, A, Spencer, J 2010, *Routledge encyclopedia of social and cultural anthropology*, Routledge, London and New York.

Bartlett, JG 2006, *Ten Years of HAART: Foundation for the Future*, Available from: <http://www.medscape.org/viewarticle/523119>. [27 June 2017].

Bartlett, JG & Finkbeiner, AK 2007, *The Guide to Living with HIV Infection: Developed at the Johns Hopkins AIDS Clinic*, Johns Hopkins University Press, Baltimore.

Bayer, R 1991, ‘Public Health Policy and the AIDS Epidemic’, *New England Journal of Medicine*, vol. 324, no. 21, pp. 1500–1504.

Benton, T 2010, *Understanding Heritage and Memory*, Manchester University Press, Manchester.

Berlant, L 2007, ‘On the case’, *Critical Inquiry*, vol. 33, pp. 663-672.

Berridge, V & Strong P (eds) 1996, *AIDS and contemporary history*, Cambridge University Press, Cambridge & New York.

Bietti, LM 2011, ‘Piercing memories: Empty spaces in the histories of Argentinean families - personal reflections’, *Memory Studies*, vol. 4, no. 1, pp. 83–87.

Black, SP 2012, ‘Laughing to Death: Joking as Support amid Stigma for Zulu-speaking South Africans Living with HIV: Laughing to Death’, *Journal of Linguistic Anthropology*, vol. 22, no. 1, pp. 87–108.

Blee, KM & Currier, A 2011, ‘Ethics Beyond the IRB: An Introductory Essay’, *Qualitative Sociology*, vol. 34, pp. 401–413.

Bottorff, JL, Gogag, M & Engelberg-Lotzkar, M 1995, ‘Comforting: exploring the work of cancer nurses’, *Journal of Advanced Nursing*, vol. 22, no. 6, pp. 1077–1084.

Bowling, A 2009, *Research methods in health: investigating health and health services*, Open University Press, Maidenhead.

British HIV Association 2013, Standards of care. Available from: <http://www.bhiva.org/documents/Standards-of-care/BHIVAStandardsA4.pdf>. [15 march 2018].

British HIV Association 2012, Standards of Care for People Living with HIV. Available from < http://www.bhiva.org/documents/Standards-of-care/BHIVAStandardsA4.pdf>. [25 June 2017].

British HIV Association 2011, The future role of primary and community care in HIV. Available from: < http://www.bhiva.org/documents/Publications/PositionStatement.pdf >. [6 June 2017].

British Sociological Association 2002, *Statement of Ethical Practice*.

Brokaw, C, Nichols, M & Hayley, M (executive producers) 2003, *Angels in America*, Home Box Office.

Carter, E & Watney, S 1989, *Taking liberties. Serpent's Tail*, Institute of Contemporary Arts, London.

Castiglia, C & Reed, C 2012, *If memory serves: gay men, AIDS, and the promise of the queer past*, University of Minnesota Press, Minneapolis.

Clarke, A, Fishman, J, Fosket, JR, Mamo, L & Shim, J 2010, *Biomedicalization: technoscientific transformation of health, illness and US biomedicine*, Duke University Press, Durham and London.

Clarke, AE & Shim, JK 2011, 'Medicalisation and biomedicalisation revisited: technoscience and transformations of health illness and American medicine' *in Handbook of the Sociology of Health, Illness and Healing*, eds Pescosolido et al., Springer, New York, pp. 173-199.

Clifford, J 1997, Routes: Travel and Translation in the Late Twentieth Century, Harvard University Press, Cambridge.

Cloke, P, Cook, I, Crang, P, Goodwin, M. Painter, J & Philo, C 2004. *Practising Human Geographies*, Sage, London.

Clum, JM 1990, 'The Time before the War: AIDS, Memory, and Desire', *American Literature*, vol. 62, no. 4, pp. 648–667.

Collins, S 2014, No HIV transmissions with undetectable viral load: interim PARTNER study results show need for longer follow-up. Available from: < http://i-base.info/htb/24904>. [10 May 2014].

Conrad, P 1985, 'The meaning of medications: another look at compliance', *Social Science and Medicine*, vol. 20, no. 1, pp. 29–37.

Cook, I 2001, ‘You want to be careful you don’t end up like Ian. He’s all over the place’ in Placing Autobiography in Geography, ed. Moss, P, Syracuse University, Syracuse, pp. 99–120.

