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Living with HIV:
Men, masculinities and health in Portugal

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Abstract

Portugal has traditionally had the highest HIV incidence in Western Europe, currently standing at 0.6% (UNAIDS, 2011). In addition, men in Portugal are disproportionately infected with HIV. Portuguese men are traditionally expected to initiate sexual activity earlier than women and not to worry about safer sex. However, little is known about how prevailing norms of masculinity may influence their experiences of living with HIV. Informed by an interpretivist epistemology and utilising multiple methods, data were gathered from in-depth interviews with 20 men living with HIV and 10 professionals involved in their care, as well as observation of clinical and social support spaces. A number of structural issues impact on men's experiences of living with HIV. In particular, for some men there was a sense of social death, one that drew on the apparent invisibility of HIV, overall ignorance regarding the virus and its effects, reduced government HIV prevention efforts, and feelings of rejection towards people living with HIV. Despite an apparent move from HIV being a fatal disease to a chronic illness globally, participants indicated that HIV in Portugal is still regarded as a dangerous disease at both social and institutional levels. Concomitantly, some men successfully adapted to living with HIV in positive and meaningful ways. Adaptation was facilitated if there had been previous experience of biographical disruption: in particular among gay men or men from ethnic minorities. The close focus, qualitative methods employed allowed for deeper insights into the complexities of structural factors associated with men's experiences of living with HIV. In particular, this study captured some of the struggles, tensions and challenges inherent to living with HIV in a developed country today.

Declaration and word count

I hereby declare that, except where explicit attribution is made, the work presented in this thesis is entirely my own.

Word count (exclusive of appendices and list of references):   70, 040   words.

Signed..

Rui Baptista-Gonçalves

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Contents

Chapter 1

Introduction

Background and context

Before describing the aims and objectives of the present study, it is appropriate to provide a few words of explanation as to why I am interested in the topic I have chosen, and how my background has influenced the development of this work. Before I began working with people living with HIV in varying capacities (as a researcher and health-care practitioner), I graduated as a nurse and worked in a variety of healthcare settings in Portugal, Sweden and the United Kingdom. This allowed me, at quite an early stage of my career, to realise that different cultural and social realities provide and promote varying concepts of, and values associated with, care, health and illness. Even in my experience of working in three 'developed countries' which are members of the European Union, I encountered significant differences between settings, ranging from the type of health system to the individual experience of health care.

These cultural and contextual differences have always captured my interest. Initially, I was intrigued to understand how distinct approaches to nursing care may affect health outcomes. As I explored this subject further, however, it became apparent that health systems and indeed hospitals or clinics operate as micro-level representations of the social reality they belong to[1]. This fact is present in most clinical interactions, from doctor-patient communication to nurse-to-nurse handover, as well as in the

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[1] For an in-depth context-specific analysis, see Zaman (2003).

clinical training of health professionals, patients' behaviour and experiences of health care, and even patient-patient interactions.

Upon moving to the UK in 2002, I began working more closely with people living with HIV, which I have done ever since. I try to support these individuals through my clinical work as a nurse, my research and my activism, in clinical, social and personal situations. This has allowed me to recognise the difficulties that such people go through, whether at a social, personal or clinical levels. Some of the research work I have undertaken in the past has also looked at the plethora of needs identified by people living with HIV, and how much hardship some people face after receiving an HIV positive diagnosis.

Shortly after arriving in the UK, I left general nursing and started working as a researcher in the academic department of HIV and Genitourinary Medicine at the Guy's King's and St Thomas' School of Medicine (Denmark Hill Campus). One of the many research projects developed by the team I belonged to, headed by Professor Philippa Easterbrook, looked at the social needs of HIV positive people in South-East London and provided some insight into the range of social needs of these individuals, as well as making recommendations for support suggested by the participants (Easterbrook et al., 2003). This cross-sectional study used structured questionnaires to elicit the desired information from participants and informants and, in retrospect, now appears to me to have been somewhat 'formal' in its approach, which is to say that the research lacked a more 'open' and exploratory methodological approach to social context and personal experience of living with HIV. Despite the fact that the questionnaire used for the project contained a number of open-ended questions, the study was first and foremost a quantitative investigation that arrived at a series of conclusions about frequencies and categories of 'need' among people livng with HIV (such as issues related to service provision, social support and so on). Examination

of what the idea of 'need' might actually mean to people in their day-to-day lives was absent from the study, and in this regard the needs of people living with HIV were assumed rather than explored within the research. As I offered the questionnaires to each participant, as well as when collecting it from them, I often engaged with conversations that tended to offer a richer insight into how some of the issues in the questionnaire affected their lives. Some participants would say that someone needed to look into their social needs, as "it was time someone did anything" about it. Others would simply refrain from asnwering the open ended questions because they felt that the information would not lead to any changes in their circumstances.

In essence, the few open-ended questions included in the study did little to alter the positivistic nature of the methodology, despite the richness of content found within that section of the questionnaire. Responses such as: "I cannot store my medication in the 'fridge because I live with family members who don't know that I am HIV positive" or "the doctor often uses words that I don't understand, but I am afraid to ask what they mean, and I am worried I am not doing what is right to look after myself" helped shed some light onto the complex realities in which people living with HIV are involved, and I realised that future research should address these realities through its concern with meaning and context.

It was during the course of this work that I also began to consider the value of other approaches to research, framed by different methods and epistemologies to those that I had been involved in thus far. If the research paradigm adopted in the study I have described had been less positivistic – delving into people's lives a little more deeply – the research would have elicited richer understanding of the complexities surrounding the lives and social needs of people living with HIV. A more interpretive

approach to a concept as complex as (social) need[2] could have generated richer insight, not only into the concept of need as defined by the individual, but also on how that need affected the experience of living with HIV.

What the study concluded was that people living with HIV experience a range of needs that are not always directly linked to being HIV-positive per se but which are engendered in the ways societies and health care are organised. Most of the respondents in that study lived in deprived socio-economic areas in South London, thus already very likely to experience a range of inequalities in regards to their access to health care, education, services or facilities. This perspective served as a starting point for the present research in which it was my initial goal to explore not only needs but, more broadly, the different experiences of people living with HIV and their carers (clinically and socially organised) in Portugal. The initial reasons for choosing Portugal as the context for this study were twofold: linked to the fact that, on the one hand, there is a significant gap in HIV social research in Portugal; even if that somehow contradicts the fact that it was, and still is, the country with the highest incidence of HIV in Western Europe. As the HIV epidemic is globally entering a new era, in terms of its social representations and social organisation, I was driven by a goal to understand how HIV is experienced in Portugal, from the point of view of those living with it, but also from the society at large, including those providing care for people living with HIV, for example.

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[2] Liss & Nordenfelt (1990) have explored the multi-faceted notion of need, and how often this remains unacknowledged and unexplored in research. The authors offer a useful three-dimensional categorisation of need: need as a motive or tension, need as the lack of something, and need as the object of need. They add that all needs have a goal and an object and, in the particular case of health care needs, for example, understanding the goal of the need will aid in ascertaining the quality (and quantity) of the care needed. Their work is highly relevant for policy work and health care planning.

The specific topic of living with HIV was chosen for its relevance to contemporary social research on HIV. The HIV epidemic has changed dramatically since early the 1980s when HIV was first identified as the micro-organism that caused AIDS.[3] Such changes have been particularly significant in developed countries in which the wider availability of treatment options as well as enhanced access to a range of medical and social support has increased the quality of life of people living with HIV, so much so that a recent study has revealed that predicted life expectancy of people living with HIV who access anti-retroviral therapy (ART) is approaching that of the rest of the population (Nakagawa et al., 2012). These advances, alongside the development and pressures exerted by HIV activists, meant that people living with HIV have gained greater visibility in rights-based policies and interventions. Notwithstanding this, structural and deeply ingrained issues such as stigma and discrimination, alongside the violation of basic human rights, are still present across the globe at institutional, political and social levels. We have, therefore, reached a moment of tension characterised by the fact that HIV, no longer the 'new kid on the block' in the panorama of epidemics, is still subject to long-lasting negative reactions across societies, even as medically the capacity for treatment of people living with HIV has been significantly advanced over the course of the last 30 years.

Against the background of these concerns, the present study took place in Portugal, which has historically and consistently been the country with the highest incidence of HIV infection in Western Europe. Surprisingly, little is known about the socio-political and cultural aspects of HIV in Portugal, and HIV infection has been a markedly under-researched subject in Portuguese social and epidemiological research (Teles e Amaro, 2006). As the epidemic has been disproportionately distributed in the country – with men accounting for over 70% of all infections (UNAIDS, 2009; INSA,

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[3] For a comprehensive description of the origins and evolution of HIV, see http://www.avert.org/origin-aids-hiv.htm

2012) – I was particularly interested in how being a man in Portugal may impact on the risks of HIV infection, as well as how men living with HIV perceive themselves with regards to their health and the impact of their diagnosis.

The study of men and masculinities offers some insights into ways in which men's lives are socially constructed in a manner that may encourage them to avoid seeking care and/or overtly demonstrate suffering or pain (Courtenay et al., 2000; Robertson, 2007). Previous studies of men who have been diagnosed with breast cancer, for example, have found that men felt embarrassed by being diagnosed with a 'female' disease (Pituskin et al., 2007). Similarly, the literature is rich in studies focusing on the lives and experiences of men who have been diagnosed with prostate cancer (Carvalho, 2012) which can shed some light into the complex issues surrounding men and health. However, not much is known about the ways in which a diagnosis of a chronic condition such as HIV can alter the ways in which men perceive and interpret their own masculinity, especially if men living with HIV feel they cannot conform to their expected social roles as men, because they are more vulnerable due to their condition, or because they are embarrassed by it.

Social and epidemiological research focusing on HIV, reproductive and sexual health has traditionally acknowledged the role of gender as a key determinant of health and wellbeing. However, the focus of much social enquiry to date has been almost exclusively concerned with women. In contrast, the present study focused on the lives of men. Through the study of Portuguese men and masculinities, the aim has been to contribute new insights into why the HIV epidemic is disproportionately distributed in Portugal (with more men than women livng with HIV). From this perspective, the goal is to explore broader issues pertaining to men's everyday lives (and their interpretations of concepts such as masculinity and machismo) as relevant

to understanding living with HIV as socially constructed and experienced through gender.

Study aims and objectives

The main aim of the present study therefore was to explore the experiences and perspectives of men living with HIV in Portugal within health care settings and beyond, examining implications for their health, wellbeing and social needs. More specific objectives included:

- Analysing cultural, political and psychosocial factors associated with HIV positive men's health in Portugal

- Analysing the range of experiences of care available to men living with HIV, in particular identifying the actions that HIV positive men can and are taking to safeguard their own health and that of others

- Interpreting how masculinities affect health-related experiences before and after a HIV diagnosis, and

- Understanding how individual experiences of living with HIV are related to broader social tensions that are affecting the social construction of HIV in Portugal

The study sought to address the following research questions:

- How do HIV positive men in Portugal perceive their health in regard to broader social, political and cultural determinants?

- What role does masculinity play in determining men's experiences of living with HIV in Portugal?

- How are concepts of health and wellbeing formulated, developed and expressed in social interactions within health care settings and beyond?

- How is HIV socially interpreted and constructed in Portugal, and how does that social construction affect individual experiences of living with HIV?

Organisation of the thesis

This thesis begins with a review of pertinent theoretical issues. Chapter two examines and reviews the literature focusing on men, masculinities and health, and the experiences of people living with HIV, in Portugal and elsewhere. Recurrent themes within the literature lay the theoretical foundations for the aims and objectives of the study. This is followed, in chapter three, by a discussion of methodology and methods of data collection and analysis used in the study. Three subsequent chapters describe the findings from the study in relation to the research questions, discussing these in relation to the theoretical background presented in chapter two. Chapter four explores how men understand masculinities in relation to health and illness, and relates this to experiences of men in Portugal today. Chapter five focuses more specifically on men's interpretations of health and illness, alongside an exploratory analysis of the trajectories men engage with when diagnosed with a chronic illness. Chapter six examines the impact of gender and health on living with HIV in Portugal, from a social, cultural, political and individual perspective. This is followed, in chapter seven, by a discussion of the findings in respect of their wider theoretical contributions and practical implications.

Overall, the thesis seeks to describe the culturally specific biography of HIV in Portugal, which is somewhat unique and may be an important factor in accounting for the unusual distribution of cases of HIV in the country. The thesis also investigates constructions of masculinity in Portugal and their influence on men's experiences of living with HIV, accessing health care and seeking help within clinical and commuity based settings. The ethnographically informed methodology adopted in this study allowed for deeper insights into the complexities of structural determinants that impact on men's experiences of living with HIV. In particular, this study captured the struggles, tensions and challenges inherent to living with HIV in an otherwise reasonably well 'developed' country.

Chapter 2

Literature Review

The experience of HIV

The present study aims to examine the experiences faced by men living with HIV in contemporary Portugal. These include, but are not limited to, their experiences of accessing health care, seeking social support, establishing personal or intimate relationships, and so on. The study aims to explore some of the deeper meanings associated with living with HIV, examining men's world views, their notions of stigma, discrimination, needs and rights, as well as wellbeing, empowerment and quality of life.

By way of background to the study itself, this chapter will look at some of the multiple ways people experience living with HIV, as reported in the literature, focusing on how HIV is experienced at health care level in hospital, clinics and health centres (i.e. in institutions providing clinical support for people living with HIV). This will be followed by a review of the literature on broader social responses to HIV, and how these affect the lives and experiences of people living with HIV. The focus here will be particularly on issues of stigma and discrimination, disclosure, barriers and opportunities in establishing relationships with friends, family and partners, including the criminalisation of HIV infection. A final section will look at some of the more positive and collective aspects of living with HIV, namely experiences of empowerment, solidarity, activism and community responses to HIV infection.

Background

> I am still the same person; the only difference is that I have AIDS – an illness like other illnesses and one loaded with taboos and prejudices. (…) I haven't died yet. I know that AIDS can kill, but I also know that prejudice and discrimination are much more deadly. (…) They want to kill people with AIDS, condemning us to a civil death. For that reason, disobediently, I am striving to reaffirm that I am very much alive.
>
> Herbert Daniel (in Daniel and Parker,1993, p.3)

Globally, an estimated 33.3 million people were living with HIV/AIDS in 2009, with a total of 24 million accumulated deaths worldwide, and 2.6 million new infections in that year alone (UNAIDS, 2010). HIV and AIDS are not merely physical conditions with associated symptoms, morbidity and mortality. From their early identification, HIV and AIDS have given rise to social responses, many stigmatising and discriminatory, but some constructive and supportive. As Adam and Sears (1996, p. xv) explain, "coping with HIV has never been simply an issue of dealing with the physical consequences of illness". In fact, it has triggered a number of responses that impacted on social, political, cultural and economical values of nations worldwide, affecting the lives of millions.

The early days of the epidemic were also characterised by a growth of research focusing on HIV. Many early studies focused on the pathological and immunological aspects of HIV, as efforts were placed on understanding the scientific and medical aspects of HIV infection and much was learned regarding the virus, the way it functions and replicates, and how can it evade treatment or create resistance, for example. But gradually, social research started to become more visible in the late 1980s and early 1990s. The contribution of social enquiry was vital to understanding a range of issues that biomedical research could not investigate. These included the process of bereavement and dealing with loss of people dying with AIDS (Lennon,

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Martin and Dean, 1990), the different coping strategies and behavioural responses used by gay men in dealing with HIV (Elford, 1987; Brendtrup and Schmidt, 1990; Schwartzberg, 1993) and the HIV prevention efforts of gay men (McCusker et al., 1989), among many other topics. These studies were valuable in defining the responses to the epidemic in its early stages, when treatments were not available. This body of research grew considerably and offered a rich insight into the practices gay men began to discern as risky and safe, and which eventually informed formal HIV prevention and safer sex promotion.

As happened with prevailing biomedical discourses at the time, most research also focused on (and therefore fostered the contested notion of) 'risk groups'. These were believed to be, on the one hand the unfortunate victims of the epidemic but, on the other hand, were socially constructed as perpetrators, to blame for the epidemic due to their behaviours and the moralisation of their characters. Hence any literature search for HIV in the 1980s and 1990s most probably features gay men or injecting drug users as key members of 'risk groups'[4]. Because of these connections,

> Moral entrepreneurs rapidly took AIDS as a symbolic weapon in the restoration of 'traditional values', 'the' family, and monogamy. Public discourse constructed white, middle-class, heterosexuals as the innocent self threatened by a guilty other of "AIDS carriers". Governments typically responded to AIDS in the early 1980s with a refusal to act, delay or neglect, or very tentative initiatives aimed less at assisting those afflicted with AIDS than protecting an ostensibly unafflicted 'general public' (Adam and Sears, 1996, p. xvi).

From the outset, and in countries such as Portugal that did not have a surveillance and notification system in place until later in the epidemic, AIDS was initially characterised as a distant entity, perceived as residing in foreign settings, and

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[4] See, for example, DeGruttola et al. (1988), Edel (1989), Dawson et al (1991) or Irwin et al (1996).

associated with a restricted number of people (the so-called risk groups) (Teles and Amaro, 2006). This was shown in the only two studies undertaken in Portugal at the beginning of the epidemic which focused on the sexual behaviour of Portuguese people (Ayres et al., 1987; Amaro, Teles and Dantas, 1995)[5]. Many people were found to be engaging in sexual risk practices, while concomitantly believing that the general population, i.e. those not belonging to one of the risk groups, was not at risk of HIV infection. This apparent process of 'othering' meant that those who did not belong to the social groups considered to be at risk had little basis from which to conceive themselves as vulnerable to HIV infection. This kind of thinking created a strong moral foundation for the stigmatisation of people living with HIV and those belonging to risk groups, which endures in the social response to HIV in Portugal today.

As Schiller, Crystal and Lewellen (1994) have argued, the creation and use of the notion of risk group contributed massively to the lethargic response of governments in addressing HIV in many Western countries. Eventually, as rates of infection began to spread into many diverse sectors of the population, governments realised that the risk of infection was not limited to risk groups alone. They turned their efforts to health protection, but still in line with a position that was segregating, as the goal was often to protect those who were healthy from those who were not[6]. These efforts included public health campaigns that resorted to shock tactics, generating fear and thus widening the gap between those within the 'risk groups' (for example,

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[5] In fact, in the study by Ayres at al. (1987), only 3% of the participants regarded the general population to be at risk of HIV infection, which contrasted with the figures for perception of risk of prostitutes (71%), injecting drug users (62%) or homosexual men (60%). The study by Amaro, Teles and Dantas (1995), which took place in 1989 in Lisbon, revealed that 25% of men who were older than 20 years of age had had their sexual debut with a sex worker.