Crang, M & Cook I 2007, *Doing Ethnographies*, SAGE Publications, London.

Crimp, D 1987, ‘How to Have Promiscuity in an Epidemic’, *October*, vol. 43, pp. 237–271.

Davis, A 2015, ‘Is it OK for doctors to swear at work?’, Available from: < http://careers.bmj.com/careers/advice/Is_it_OK_for_doctors_to_swear_at_work%3F>. [8 August 2017].

De Cock, KM & Johnson AM 1998, ‘From exceptionalism to normalisation: a reappraisal of attitudes and practice around HIV testing’, *British Medical Journal*, vol. 316, no. 7127, pp. 290–293.

Denizen, N & Lincoln, Y 1994, *Handbook of qualitative research*, SAGE Publications, California.

Desai M, Field N, Crompton J & Ruf, M 2011, ‘Information for action: a method to inform HIV shared care planning in primary care at the PCT level’, Sexually Transmitted Infections, vol. 87, no. 4, pp. 295.

Dowsett, GW 2009, ‘Dangerous desires and post-queer HIV prevention: Rethinking community, incitement and intervention’, *Social Theory & Health*, vol. 7, pp. 218–240.

Dowsett, G 1996, *Practicing desire: Homosexual sex in the era of AIDS*, Stanford University Press, Stanford.

Dubois, RM, Braitwaite, MA, Mikhail, JR *et al.* 1981, 'Primary Pneumocystis Carinii and Cytomegalovirus Infections', *The Lancet*, vol. ii, pp. 1339.

Duncan, J 1981, ‘The Problems and Perils of the Superorganic in Cultural Geography’, *Annals of the Association of American Geographers*, vol. 70, pp. 181–90.

Emerson, JP 1973, ‘Negotiating the serious import of humour’ in The Sociology of the Familiar, eds. Birenbaum A & Sagarin E, Nelson, London, pp. 267-280.

Epstein, S 1996, *Impure Science: AIDS, Activism, and the Politics of Knowledge*, University of California Press, Berkeley & Los Angeles.

Erll, A 2010, *A companion to cultural memory studies*, De Gruyter, Berlin.

European Centre for Disease Prevention and Control 2017, Hepatitis A outbreaks in the EU/EEA mostly affecting men who have sex with men – third update. Available from: <https://ecdc.europa.eu/sites/portal/files/documents/RRA%20hep%20A%20outbreak%20EU%20EEA%20in%20MSM%20third%20update%2028%20June%202017_0.pdf>. [19 August 2017].

Fischl MA, Richman DD, Grieco MH, et al 1987. ‘The efficacy of azidothymidine (AZT) in the treatment of patients with AIDS and AIDS-related complex. A double-blind, placebo-controlled trial’, *The New England Journal of Medicine*, vol. 317, pp. 185-191.

Flowers, P 2001, ‘Gay Men and HIV/AIDS Risk Management’, *Health*, vol. 5, no. 1, pp: 50–75.

Flowers, P & Church, S 2002, ‘To Test or Not? HIV Antibody Testing Amongst Gay Men’, *Culture, Health & Sexuality*, vol. 4, no. 1, pp: 43-65.

Foucault, M 1990, *The History of Sexuality. Volume 1: An Introduction*, Vintage Books, New York.

Fraser, S & Seear K 2011, *Making Disease, Making Citizens*, Ashgate, Burlington.

Garcia, R, Lima, MG, Gorender, M, Badaró, R 2005, 'The importance of the doctor-patient relationship in adherence to HIV/AIDS treatment: a case report', *Brazilian Journal of Infectious Diseases*, vol. 9, no. 3. Available from: <http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-86702005000300008>. [5 November 2015].

General Medical Council 2017, *Good medical practice*. Available from: http://www.gmc-uk.org/guidance/index.asp. [25 Septmeber 2016].

Gerring, J 2004, 'What Is a Case Study and What Is It Good for?', *The American Political Science Review*, vol. 98, no. 2, pp. 341-354

Goldsmiths, University of London 2017, *Ethical Approval Form*. Available from: <http://www.gold.ac.uk/research/ethics/>. [26 August 2017].

Gould, DB 2009, *Moving politics: emotion and act up's fight against AIDS*, The University of Chicago Press, Chicago.

Gunaratnam, Y 2009, 'Narrative interviews and research' in *Narrative and Stories in Health Care: Illness, Dying, and Bereavement*, eds Y Gunaratnam & D Oliviere, Oxford University Press, Oxford.