[6] As Crawford (1994, p.1348) has argued, 'health' is a key symbolic domain for creating and recreating the self, in the sense that the notion of health is not merely biological or physical but enriched in metaphors, one of which relating to how the "healthy self" is only sustained in part through the creation of "unhealthy others".

homosexually active men, injecting drug users, sex workers) – and those who were believed not to be at risk (traditionally heterosexual, middle class White people). They thus fuelled the already evident differentiation between these two sectors, and fostered the marginalisation of those believed to be at risk.

In the UK, for example, the then Conservative government led by Margaret Thatcher funded a television campaign first aired in 1986, named "AIDS: Don't die of ignorance!" which depicted a large tombstone with AIDS written onto it. A leaflet which accompanied the television advertisement was posted to every household in Britain. It read:

> By the time you read this, probably 300 people will have died in this country. It is believed that a further 30,000 carry the virus. This number is rising and will continue to rise unless we all take precautions...

Similar responses became common in other countries (including Portugal) attempting to emphasise that, as Aggleton (2009, p.2) suggested, "knowledge rather than ignorance was the answer to the epidemic".

Additionally, most campaigns were not properly evaluated for their impact, nor were they implemented after prior investigation into what kind of approach would work best. The inefficient and flawed approaches that such campaigns offered, allied to the increasing numbers of people infected, motivated the organisation of groups offering support to those living with HIV. A number of non-governmental organisations (NGOs) were created out of these altruistic efforts, and some still operate, offering valuable support to people living with HIV, their families and friends. Examples include the Terrence Higgins Trust in the UK and Abraço in Portugal.

In a review undertaken in 1994, Schiller, Crystal and Lewellen (1994) called for an alternative view of HIV transmission: one that focused on risk taking behaviour rather

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than risk groups. The authors argued that risk groups as epidemiological categories "took on a life of their own and began to be used for purposes such as AIDS education (p.1338)." They also alluded to the fact that, as a group, gay men are varied and therefore the cultural behaviours of some (what were regarded to be the key factors for the spread of HIV) should not be stereotypically generalised to all members of the group. It is now widely understood that the notion of risk group was both limited and limiting and, despite still visible in some recent literature, much public health work tends to refrain from using such a term. It came to be replaced with more encompassing notions of risk behaviour, risk environments (Rhodes, 2009) or sexual (risk) practices (Kippax et al., 1997; Race, 2009) as the epidemic began to expand and affecting a great number of people from all social groups and sexual orientations. However, such concepts were also less than useful in that they implied that everyone was at equal risk. With time, more nuanced understandings of sexual and drug-related *practice* and the contexts in which risk is greatest, have come into circulation.

Concomitant with these shifts in discourse, in which a number of terms were replaced to better suit the experiences and contexts associated with acquiring and living with HIV[7], improvements have been achieved in managing HIV. In particular, the development of a number of anti-retroviral pharmaceuticals that significantly limit the progression of HIV, have improved life expectancy, wellbeing and quality of life[8]. The idea of HIV and AIDS as a death sentence gradually started to subside in most socio-

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[7] Other changes include, for example, prostitution which was replaced by sex work, or gay men, which is now usually termed as men who have sex with men (MSM).

[8] For the purpose of this study, the term quality of life will be used as defined by Boulton (2004, p.112) to describe "the individual's sense of social, emotional and physical wellbeing, which influences the extent to which s/he can achieve personal satisfaction with their life circumstances". As so defined, the term encompasses another relevant concept to the present study, wellbeing, which is a context and situation related state of soundness of physical and mental health, as well as happiness and prosperity.

economically developed countries. However, as Vitorino (2003), as well as Teles and Amaro (2006), explained – and specifically for the Portuguese context but certainly generalisable to the Western world – all of these changes (in terminology, pharmaceutical advances and improved quality of life) did not directly translate into a clearer notion of what it means to be living with HIV from society's viewpoint. The epidemic continues to be imbued with myths, misconceptions and taboos. HIV infection is thus unique in that, from the outset, it came to be socially constructed in very specific ways. As Sontag (1990, p.106) put it, AIDS has been "a clinical construction, an inference [that] takes its identity from the presence of some among a long, and lengthening, roster of symptoms".

Based initially on her own personal observations, Sontag analysed some of the metaphors associated with cancer and how some of these could be linked to AIDS. These include the fact that both illnesses are often described using military metaphors: the body is invaded and attacked from within and people battle against, win or lose a fight against such diseases. These metaphors imply human volition over these illnesses, through a discourse that denotes different types of struggle. Despite writing in a period in which ART was not available, and many people were dying of AIDS-related illnesses, Sontag's account of AIDS is remarkable and to a certain degree timeless. She also emphasised how, wrapped up in misunderstandings, AIDS was also seen as a plague by some, in which punishment and pain were the price to pay for those who brought the disease upon themselves through unsafe sex and drug use. Watney (1989, p.16) added that:

> Many of the most basic misunderstandings about HIV infection and AIDS stem from a fundamental failure by journalists and others who mediate medical information to non-professionals to appreciate the significance of the distinction between HIV, with its well-established, limited modes of transmission, and AIDS. To describe the syndrome as if it were a disease is an easy option (...) has led to any number of misleading assumptions and ill-informed beliefs about almost every aspect of the epidemic. For example,

many people still talk about 'catching AIDS', as if you could contract a syndrome.

Thus, HIV infection has historically and traditionally been swathed in misunderstandings, myths and misperceptions at social, cultural and individual levels, which ultimately impact on all those affected by it. HIV infection is both a social and an individual experience, and it is only possible to understand what an HIV positive diagnosis means through exploring and gaining insight of the experiences and perspectives of those living with HIV.

HIV, health and wellbeing

Receiving an HIV positive diagnosis initiates a process of ritualism within health care institutions, and triggers a patient career that is multi-layered and complex. At a macro-level, people with HIV need access to health care services and, by doing so, become participants in the highly medicalised institutions from which they receive support. At a micro-level, the support that each person receives (treatments, examinations, consultations and so forth) represents an individual response to living with HIV in its more basic form: managing side effects, adhering to therapeutic schemes and adapting to the diagnosis.

Infection with HIV occurs by the transfer of infected blood, semen, vaginal fluid, pre-ejaculate or breast milk. HIV infection is a progressive illness that may have life-threatening consequences, some of which are known as AIDS-defining illnesses. According to the US Centers for Disease Control's website,

> HIV attacks the immune system which gives our bodies the ability to fight infections. HIV finds and destroys a type of white blood cell (T cells or CD4 cells) that the immune system must have to fight infection (…). Having AIDS

means that the virus has weakened the immune system to the point at which the body has a difficult time fighting infections.

In the early days of the epidemic, most people who received an HIV positive diagnosis had limited life expectancy due to the disease's often rapidly progressive nature. The lack of therapeutic options allied to inadequate provision of health care meant that many people ended up progressing to AIDS and dying within a relatively short period after infection. The advent of more effective forms of ART in 1996 brought new meaning to the lives of millions living with HIV, and indeed to the social construction of HIV more widely. In the clinical settings of the Western world, the acronym AIDS came progressively to be replaced by a better suited HIV-infection (or HIV disease), as studies reported significant reductions in AIDS-related deaths.

At the same time, ART greatly contributed to an improvement in (some) people's quality of life and a marked increase in life expectancy (Nakagawa et al., 2012). In the Western world, no longer was HIV infection portrayed as a fatal epidemic, it is now commonly regarded as a chronic illness[9]. This shift carried significant challenges, especially in terms of increased levels of morbidity and/or associated consequences of living longer with a chronic illness. At a macro-level (i.e. the contextual and structural factors of living with HIV), it becomes clear that as soon as ART became widely available, it occupied a central place in the discussions of needs of people living with HIV. However, new forms of ART, despite being life changing and carrying a very significant value to the improvement of the quality of life of

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[9] Bury (1991) has described chronic illness as being a biological disruption in which there are three major dimensions associated this process: coping (or the cognitive processes involved in dealing with having that particular illness and its effects on body and mind), strategy (or managing side effects, treatment plans, and so forth) and style (or lifestyle that is characterised by an adjustment to the role as someone with that particular condition, including the management of disclosure, for example). The applicability of this framework to many people living with HIV in the developed world is possible, and thus HIV has come to be conceptualised as a chronic illness.

millions, are not all that is required by (and indeed relevant to) someone living with HIV (Bell et al., 2007).

Similarly at a macro-level, other factors can play a role in determining the experience of health care. For example, Adam and Sears (1996) found that place of residence differentiated and influenced experiences of HIV care. Comparative study of public (Canada) versus private (USA) health systems revealed that those receiving health care in a heavily privatised system suffered greater levels of inequality than those receiving public based care. A privatised system was found to widen the gap between those who could afford health insurance and those living in poverty (who therefore cannot afford health insurance and are concomitantly at a greater risk of ill-health).

Research by Buseh et al. (2006) of the experiences of African-American men in Milwaukee, Missouri highlighted the severe impact of receiving a positive diagnosis for HIV. The hardship faced by the men in the study may well be linked to residing in a country (the USA) with a largely privatised health system, in which it is still difficult to access health care if living in poverty. This implies that the hardship faced by these men is as much about poverty as it is about living with HIV. However, as Alcorn (1988) pointed out, HIV/AIDS is, above all, a disease of difference, triggering a differentiation of response in the way in which health care is organised to deal with it, some of which is embedded in prior cultural difference including stigma and discrimination on grounds of ethnicity, race, sexuality and so on.

One key aspect of living with HIV is that of mental health and psychological support. Mental health problems can arise, for example, from having to take regular medication and feeling dependent on it to survive. Factors such as depression can have a knock-on effect on adherence and quality of life. There is some evidence to

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show that depression amongst people living with HIV remains high, with about 44% of all people living with HIV having experienced depression worldwide[10] (International HIV/AIDS Alliance, 2006; Bell et al., 2007; Simbayi et al., 2007; Doyal, Anderson and Paparini, 2009). Even though the incidence of depression may be currently lower due to advances in ART alongside other therapeutic intervention, it may still exist related to other factors influenced by an increase in life expectancy, such as issues of sexuality, disclosure of HIV status or ageing.

Along the same lines, Bell et al. (2007) have suggested that positive prevention[11] has a role to play in helping people with HIV cope with some of the more common psychological and mental health issues such as anxiety, depression and feelings of loss of self worth, which may arise when initially trying to deal with the diagnosis but may endure throughout the person's life. These can also deeply influence the way the person responds to any support they receive. As HIV is still going through a paradigm shift from being a fatal infection to a chronic disease, it may leave those living with HIV feeling somewhat confused about what to expect. This can engender a number of existential issues, or even contradictory feelings: living with HIV may be depressing, but it can also be life-affirming, as will be explored later.

Other micro level issues worthy of exploration include looking at how affected individuals adapt to their diagnosis. In particular, managing a treatment plan, dealing

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[10] However, depression is a culturally constructed notion/experience, and how these estimates are arrived at has also been contested by, for example, Kleinman and Good (1986) – even if not pertaining to HIV specifically.

[11] Positive prevention, according to Bell et al. (2007), includes all strategies used to improve the quality of life of HIV-positive people, be it in relation to sexual health, reproduction, nutrition or peer support. This is particularly important, as most preventive measures that are used currently tend to lead to a degree of prevention fatigue amongst people living with HIV. The authors argue for new and innovative approaches to prevention, such as HIV specialised centres that house a range of relevant services for people with HIV (sexual health clinics, counselling services, drugs counselling and support, etc.).

with the secondary effects of medication, organising clinical appointments and following prescription plans meticulously are all aspects of a new reality for those living with HIV in the post-ART era. Unfortunately, early ARTs were not suitable for all and, despite initial popular belief indicating otherwise, they did not offer a cure to HIV infection. According to Gilbert and Walker (2009), despite improving the levels of quality of life and general health to standards never thought possible in the early days of the epidemic, people were not always comfortable about starting therapy, as they sometimes refused to engage in such long term commitment. Part of the problem also related to the range of side-effects associated with some early forms of ART: nausea, vomiting and diarrhoea. These limited people's social interactions to such an extent that many people would rather stay indoors and in isolation, for fear of experiencing these side-effects in public. Some people's experiences of side-effects of ART were reported to be worse than the diagnosis of HIV itself. Not only did they impact on the ability of people to maintain some level of social interaction, they also had profound implications for people living with HIV and related stigma and discrimination.

The classic example of this is lipodystrophy[12], one of the most feared side effects of early forms of ART. Because it involves the loss of adipose tissue in the cheeks, lipodystrophy was often associated with some level of facial disfigurement and the 'buffalo hump' (a slight rise made up of a deposit of adipose tissue at the basis of the cervical spine). This could be particularly difficult to deal with, as it affected visible, rather than less exposed, parts of the body, and therefore became an embodied sign of the illness, and as Sontag (1990, p.127) has argued:

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[12] Lipodystrophy is a medical condition characterised by a redistribution of fat and adipose tissue. It was a side effect of ART under some regimens, and it includes loss of fat tissue of the cheeks (lipoatrophy) and buttocks, the formation of humps on the back of the neck or increased fat distribution around the abdominal area. One particular medicine (d4T) was associated with lipodystrophy, but others may also cause it even if to a smaller extent.

however lethal, illnesses like heart attacks and influenza that do not damage or deform the face never arouse the deepest dread (...) [because] underlying some of the moral judgements attached to disease are aesthetic judgements about the beautiful and the ugly, the clean and the unclean, the familiar and the alien. (...) What counts more than the amount of disfigurement is that it reflects underlying, ongoing changes, the dissolution of the person, (...) [thus], the marks on the face (...) of someone with AIDS are the signs of a progressive mutation, decomposition, something organic.

More recent forms of ART do not cause so severe side effects. These days, a wider availability of different drugs also means that there are a number of options available. Pharmaceutical advances have, for example, allowed one-pill a day regimens, which has been a significant improvement in ensuring good levels of adherence.

Adherence has gained such a central role in living with HIV that Gray (2006) and Karasz, Dyche and Selwyn (2003) consider it to have replaced death as the main issue in caring for people with HIV in the post-ART era. This is due to the fact that, in line with the guidelines set by WHO (2003) and national authorities, ART requires somewhat strict adherence, as the failure to take medication as scheduled may result in a drop in treatment effectiveness, viral mutation and increased resistance (Gazzard and Jones, 2006; Rogowska-Szadkowska and Chlabicz, 2009), including multi-drug resistance (MDR). During the past several years, a number of advances have simplified many regimens dramatically, particularly those for treatment-naive patients. Prescribing regimens that are simple to take, have a low pill burden and low-frequency dosing, have no food requirements and have low incidence of adverse effects will facilitate adherence (Raboud et al., 2011). When adherence levels are around 100%, there are significant improvements in quality of life and also improved immunological results (increased levels of CD4 cell counts and decrease in viral load[13]). Unfortunately, though, 100% adherence is not always possible, due to a number of reasons.

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[13] CD4 count and viral load are closely linked to HIV-related illness and mortality. They give prognostic information on HIV progression and on response to therapy.

From a biomedical point of view, Gazzard and Jones (2006) suggested that key barriers to good adherence include pill burden, dosage frequency and the need for food intake. Progress in treatment regimens has contributed to greater adherence to ART but, as Gray (2006) has shown, personal factors can also severely impact on adherence levels. Particularly important are the health beliefs of individuals, as well as the individual's willpower and level of self-efficacy or the belief someone has about being able to achieve a certain goal or maintain a certain health-promoting behaviour (Burton and Hudson, 2001; Russell et al., 2003; Gray, 2006; Simoni et al., 2006).

Some of these issues only apply to those who can access and afford ART, or to those to whom ART is provided free of charge. In many parts of the world, there are still people needing ART who cannot access treatment – either because they cannot afford it or because there is limited availability of ART and this includes some people in developed countries (Atun, 2006).

People with HIV have complex needs that are often intertwined with other equally complex features of living. For example, some of the symptoms associated with HIV infection can impact on the way individuals go about their daily lives. People who suffered memory loss secondary to HIV infection, which was common in the early days of the epidemic, were more likely to disengage from a therapeutic programme, which in turn could lead to worsening of the symptoms and/or resistance to treatment (Adam and Sears, 1996). Notwithstanding this, and as the clinical focus tends to be often on ART and the management of side effects, other psychosocial and developmental needs have come to be regarded as less of a priority. This is intimately associated with the overall medicalisation of HIV, which marginalises these other concerns and indeed makes a response to an HIV diagnosis more complex.

Being HIV-positive initiates a 'new adjusted lifestyle'. In a study of heterosexual African men living with HIV in London, participants had experienced numerous HIV-related symptoms before being diagnosed, but often avoided being tested (Doyal, Anderson and Paparini, 2009). Once diagnosed, being HIV-positive was felt to lead to loss of identity as a man (for feeling weaker and unable to work), with some men experiencing isolation, rejection by others and dependency on drugs for life. After diagnosis, to which many of the men in the study reacted with shock, informants were forced to rearrange many aspects of their lives (re-adjustment). Some men reported stopping engaging in some of their favourite activities altogether, which the authors related to both the lack of funds to do so and the physical inability to engage in those activities.

Research by Buseh et al. (2006), mentioned above, corroborated some of these findings. Most participants in the study talked about the lethargy that could leave them so weak they could not even travel to their clinic. More positively, however, these men also described developing a sense of expertise in dealing with the side-effects by listening to their bodies and re-analysing their attitudes towards the disease itself. As the authors of the study pointed out, these accounts emphasise the unique experience of illness as a key factor for better management of symptoms. As seen earlier, some of the contextual barriers that these particular groups of men encountered on a daily basis, such as poverty and racial discrimination, may have a detrimental impact on adjusting to living with HIV. However, HIV can simultaneously be a trigger to self-care and greater self-awareness.

So far, this chapter has identified a number of important factors that play a role in the health and wellbeing of people living with HIV, including ART, adherence and mental health support. One final aspect concerns the role of health care professionals. The

first studies looking at the views of health professionals working in the field of HIV started to appear during the 1990s. A review by Barbour (1994), for example, found that this had been a neglected area of research, but available evidence pointed to the existence of stigma and discrimination. Eastham, Thompson and Ryan (1991), for example, found that 38% of professionals surveyed would actively avoid looking after someone who was HIV-positive. These findings were corroborated in a study in the same year by Dworking, Albrecht and Corksey (1991), in which the authors pointed to an apparent relationship between level of discomfort of health professionals and invasiveness of procedures with an HIV-positive client. Most health professionals in the study also expressed high levels of distress and worry about caring for someone with HIV, as well as fear of becoming infected. Research looking at the perceptions and satisfaction levels of received care by people living with HIV appeared only a decade later than those focused on carers. Initially, it tended to focus mostly on experiences of testing for HIV (Clarke et al., 1988; Lupton, McCarthy and Chapman, 1995), and it was only in the late 1990s that more comprehensive studies were developed focusing on the experiences of living with HIV (for example, Davies, 1997; Brashers et al., 1998; Pierret, 2000).