Halbwachs, M & Coser, LA 1992, *On collective memory*, University of Chicago Press, Chicago.

Halperin, DM 2012, *How to be gay*, Belknap Press of Harvard University Press, Cambridge.

Halperin, DM 2009, *What do gay men want?: an essay on sex, risk, and subjectivity*, University of Michigan Press, Ann Arbor.

Hammer SM, Katzenstein DA, Hughes MD, *et al.* 1996, 'A trial comparing nucleoside monotherapy with combination therapy in HIV-infected adults with CD4 cell counts from 200 to 500 per cubic millimeter, AIDS Clinical Trials Group Study 175 Study Team', *The New England Journal of Medicine*, vol. 335, pp. 1081-1090.

Hawkins, PS 1993, 'Naming Names: The Art of Memory and the NAMES Project AIDS Quilt', *Critical Inquiry*, vol. 19, no. 4, pp. 752-779.

HIV i-Base 2013, *Introduction to Combination Therapy*. Available from: < http://issuu.com/i-base/docs/starting2013>. [26 June 2013].

Holt, M 2011, 'Gay men and ambivalence about "gay community": from gay community attachment to personal communities', *Culture, Health & Sexuality*, vol. 13, pp. 857–871.

How common is HIV?, 2017. Available from: < http://www.tht.org.uk/sexual-health/About-HIV/How-common-is-HIV_qm_ >. [26 November 2016]

Hutchinson, J, Sutcliffe, LJ, Williams, AJ & Estcourt, CS 2016, 'Developing new models of shared primary and specialist HIV care in the UK: a survey of current practice', *International Journal of STD & AIDS*, vol. 27, no. 8, pp. 617–624.

Jackson A, Else L, Tija J et al. 2012, 'Rilpivirine-LA formulation: pharmacokinetics in plasma, genital tract in HIV- females and rectum in

males'. Paper presented at the *19th Conference on Retroviruses and Opportunistic Infections*, Seattle.

Kafer, A 2013, *Feminist, queer, crip*, Indiana University Press, Indiana.

Kahn, J 2002, 'Preventing Hepatitis A and Hepatitis B Virus Infections among Men Who Have Sex with Men', *Clinical Infectious Diseases*, vol. 35, no. 11, pp. 1382–1387.

Katz, C 1994, 'Playing the field. Questions of fieldwork in Geography', *Professional Geographer*, vol. 46, no. 1, pp. 67–72.

Kent, SK 1999, *Gender and Power in Britain 1640-1990*, Routledge, London.

King, E 1993, *Safety in numbers: safer sex and gay men*, Cassell, London & New York.

King, TA 1994, 'Performing 'Akimbo': Queer Pride and Epistemological Prejudice' in *The Politics and Poetics of Camp*, ed. M. Meyer, Routledge, London, pp. 23-50.

Kingori, P 2013, 'Experiencing everyday ethics in context: Frontline data collectors' perspectives and practices of bioethics', *Social Science & Medicine* vol. 98, pp. 361–370.

Kippax, S, Connell, RW, Dowsett, GW & Crawford, J 1993, *Sustaining safe sex: Gay communities respond to AIDS*, The Falmer Press, London.

Kippax, S & Race K 2003, 'Sustaining safe practice: twenty years on', Social Science & Medicine, vol. 57, no. 1, pp. 1–12.

Kippax, S & Stephenson, N 2012, 'Beyond the Distinction Between Biomedical and Social Dimensions of HIV Prevention Through the Lens of

a Social Public Health', *American Journal of Public Health*, vol. 102, no. 5, pp. 789–799.

Klot, JF & Nguyen, VK 2009, *The Fourth Wave: Violence, Gender, Culture & HIV in the 21st Century*, UNESCO. Available from: < http://www.unesco.org/fileadmin/MULTIMEDIA/HQ/BSP/GENDER/PDF/Fourth-Wave12.pdf>. [5 January 2017].

Law, J & Urry, J 2004, 'Enacting the social', *Economy and Society*, vol. 33, no.3, pp. 390–410.

LeCompte, MD & Schensul, JJ 2010, *Designing & conducting ethnographic research: an introduction*, AltaMira Press, Lanham.

Lieber, DB 1986, 'Laughter and humor in critical care', *Dimensions of Critical Care*, vol. 5, no. 3, pp. 163–165.

London Sexual Health Transformation Programme 2017, Available from: < http://www.londoncouncils.gov.uk/our-key-themes/health-and-adult-services/public-health/sexual-health-0/london-sexual-health>. [5 September 2017].