HIV and society

As has been shown so far, stigma and discrimination affect a number of aspects of the lives of people living with HIV. A study by Weatherburn et al. (2008) in the UK found that discrimination on the basis of HIV status was common, despite being often experienced alongside other forms of prejudice on the grounds of sexuality, ethnicity, disability, age and gender. This affects the ways in which people may or may not relate to others. People with HIV may find it difficult, for example, to disclose their status to a new sexual partner, or even engage in a long-term relationship with

someone who is sero-negative. The challenges are not exclusive to HIV, as other chronic illnesses may cause similar concerns for those living with them. However, because HIV is so closely linked to sexuality and sexual health, people living with HIV often find themselves uncertain as to how to reconstruct their sexual and relationship lifestyles and practices after being diagnosed (Adam and Sears, 1996).

Issues surrounding disclosure are particularly complex. On the one hand, a newly diagnosed person may struggle with deciding whom to tell or when to tell. Being HIV-positive can become a secret that is only shared within a limited few. This may have a knock-on effect on the establishment of new relationships as, in order to maintain secrecy, it is often easier not to create strong bonds with people. On the other hand, it may be that, as pointed out earlier, if physical manifestations of HIV are visible, disclosure may become involuntary – thus generating stronger enactments of stigma by society at large.

Stigma and discrimination

Stigma and discrimination affecting people living with HIV have been at the core of work by activists, researchers and health professionals from the beginning of the epidemic to date. This is due to the fact that not only do stigma and discrimination exist within society at large, they are also present in health service delivery which is supposed to ameliorate, rather than exacerbate, the experience of living with an illness such as HIV (Nyblade et al., 2009). For example, in a study by the Asia Pacific Network of People Living with HIV/AIDS (2004) in four Asian countries, 80% of participants reported having experienced some form of discrimination, including from their health care providers[14]. Stigma and discrimination then become barriers to

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[14] For a comprehensive review of a number of studies analysing issues surrounding HIV-related stigma in health care, see Nyblade et al. (2009).

effective support of people living with HIV in meeting their most basic needs and respecting their rights.

Stigma and discrimination are inter-related concepts . As Wood and Aggleton (2004, p.5) explained, "stigma lies at the root of discriminatory actions, leading people to engage in actions or omissions that harm or deny services or entitlements to others". Stigma and discrimination have been associated with HIV ever since the early days of the epidemic. Jonathan Mann was one of the first people to draw attention to AIDS as a generator of intense social and political responses, when he addressed the United Nations in 1987 (Parker and Aggleton, 2003). The third epidemic, that of the negative social response to AIDS as Mann defined it, was multifaceted in that it involved detrimental community responses as well as lack of governmental support or denial to acknowledge that HIV even existed, as happened in a number of countries. Despite Mann's conceptualisation dating back to 1987, its core principles still apply. Social responses to HIV, mostly characterised by stigma, have been extensively analysed in a number of studies (see Alonzo and Reynolds, 1995; Link and Phelan, 2001; Parker and Aggleton, 2003; ANP+, 2004; Ogden and Nyblade, 2005; Gatsi-Mallett, 2006; Reidpath and Chan, 2006; Bell et al., 2007; Nyblade et al., 2009). However, before examining these in detail, the current discussion will focus on stigma and discrimination more generally, so as to understand different theoretical approaches that have been employed in its study and understanding.

Probably the most influential writer on stigma was Erving Goffman who, in 1963, published the classic book entitled *Stigma: Notes on the Management of Spoiled Identity*. In this work, Goffman put forward the notion that stigma implies a social process of devaluation, used to 'mark' those whose characteristics deserve to be devalued. He went on to identify three main characteristics of stigma:

> First there are abominations of the body — the various physical deformities. Next there are blemishes of individual character — weak will, domineering or unnatural passions, treacherous and rigid beliefs, or dishonesty. Blemishes of character are inferred from, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, or radical political behavior. Finally there are the tribal stigma of race, nation, and religion — beliefs that are transmitted through lineages and equally contaminate all members of a family (Goffman, 1963, p.14).

Goffman argued that all three characteristics of stigma are socially, culturally and historically variable. The role of context is particularly important in defining what is and what is not acceptable; what is deviance and what is normalcy (Weiss, Ramakrishna and Somma, 2006). More importantly, the term stigma:

> conceal[s] a double perspective: does the stigmatized individual assume his differentness is known about already or is evident on the spot, or does he assume it is neither known about by those present nor immediately perceivable by them? In the first case one deals with the plight of the discredited, in the second with that of the discreditable (Goffman, 1963, p.14).

Consequently, as Williams (2004, p.69) pointed out, "the discredited primal dramaturgical task is one of managing tension, [whereas, for the discreditable] it is one of managing information: to tell or not to tell, to reveal or conceal, that is the question"!

Thus, in its broader sense, stigma exists in a variety of forms and originates from a number of sources: public attitudes, biomedical discourses, cultural values and personal attributes. Felt stigma, as the quote above suggests, is the result of a process that is socially constructed, learned and applied to oneself, thus perpetuating prejudice whilst being the main subject of its effect. And the manifestations of felt stigma, as the current study will explore, can be multifaceted and have contrasting effects on people.

Goffman was not alone however in highlighting the social construction and relativity of stigma. In fact, his theory echoed those of other interactionist perspectives, such as Becker's (1966) labelling theory. This theory, which analyses the role of labelling and social deviance, offers complementary arguments regarding the role of stigma within society. According to Becker (1966), deviance linked to the presence of a disease ties closely to political control and power dynamics in the social arena. Different groups hold different levels of power, and those creating the rules will inevitably encounter groups that will break those rules. Thus, deviance involves the creation of new social groups. Those who break the rules may be, after some time, labelled as outsiders, and this label tends to carry an additional burden; those considered outsiders will be judged by those in power and punished or penalised in one way or another.

The parallel between notions of stigma in Goffman's work and deviance in Becker's analysis is evident in that both authors consider those processes to damage identity, as well as being constructed by society and perpetuated and negotiated by social groups. However, as Parker and Aggleton (2003) argued in their socio-structural analysis of stigma, the interpretation of stigma as defined by Goffman (and other interactionists) tends to offer a notion of stigma as:

> a kind of thing (in particular, a cultural or even individual value) – a relatively static characteristic or feature, albeit one that is at some level culturally constructed (Parker and Aggleton, 2003, p.14)

Further explanations for the process of stigmatisation come from within social psychology, stressing the links between stigma and individual attitudes and behaviours that are directed towards a group or an individual. Indicative studies, such as Herek's (2002) work, offer a framework for stigma related, in this particular case, to the notion of risk groups discussed earlier. As noted, initial public health

discourses surrounding HIV referred to risk groups as 'fixed entities', membership of which would increase or decrease one's likelihood of acquiring infection. This general form of analysis fuelled understanding of HIV as a 'gay disease'. This approach, which focused on the position of certain stigmatised groups in society, has traditionally lain at the heart of discussions around stigma and HIV. However, it has also been criticised for the apparent neglect of socio-cultural factors and their role in generating stigma.

Thus, for the purpose of the current study, stigma will be defined as "a broad and multidimensional concept whose essence centres on the issue of deviance (...) [i.e.] a construction of deviation from some ideal or expectation (Alonzo and Reynolds, 1995, p.303)". Discrimination on the other hand, as defined by UNAIDS (2000), refers to any kind of exclusion or restriction affecting a person due to a specific inherent characteristic, or because that person belongs to a specific group. In sum, as Wood and Aggleton (2004, p.5) explained, "discrimination is the enactment of stigma".

HIV-related stigma and discrimination

Goffman took a symbolic interactionist approach[15] to the study of stigma in that he sought to understand and explain how stigma takes place and how it is constructed socially. He also distinguished between notions of felt and enacted stigma[16].

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[15] Goffman also focused on the analysis of human interaction, and the way people present themselves and how they establish relationships. In his earlier work *The Presentation of Self in Everyday Life*, he analysed how 'normal' people interacted, which then served as a basis for his work on those considered 'abnormal', i.e. containing a 'spoiled identity' and thus suffering stigma (Slattery, 2003).

[16] Felt stigma refers to the social rejection that someone living with a condition perceives and shares, whereas enacted stigma occurs whenever someone is socially rejected on the basis of the illness.

Alongside the notion of internalised[17] stigma, these terms are central in the analysis of the experiences of people living with HIV. They have been also used to describe experiences associated with a number of other conditions, including psychiatric disorders, blindness or leprosy. When it comes to HIV, however, Zhou (2007, p.285) has suggested that:

> People living with HIV and AIDS's felt stigma is not only their internalization of the AIDS stigma, but also an effect of their interactions with others or actual experiences with public attitudes through which AIDS-related social standards are manifested.

Parker and Aggleton (2003) focused on the construction of stigma as a social process, i.e. emphasising that stigma is constructed within deep social structures. The innovative approach by Parker and Aggleton (2003) focused specifically on HIV-related stigma, unlike Goffman or Becker, and it emphasised that in order to understand HIV-related stigma, there must be an appreciation of how it is linked to deeper social divisions (such as race, class and sexuality, for instance). Thus, HIV-related stigma gets its material grounding in levels of inequality in society. People living with HIV may, therefore, suffer stigma and discrimination because of their diagnosis, but they may already have experienced it due to other factors such as gender, race, class and sexuality. Parker and Aggleton (2003) also argued that stigma must not be conceptualised as a static entity, for it is in constant change.

Much of the literature on stigma and HIV has traditionally been emotionally charged, and focuses on negative attitudes. Consequently, the recurring message that tends to come out of such studies is twofold: people living with HIV and AIDS are subject to discrimination and stigma from a number of actors (health professionals, family

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[17] Despite not being made explicit in Goffman, internalised stigma has become more visible in recent literature (Herek et al., 2009). It is defined as a multidimensional notion, which has been described as including a number of pre-set categories: difficulty telling others, feeling dirty, guilt and feeling ashamed and worthless (Duffy, 2005; Buseh et al., 2006; Simbayi et al., 2007; Gaudine et al., 2009).

members, partners, etc.); and the way to fight against such stigma is to improve tolerance levels, by providing information and demystifying stereotypes associated with the illness (see Parker and Aggleton, 2003, for a critical account of this perspective).

The present study aims to address notions of HIV-reated stigma and discrimination beyond these relatively simple approaches. Starting with specific accounts of experienced stigma and discrimination in Portugal, the study explores ways in which stigma and discrimination are social processes that "can only be understood in relation to broader notions of power and domination (...) in specific contexts of culture" (Parker and Aggleton, 2003, p.16-17). In other words, when exploring men's accounts of stigmatising experiences, the analysis must go beyond the description of these experiences to provide an in-depth analysis of the deeper structural factors influencing discrimination. By acknowledging the role of power in determining the forms stigma takes, it is possible to address some of the criticisms that have traditionally been associated with interactionist and social psychological approaches analysed earlier.

But how do these theoretical approaches to stigma apply to HIV at a practical level? One answer to this question has been suggested by Brimlow, Cook and Seaton (2003, p.12):

> HIV infection fits the profile of a condition that carries a high level of stigmatization. First, people infected with HIV are often blamed for their condition and many people believe HIV could be avoided if individuals made better moral decisions. Second, although HIV is treatable, it is nevertheless a progressive, incurable disease. Third, HIV transmission is poorly understood by some people in the general population, causing them to feel threatened by the mere presence of the disease. Finally, although asymptomatic HIV infection can often be concealed, the symptoms of HIV-related illness cannot. HIV-related symptoms may be considered repulsive, ugly, and disruptive to social interaction.

A study by Zhou (2007) offers a good example of the impact of stigma on people living with HIV, and how stigma is multidimensional. After consulting with health professionals and people living with HIV in China, the author found pronounced levels of (felt and enacted) stigma and discrimination towards people living with HIV, but demonstrated how these were deeply rooted in notions of morality and judgement towards particular risk groups. Similarly to China, in Portugal HIV is still regarded as strongly associated with certain groups (Teles and Amaro, 2006), and this therefore plays into and widens inequalities. In particular, it fuels discrimination towards groups that are traditionally and socially under-valued, including migrants, men who have sex with men and sex workers.

A study by Lee, Kochman and Sikkema (2002) showed that the large majority of participants in two US cities were ashamed of living with HIV, and that the experience of internalised stigma impacted severely on their levels of mental health and coping abilities. So how much of internalised stigma is undergirded by shame? The results of a cross-sectional study by Simbayi et al. (2007) in Cape Town offered one possible approach to answering this question. Whilst the majority of respondents reported having experienced discrimination as a result of their HIV status, internalised stigma was also felt by most of the participants.

Zhou (2007) has highlighted how these socially constructed responses affect how someone living with HIV understands and attributes meaning to their experience of being HIV-positive. She stressed that enacted, felt as well as internalised types of stigma exist in a 'hierarchy of stigmas'. For Gaudine et al. (2009), this hierarchy is often framed in terms of the polarization between innocence and guilt, which can be useful when analysing expressions of HIV-related stigma. For example, there appear to be different social responses to those who were infected under circumstances that were out of their control (such as vertical transmission from mother to child),

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compared to those who were infected as a result of their own behaviour (such as through unprotected sexual intercourse). These hierarchical[18] conceptualisations of stigma are widely assimilated, including by those at risk or already living with HIV, which ultimately affects how one responds to HIV socially or individually.

Ultimately, stigma may also influence risk perception through the process of othering described earlier in the chapter, which is common in the construction of HIV by those who are not – or think they are not – HIV-positive (Reidpath and Chan, 2006). This means that, in practice, some people may refuse to accept their risky practices as having the potential for HIV-infecting transmission, whereas others may refuse to seek support for any related ill-health they may experience.

Criminalisation of HIV infection

In recent years, HIV-related stigma has been compounded by laws that criminalise the transmission of HIV. As more countries enact such laws, an extra burden is added to the concerns that people living with HIV have to deal with. In Europe, for example, a total of 14 countries had, by 2008, approved legislation that deals with the criminalisation of HIV transmission (Nyambe and Gaines, 2005; UNAIDS, 2008). In countries such as the USA and Australia, criminalisation can occur without a requirement to prove that HIV transmission has taken place. In consequence, as

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[18] Hierarchies of stigmas, such as these, echo the hierarchy of transmission categories used in the early days of the epidemic, such as the one used by the US CDC. As Schiller, Crystal and Lewellen (1994) explain, the hierarchy of transmission ranged from 1- male homosexual/bisexual contact, 2- intravenous drug user and so on up until 5- heterosexual contact. These conceptualisations, deriving from misconceptions and the social inequality of certain groups in relation to others, often stand in the way of effective prevention efforts and even health care support. Note, for example, how homosexual and bisexual men are grouped together, when in fact these two groups have significantly different sexual behaviour patterns.

Bray (2003) described, a number of individuals with HIV have been sentenced for up to life imprisonment for biting or spitting at others[19].

UNAIDS (2008) has published a report in which it criticises the use of such laws and suggests that these should be reserved for situations in which it is proved that transmission was intentional. More importantly, it stresses that there should be alternatives to criminal sanctions, including the call for increased government support of programmes and interventions aimed at reducing transmission of HIV whilst protecting the rights of those living with HIV as well as those who are sero-negative.

In Portugal, where the present study took place, there are specific legal frameworks condemning any form of discrimination against people living with disability or ill-health, thus protecting the human rights of people living with HIV (Dec. Lei 34, 2007). The report by Nyambe and Gaines (2005) could not specify if there had been any cases of prosecution based on HIV transmission in this country, as no information was available at that time. When it comes to the criminalisation of HIV, there is only one Law that dates back to 1949 (Dec. Lei 183), regarding the prevention and control of infection for public health, which has been used in cases of transmission of HIV. The current government is working on updating this law so as to focus on a wider range of infectious diseases – such as avian and swine flu and also HIV. According to GAT (2010), little is known about this at present, but the Portuguese government is following closely other European countries and their responses in this respect.

In 2008, the Portuguese Supreme Court ruled as lawful the decision of a hotel manager to dismiss a cook from his staff, based on the fact that the latter was HIV-positive. The erroneous justification read that:

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[19] For a review of the criminalisation of HIV in the UK, see Dodds et al. (2005).

> HIV can be transmitted in situations of drops of blood, saliva, sweat or tears over food served uncooked or consumed by people who have wounds in their oral mucosa (GAT, 2008, p.4)

This decision caused widespread controversy for being based on unfounded information which violated that individual's human rights. In one of the most publicised responses to this case, Maria do Céu Rueff[20] (2008) emphasised that the 'civil death' of people living with HIV remains a reality because discrimination is actively and directly fuelled by the highest judicial institutions in the country. Given this current legislative context, the present study sought to understand how relevant these legal frameworks are to the daily living experiences of HIV-positive men in Portugal.

Being (HIV) positive

This chapter has so far focused on a number of issues that lie at the core of the experience of living with HIV. It is perhaps little wonder that most of these experiences are somewhat negative, and affect the lives of millions in a less than constructive way. This is also a reflection of the dominant literature on HIV/AIDS, which has accustomed readers to the notion that receiving a positive HIV diagnosis is a life-changing (and sometimes life-threatening) experience, usually for the worse.

Adam and Sears (1996), for example, in their classic book entitled *Experiencing HIV*, started by stating: "The diagnosis of being HIV-positive opens a new and difficult journey of restabilising a life jarred from its foundations" (p.1). Since the early days of

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[20] Maria do Céu Rueff is a lawyer and a professor at the University of Coimbra, and a member of the Ethics committee of the Faculty of Medicine of the University of Lisbon. Her doctoral thesis focused on the criminalisation of HIV in Portugal and has become a reference point in the study of legal frameworks and people living with HIV in Portugal and in Europe.

the epidemic, HIV infection has carried social connotations that are traditionally seen as damaging. To many, HIV was and will always be seen as an infirmity that only affects those who are promiscuous and thus deserve to be punished. Overall, and despite the fact that some 30 years have passed since the first case of HIV infection was identified, most people living with HIV today still face a number of difficulties that may negatively affect their daily living.

However, the advent of ART has meant that HIV is now a more manageable condition for many. The literature has traditionally failed to acknowledge this less negative side of the epidemic, as well as the joy and optimism that some have drawn from their positive diagnosis both at a personal and at a community levels. In Adam and Sears's (1996) work, for example, this idea is briefly alluded to under the heading "active coping", which focuses on positive responses to the diagnosis. According to these authors, and to a number of studies they cite, at a personal level, active coping improves quality of life and provides those living with a chronic illness with an enhanced sense of wellbeing.