Lutfey, K 2005, 'On practices of 'good doctoring': reconsidering the relationship between provider roles and patient adherence', *Sociology of Health and Illness*, vol. 27, no. 4, pp. 421–447.

Maier, GJ & Miller, R D 1993, 'Toward the therapeutic use of obscene language: A legal
and clinical review', *Bulletin of the American Academy of Psychiatry and the Law*, vol. 2, no. 2, pp. 227–243.

Mallett, J & Ahern, R n.d., 'Comparative distribution and use of humor within nurse-patient communication', *International Journal of Nursing Studies*, vol. 33, pp. 530–50.

Maseide, P 1991, ‘Possibly abusive, often benign, and always necessary. On power and domination in medical practice’, *Sociology of Health and Illness*, vol. 13, no. 4, pp. 545–561.

McGrath, R 1993, ‘Health, Education and Authority: Difference and Deviance’ in *Pleasures Principles. Politics, Sexuality and Ethics*, eds. V Harwood, D Oswell, K Parkinson & A Ward, Lawrence and Wishart, London.

Mehta, S, Garg, A, Gupta, LK, Mittal, A, Khare, AK & Kuldeep CM 2011, ‘Kaposi's sarcoma as a presenting manifestation of HIV’, *Indian Journal of Sexually Transmitted Diseases*, vol. 32, no. 2, pp. 108-110.

Mol, A 2006, *The logic of care: health and the problem of patient choice*, Routledge, London & New York.

Morris, A, Lundgren, JD, Masur, H, Walzer, PD, Hanson, DL, Frederick, T, Huang, L, Beard, CB & Kaplan, JE 2004, ‘Current epidemiology of Pneumocystis pneumonia’, *Emerging Infectious Diseases*, vol. 10, no. 10, pp. 1713-20.

Morsy, S 1996, ‘Political economy in medical anthropology’ in *Medical anthropology: Contemporary theory and method*, eds. CF Sargent & T M Johnson, pp. 21–40, Praeger, New York.

Mykhalovskiy, E & Rosengarten, M 2009, ‘Commentaries on the nature of social and cultural research: Interviews on HIV/AIDS with Judy Auerbach, Susan Kippax, Steven Epstein, Didier Fassin, Barry Adam and Dennis Altman’, *Social Theory & Health*, vol. 7, no. 3, pp. 284–304.

National Institute for Health and Care Excellence 2018. Available from: <https://bnf.nice.org.uk/treatment-summary/hiv-infection.html>. [15 March 2018].

Nguyen, VK 2012, ‘The social science of HIV: Sustaining advances in prevention, treatment and social justice’. Paper presented at the *Australasian HIV/AIDS Conferences*, Melbourne, Australia.

Nguyen, VK, Bajos, N, Dubois-Arber, F, O’Malley, J & Pirkle, CM 2011, ‘Remedicalizing an epidemic: from HIV treatment as prevention to HIV treatment is prevention’, *AIDS*, vol. 25, no. 3, pp. 291–293.

Nguyen, VK & Hardon, A 2011, ‘Locating theory: HIV, social change, and anthropology’. Paper presented at the *Locating the Social: The 1st International HIV Social Science and Humanities Conference*, Durban, South Africa.

Noor, KBM 2008, ‘Case Study: A Strategic Research Methodology’, *American Journal of Applied Sciences*, vol. 5, pp. 1602–1604.

Ohnishi M, Golparian D, Shimuta K, Saika T, Hoshina S, et al. 2011, ‘Is *Neisseria gonorrhoeae* initiating a future era of untreatable gonorrhea?: detailed characterization of the first strain with high-level resistance to ceftriaxone’, *Antimicrobial Agents and Chemotherapy*, vol. 55, pp. 3538–3545.

Oxford Dictionaries 2017, Alliance. Available from: < https://en.oxforddictionaries.com/definition/alliance>. [13 July 2017].

Palazzo, FF, Warner OJ 1999, ‘Surgeons swear when operating: fact or myth?’, *British Medical Journal*, vol. 319, pp. 1611.

Palella FJ Jr, Delaney KM, Moorman AC*, et al.* 1998, ‘Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators’, *The New England Journal of Medicine*, vol. 338, pp. 853-860.

Paparini, S & Rhodes, T 2016, ‘The biopolitics of engagement and the HIV cascade of care: a synthesis of the literature on patient citizenship and antiretroviral therapy’, *Critical Public Health*, vol. 26, no. 5, pp. 501–517.

Patton, C 1990, *Inventing AIDS*, Routledge, New York.

Patton, C 1985, *The Politics of AIDS*, South End Press, Boston.

Persson, A 2013, ‘Non/infectious corporealities: tensions in the biomedical era of ‘HIV normalisation’: Tensions in the biomedical era of ‘HIV normalisation’, *Sociology of Health & Illness*, vol. 35, no. 7, pp. 1065–1079.

Poole, R 2008, ‘Memory, history and the claims of the past’, *Memory Studies*, vol. 1, no. 2, pp. 149–166.

Prevention Access Campaign 2017, Available from: < https://www.preventionaccess.org>. [14 August 2017].

Public Health England 2017, *HIV: surveillance, data and management*. Available from: < https://www.gov.uk/government/collections/hiv-surveillance-data-and-management>. [30 May 2017].

Public Health England 2016, United Kingdom National HIV surveillance data tables.

Race, K 2009, *Pleasure consuming medicine: the queer politics of drugs*, Duke University Press, Durham.

Race, K 2001, ‘The Undetectable Crisis: Changing Technologies of Risk’, *Sexualities*, vol. 4, no. 2, pp. 167–189.

Reyners AK, Sprenger HG, Suurmeijer AJ & van der Graaf WT 2006, ‘Diagnosis and treatment of HIV-related Kaposi's sarcoma’, *Ned Tijdschr Geneeskd*, vol. 150, no. 26, pp. 1438.

Ritzer G, ed. 2007, The Blackwell Encyclopedia of Sociology, Blackwell Publishing Ltd, Oxford, UK, Malden, USA and Carlton, Australia.

Rose, N 2006, *The politics of life itself: biomedicine, power, and subjectivity in the twenty-first century*, Princeton University Press, Princeton.

Rose, N & Novas, C 2005, ‘Biological Citizenship’ in *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, eds. Ong, A & Collier, SJ, Blackwell Publishing Ltd, Oxford, pp. 439–463.

Rosengarten, M 2012, ‘PrEP: time to rethink prevention, effectiveness and ethics?’, *Somatosphere*. Available from: < http://somatosphere.net/2012/06/prep-time-to-rethink-prevention-effectiveness-and-ethics.html>. [6 November 2014].

Rosengarten, M 2009, *HIV interventions biomedicine and the traffic between information and flesh*, University of Washington Press, Seattle.

Rosengarten, M 2004, ‘The Challenge of HIV for Feminist Theory’, *Feminist Theory*, vol. 5, no. 2, pp. 205–222.

Rosenstock, IM 1974, ‘Historical Origins of the Health Belief Model’, *Health Education & Behavior*, vol. 2, no. 4, pp. 328–335.

Savage, EJ, Marsh, K, Duffell, S, Ison, CA, Zaman, A & Hughes, G 2011, ‘Rapid increase in gonorrhoea and syphilis diagnoses in England in 2011’, Eurosurveillance, vol. 17, no. 29.

Sedgwick, EK 2008, *Epistemology of the closet*, University of California Press, Berkeley.

Segall, A & Roberts, LW 1980, ‘A comparative analysis of physician estimates and levels of medical knowledge among patients’, *Sociology of Health and Illness*, vol. 2, no.3, pp. 317–334.

Singer, M 2004, 'Critical Medical Anthropology’ in *Encyclopedia of Medical Anthropology. Health and Illness in the World’s Cultures*, eds. CR Ember & M Ember, Kluwer Academic & Plenum Publishers, New York, London &Moscow.

Squire, C 2013, *Living with HIV and ARVs: HIV in the treatment possibility era*, Palgrave Macmillan, Basingstoke.

Stengers, I 1997, *Power and Invention: Situating Science (Theory Out of Bounds)*, University of Minnesota Press, Minneapolis.

Stimson, GV 1974, ‘Obeying doctor’s orders: a view from the other side’, *Social Science and Medicine*, vol. 8, no. 2, pp. 97–104.

Stone, TE, McMillan, M & Hazelton, M 2015, ‘Back to swear one: A review of English language literature on swearing and cursing in Western health settings’, *Aggression and Violent Behavior*, vol. 25, pp. 65-74.

Stull, G 2001, ‘The AIDS Memorial Quilt: Performing Memory, Piecing Action’, *American* Art, vol. 15, no. 2, pp. 84–89.