At a community level, active coping is also present in the actions of groups who have gathered strength and offered support to those who were infected and affected by HIV, as in HIV treatment activism (Adam and Sears, 1996). This is, nevertheless, one of the few references to this positive side of living with HIV in the USA and Canada. Earlier literature gave little attention to this aspect of the experience of living with HIV, for the focus tended to be on how to survive the then lethal infection, be this in terms of physically resisting the effects of infection or socially coping with the range of stigmatising issues associated with AIDS. Writing early in the epidemic, Weeks (1988) described HIV as the symbol of an age "where fear, prejudice and irrationality battled against reason, responsibility and collective endeavour [and] it is by no means clear which will triumph" (p.17).

A couple of decades have gone by since this statement was written, and it is still difficult to provide an exact answer to Weeks' doubt. HIV remains a symbol of a struggle between opposing forces, generating multiple social responses that can be either negative or constructive. To some extent, as discussed earlier, fear, prejudice and irrationality still abound and are very much present across the world. However, progress has also been achieved through reason, responsibility and collective endeavour. This section will take these three core concepts and positive aspects of the response as starting points for a discussion of the more positive side of living with HIV. This section will then highlight some of the success that has been achieved in ensuring this gain in quality of life, as well as describing some of the constructive experiences that people have had since being diagnosed.

Reason

Reason has been a key concept in the battle against HIV. It is linked to the idea of making sound judgements, using good sense, as well as the justification for any given course of action. When it comes to responses to the epidemic, whether at an individual or community level, these have benefited from sound judgements on some of the key aspects of what it means to live with HIV. Research has led to better understanding of the virus and those living with it, all in order to better articulate efforts, plan interventions and improve quality of life. Researchers have brought to the fore notions of stigma associated with this illness (Bell et al., 2007; Zhou, 2007), new interpretations of health and illness (Doyal, Anderson and Paparini, 2009) and even healing practices (Suarez, Raffaelli and O'Leary, 1996) that have been used to respond to HIV infection.

We have, therefore, reached a moment in time that is, in some ways, very distant to

the early days in which fear and ignorance were strongly associated with HIV infection. Advances in treatment and provision of ART, as well as improved quality of life, have allowed for new understandings and conceptualisations of HIV – now seen more as a chronic disease and less as a deadly infection. These events have consequently reshaped the lives of many, who now have better standards and quality of life and increased life expectancy (Nakagawa et al., 2012).

It is not surprising therefore that there is greater visibility of people living with HIV in society at large. A search for online testimonials from people living with HIV returns a number of interesting accounts, most of which reflect this shift to HIV as a chronic, manageable condition rather than a deadly infection. For example, the National AIDS Map website (NAM, 2010) provides visitors with the following narratives of living with HIV:

> I am actually feeling okay about [living with HIV]. (…) I feel like I know what to expect now. I have a different outlook on things. I feel better for knowing my status and I'm making so much more of my life than I was before. (Rob)

> Living with HIV has changed everything in my life. (…) Now I know I am not alone. I have support from people and I give support to others as well. I think living with HIV made me stronger and I believe that once I accepted it and learnt to move on, life becomes easier. (Maureen)

> My self-esteem has rebounded to its previous monstrous proportions – to the extent that I believe most men would be lucky to have me, regardless of my HIV positive status. (Susan)

Another site, this time that of another UK-based organisation AVERT (2010), provides a range of similar accounts:

> Now that I am older and have had more time to think about it all, I realised that my dreams aren't shattered. There's just one more thing to make me stronger and that's exactly what it is doing. Being 17 my life is great, I'm in a relationship and we are both comfortable with it. (Ben)

> In a way I am glad I got it, otherwise we wouldn't know [my partner] had it too, to start on medication, or that his children, from previous relationship, were born with it. Now we can prevent any children we have from getting it. (Kerry)

Each person living with HIV has a story to tell and points to experiences and perspectives that many are now more willing to share out of their wish for a better understanding of the illness itself, but also to ensure that reason and sound judgment lie at the heart of the fight against HIV infection. This is seen by some as contributing to individual or self-empowerment (Hassin, 1994; Flynn et al., 2000). There has been, therefore, a progressive shift, in that the uncertainty faced by those diagnosed with HIV infection common in the early literature (Morin et al., 1984; Segerstrom et al., 1996) is now gradually being replaced by notions of a 'new beginning', which is partly a result of individuals gaining greater control over their lives (Schwartzberg, 1993; Grilo, 2001; Buseh et al., 2006).

Concepts of empowerment have been used in relation to HIV in many different contexts, sometimes quite loosely. In trying to address this issue, a framework has been put forward by Barbot (2006) to clarify the notion of empowerment in relation to HIV. By studying the work of French HIV/AIDS activism organisations, Barbot (2006) argued that the notion of an 'active patient' as one who is, in essence, empowered is complex and rooted in different historical and social traditions. She deconstructs the notion of the active patient into four types: the self-empowered patient, the 'patient manager of his illness', the 'science-wise' patient, and the experimenter. Barbot (2006) argued that the active patient, as well as the four types identified in the study, carry specific associations. Different HIV organisations may use different working definitions, which in turn impact on their particular responses to the epidemic and to the people they support. Different perceptions of the active patient also affect the way in which biomedical knowledge is produced in relation to HIV, as HIV activists have historically been at the forefront of participating in processes of knowledge construction around HIV science in general (Epstein, 1995).

Despite offering a sophisticated framework that can be used to understand how people living with HIV may establish and manage their relationships with different actors within health systems, Barbot's analysis failed to provide a definition of self-empowerment, which is common with much of the wider literature on patient-doctor relationships (Flynn et al., 2000). For Barbot the self-empowered patient is solely a member of a community of "strong sufferers [who] denounce concrete situations of domination [and] exercise a counter power" (Barbot, 2006, p.548).

Despite the framework being HIV specific, in reality, it may be difficult to separate out the four different types of active patient when working with people living with HIV. The framework also suggested a certain level of rigidity of normative roles, which may not occur as such in real life encounters. One of the categories provided, though, has gained wider visibility in the literature and has been discussed earlier: this is the science-wise patient, also known as the expert patient. This concept, which was problematised and reviewed by Wilson (2001), has recently come to gain a central role in policy work, as well as in research studies. In the UK, for example, the term has been used by the Department of Health (2001) to suggest empowerment and improvement in quality of life. Expert patients actively seek information about their condition, and are keen on taking a leading role in dealing with their progress, mostly in terms of gaining the necessary medical knowledge and making informed decisions about the medical and health care procedures suggested to them.

Expert patients exist in relation to a number of conditions, but the literature tends to focus particularly on how the diagnosis of chronic illness may enhance the drive to take control over the individual's health. As HIV infection's identity as a chronic illness is more widely recognised, it is no surprise that a greater number of people living with HIV are well informed and take the lead in the management of their patient careers. However, as is true of notions of self-empowerment, the expert patient is not

a universal type, and mostly reflects a reality that is more commonly associated with the developed world. Even here it may ignore "entrenched professional power and structural constraints to do with access to resources, and conflates experience and education" (Fox, Ward and O'Rourke, 2004, p.1300).

However, in relation to HIV, and according to Treichler (1999), it was through the construction of expert patients that clinicians and researchers were first challenged in their practice, namely in failing to respect ethical codes when involving people living with HIV in clinical trials. As some of the early forms of ART were discovered, expert patients were also at the forefront of the fight to ensure treatment access.

Responsibility

The concept of the expert patient is also linked to the notion of responsibility. Taking responsibility for one's health was one of the principles of the Ottawa Charter of Health Promotion (WHO, 1986). The charter stressed that "health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members" (p. 3). It therefore shed light onto the potential that exists in each and every individual for ensuring that wellbeing and a good standard of health can be experienced by all. This notion of responsibility, in which the focus tends to be on the ability to make decisions, represents only aspects of responsibility as it relates to health and HIV. Lying at the heart of medicalisation, responsibility is often used as an argument for positive living, as an empowering factor for making healthier choices. When creating campaigns encouraging people to voluntarily test for HIV, for example, governments are actually exerting pressure over individuals to feel responsible for their own health. This is where responsibility and reason come together, for responsibility is often used as a

reasoned argument for better living.

Responsibility may also carry connotations of reliability, trust and accountability. In any case, when it comes to HIV, the notion of responsibility has lain at the core of the epidemic from its beginning, even if carrying different meanings throughout (Chan and Reidpath, 2003). For example, Western governments are often urged to take responsibility for rising rates of infection and thus assist Sub-Saharan Africa as the part of the world with the highest rates of HIV infection and related mortality. At a more micro level, individuals living with HIV are often encouraged to take responsibility for their own illness. This is encouraged by the media or through campaigns developed by the various organisations that support people living with HIV[21]. For example, the recent animated 'Scrutinize' campaign in South Africa, directed at young people, aimed at raising awareness of sexual risk behaviours and encouraging young people living with HIV to take responsibility of their health. In the UK, Gay Men Fighting AIDS (now GMFA)'s campaign for World AIDS Day 2009 was entitled 'Take Responsibility for Safer Sex'. According to the Head of Programmes at GMFA, Matthew Hodson, the rationale behind this campaign was:

> Many HIV-negative men believe it's up to positive men not to infect others, while many HIV-positive men believe HIV-negative men should take responsibility to protect themselves. The truth is we are all responsible for our own health as well as that of our partners. (Hodson, 2009, online)

When bearing in mind the recent criminalisation of HIV transmission, it is little wonder that issues of responsibility must be addressed in the public health sector. Behaving responsibly is a requirement placed on everyone in society, but there are added demands exerted over people living with HIV. However, certain groups that were initially considered responsible for the epidemic were also in charge of the

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[21] For a comprehensive analysis of the conceptualisations of responsibility see Chan and Reipath (2003). The authors argue that sex workers, for example, have traditionally been asked to be responsible for preventing HIV transmission, which is often not possible and also may enhance some of the vulnerabilities in which some sex workers may already be in.

movements that have driven the fight against HIV, and improved the overall

experiences for those living with HIV. It was out of the need for responsibility that civil

society woke up to the epidemic and actively engaged in supporting those living with

HIV, which in turn allowed affected individuals to help others in similar situations.