Svarstad B 1986, ‘Patient–practitioner relationships and compliance with prescribed medical regimens’ in *Applications of social science to clinical medicine and health policy*, eds L Aiken L & D Mechanic, Rutgers University Press, New Brunswick, pp. 438–459.

Terrance Higgins Trust 2017, *Uncharted Territory. A report into the first generation growing older with HIV*. Available from: <http://www.tht.org.uk/~/media/Files/Publications/Policy/uncharted_territory_final_low-res.pdf>. [27 June 2017].

The Lancet HIV 2017, Preparing for an ageing HIV epidemic. Available from: < http://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(17)30114-5/fulltext>. [27 June 2017].

Thompson, MA, Mugavero, MJ, Amico, KR, Cargill, VA, Chang, LW, Gross, R, Orrell, C, Altice, FL, Bangsberg, DR, Bartlett, JG, Beckwith, CG, Dowshen, N, Gordon, CM, Horn, T, Kumar, P, Scott, JD, Stirratt, MJ, Remien, RH, Simoni, JM & Nachega, JB 2012, Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care panel, *Annals of Internal Medicine*, vol. 156, no. 11, pp. 817-833.

Treichler, PA 1987, 'AIDS, homophobia and biomedical discourse: An epidemic of signification', *Cultural Studies*, vol. 1, no. 3, pp. 263–305.

UK Research Integrity Office 2009, *Code of practice for research. Promoting good practice and preventing misconduct*, London.

Unemo, M, Ison, CA, Cole, M, Spiteri, G, de van Laar, M & Khotenashvili, L 2013, 'Gonorrhoea and gonococcal antimicrobial resistance surveillance networks in the WHO European Region, including the independent countries of the former Soviet Union', *Sexually Transmitted Infections*, vol. 89, pp. iv42-iv46.

Unemo M, Nicholas RA 2012, 'Emergence of multidrug-resistant, extensively drug-resistant and untreatable gonorrhea', *Future Microbiology*, vol. 7, pp. 1401–1422.

Waldby, C 1996, *AIDS and the Body Politics, Routledge*, London & New York.

Watney, S 2000, *Imagine hope: AIDS and gay identity (Social aspects of AIDS)*, Routledge, London & New York.

Watney, S 1997, *Policing desire: pornography, AIDS, and the media*, 3rd ed., Cassell, London & Herndon.

Watney, S 1987, *Policing desire: pornography, AIDS, and the media*, Cassell, London & Herndon.

Weatherburn, P, Keogh, P, Reid, D, Hammond, G & Jessup, K 2013, *My Care, I Care. A study of what people with HIV value about NHS HIV services across London*, London School of Hygiene & Tropical Medicine, London.

Weeks, J 2009, Sexuality, Routledge, New York.

Welzer, H 2010, 'Re-narrations: How pasts change in conversational remembering', *Memory Studies*, vol. 3, no.1, pp. 5–17.

Wender, RC 1996, 'Humor in medicine', *Primary Care*, vol. 23, no. 1, pp. 141–154.

What is the life expectancy for someone with HIV?, 2015. Available from: < http://www.nhs.uk/chq/Pages/3106.aspx?CategoryID=118&SubCategoryID=126>. [30 May 2017].

Whitehead, T 1989, 'The voluntary sector: five years on' in *Taking liberties. AIDS and cultural politics*, eds Erica Carter and Simon Watney, Serpent's Tail, London, pp. 107-112.

WHO, HIV/AIDS: WHO online Q&As about HIV/AIDS 2018. Available from: < http://www.who.int/features/qa/71/en/>. [6 May 2018]

WHO 2012, *Global action plan to control the spread and impact of antimicrobial resistance in Neisseria gonorrhoeae*, Geneva.

WHO in partnership with UNICEF and UNAIDS 2013, *Global update on HIV treatment 2013: results, impact and opportunities*. Available from: < http://apps.who.int/iris/bitstream/10665/85326/1/9789241505734_eng.pdf?ua=1 >. [23 August 2013].

Yin, R 1989, *Case Study Research*, Sage Publications, California.

Yuels, WC & Clair, JM 1995, 'Laughter in the clinic: humour as social organisation', *Symbolic Interaction*, vol. 18, no. 1, pp. 39–59.

Zimmerman, DJ, Stern, TA 2010, 'Offensive Language in the General Hospital', *Psychomatics*, vol. 51, no. 5, pp. 377–385