This sense of activism, of community development and social capital, drove the

overall initial response to the epidemic, and has continued to influence campaigns,

interventions and social support directed towards millions of people affected by HIV.

The French philosopher André Glucksman (1994) illustrated thus how responsibility

and empowerment provided the starting point of a response to the epidemic:

> This chilling and unique plague of our time internalizes a sense of general
> panic. A crisis of double standards gnaws at the individual, and pitches him
> against himself. The medical world acknowledges an unprecedented
> impotence. The public wonders, perplexed, what should be done, and freezes
> still. Patients, real or potential, no longer agree to behave as mere objects of
> care; they stand as tragic heroes of a story filled with commotion and fury.
> (p.174)

The last sentence of this quotation reiterates how those first infected or affected by

HIV were often at the forefront of the fight against the epidemic, driven by reason and

responsibility. Park (2006) reflected upon this response, which he described as being

initially driven by gay organisations such as Terrence Higgins Trust in London and

Gay Men's Health Crisis in New York City, and questioned how much of the push for

empowerment that was felt then is still present in the current response to the

epidemic. From the outset, organisations supporting people living with HIV have

advocated a shared responsibility between those infected and those uninfected,

which allowed for HIV prevention to become a universal matter (Daniel and Parker,

1993).

The notion of shared responsibility here implies an enhanced engagement by civil

society in the fight against HIV. This can be seen in the response to HIV in a number

of developed countries and it implies a deep understanding of what it means to live with HIV. However, the notion of shared responsibility emerges out of context when looking at the current state of affairs in relation to the criminalization of HIV infection, for example. Recent laws that criminalise HIV infection, whether in the UK or in Portugal, place the onus of responsibility on the individual who is HIV positive, constructing him/her as a reckless criminal for failing to disclose their status, rather than analysing the act from the perspective of two individuals' shared equal levels of responsibility to disclose each other statuses and take appropriate measures to prevent infection.

In any case, in principle, shared responsibility allows people living with HIV to feel more equal and less excluded from society. It also allows everyone to take part in collective work to fight against HIV, with those living with the virus being in a privileged position to instigate a proactive outlook towards the prevention of new infection, and the promotion of wellbeing amongst those already infected.

Community endeavour

According to Patton (1985), the ties that bound the LBGT community together in the initial response to the HIV epidemic were linked to a shared history of oppression. Community participation has been a fundamental aspect of HIV prevention across the world, and has consequently informed other responses, be it at individual, governmental or institutional levels (Kippax et al., 1992). At a micro level, the role of community support groups has been vital in managing HIV, as well as in supporting those already living with HIV. Bell et al. (2007) found that people living with HIV frequently benefited from taking part in support groups, both as support seekers or providers. The bonds of solidarity that are generated are also positive and may reduce stigma as well as improve levels of wellbeing for people living with HIV (Duffy,

2005).

At a macro level, the extent to which this kind of response has been beneficial is arguable. On the one hand, Greenberg (1992, p.1), when writing about the role of ACT UP[22], highlighted the fact that "because of ACT UP, AIDS and the public's perceptions of the disease and the institutions of our society have been radically transformed and changed". On the other hand, Park (2006), for example, stated that "twenty-some years of AIDS activism and education has not made it much easier for HIV positive people to disclose their status whether privately or publicly" (p.21), but then goes on to acknowledge that HIV infection no longer poses a threat to society and therefore people living with HIV are less discriminated against now than they used to be in the early days of the epidemic.

The process underlying this set of achievements, in which "HIV is no longer an issue for most people" is nevertheless underpinned by AIDS activism and community support. The author also pointed out that "it is unlikely that there will ever again be a movement of the infected and affected like the one that emerged from the gay community in the mid-1980s" (Park, 2006, p.24). This statement presupposes the positive contribution that community efforts have made in allowing greater visibility and understanding of HIV by society at large. Thus, despite the acknowledgement that HIV activism can be effective in dealing with stigma and discrimination, HIV disclosure is still difficult in certain social contexts, including in some countries where rates of infection have only recently started to reach epidemic levels – like China, for example (Zhou, 2007), or others in which there may be cultural and socio-political

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[22] ACT UP is an international direct action advocacy group – initially created in New York city but now spread all across the world – working to impact the lives of people living with HIV/AIDS and to bring about legislation, medical research and treatment and policies to ultimately bring an end to the disease by mitigating loss of health and lives (from ACT UP's website, www.actupnyc.org).

barriers to disclosure. So, as Park (2006) suggested, early models of community activism may be regarded as best practice in responding to the epidemic in these newly affected countries.

Plummer (1988) has pointed out that even the earliest community responses to the epidemic had a dual impact on the communities they were intended to support: AIDS decimated whilst simultaneously strengthening the gay community. This process of strengthening was not merely a result of getting together and gathering resources to support those that were dying. In addition, the initial community responses that were organised around AIDS offered an opportunity for affected communities to 'begin again', i.e. they opened up a forum for these communities to deal with the challenges that had been left over from earlier discussions around race, gender and other inequalities (Patton, 1985). This allowed some groups to deal with their own prejudices, and to create a shared consciousness that laid the foundations for later community empowerment.

It is now widely documented that the level of social cohesion in society determines overall susceptibility to HIV. Uganda is a classic and successful example of how different communities came together initially in responding to the growing epidemic. Community coping systems were developed and put into place resulting in a strengthened sense of community development to prevent HIV infection and support for those living with it. Uganda's response proved that social cohesion could absorb some of the shock resulting from the suffering from living with HIV (Ssengooba, 1999; Barnett and Whiteside, 2002). Despite this, Uganda is still struggling in dealing with a number of other issues that may indeed impact in the social response to HIV. For example, the killing of David Kato in 2011, a gay rights activist, was widely reported as evidence that homophobia is very much ingrained in the cultural make up of the country. Similarly, the Ugandan government was presented with the anti-

homosexuality bill in 2009 and 2011 which supported the death penalty for people engaging in sex with others of the same sex (Hensman, 2009; Editors, 2011).

Earlier, in Brazil, Daniel (1989) explained that the foremost element of the fight against HIV/AIDS should always be the respect for the rights of those living with HIV, whether at individual or collective level. Daniel also highlighted the role of social solidarity, which, according to him, is the safest effective tool against the civil death that many people living with HIV suffered in the early days of the epidemic in Brazil, and in many other countries (Galvão, 2000). Daniel and Parker (1993) highlighted how the initial response to the epidemic in Brazil was founded in pre-existing prejudices and assumptions regarding those who were the 'victims' of the epidemic at the time: gay men and injecting drug users. Significantly, Galvão (2000) noted that news of AIDS arrived in Brazil (via the mass media), before the first case was officially recorded. Thus, early social representations of this new illness in Brazil were mostly based on the portrayals created elsewhere (mostly the USA and the UK, as the first countries to have recorded cases of HIV infection, or GRID[23], as it was known then).

In Portugal, there was somewhat a similar response. The mass media, which Teles and Amaro (2006) regarded as the main vehicle for transmission of HIV-prevention information to the general public in the country, promoted the idea of relative safety, more so in the early days of the epidemic. By sustaining the impression that the epidemic was something foreign, that had not really reached Portugal, it emphasised the need for membership of a certain risk group for infection to occur (Ponte, 2005). Ponte (2005)'s early analysis of Portuguese mass media news headlines revealed that 'homosexuality' was in fact the most common term associated with HIV, which

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[23] For Gay-Related Infectious Disease, as HIV infection was initially named when only little was known about the disease itself.

tended to be portrayed as the result of risky practices and immoral behaviours. This led to gay-related prejudice compounded with people's preconceived ideas about HIV infection, generating fear and relegating those considered to be members of risk groups to the margins of society. It also meant that, due to the fear of stigmatisation, there was an under-notification of HIV infections in Portugal in the early days of the epidemic (Cunha, Teles and Amaro, 2006)[24]. It was only with the development of various NGOs that some of these issues started to be dealt with more effectively. Thus, despite quite a convoluted initial response, it was thanks to community activism that the some of the misrepresentations of HIV in Portugal were addressed at political and social levels.

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[24] It was only in 1982 that homosexuality ceased to be considered a crime under the Portuguese judicial system (Cunha, Teles and Amado, 2006).

Men, Masculinities and Health

When gender became a recognised category for social as well as epidemiological enquiry in the 1970s, an increasing number of studies came to examine the differences and relationships between men and women (Standing, 1998). Some of the more comprehensive approaches to gender and health appeared in the 1980s, mostly in response to actions by the women's movement (Sabo and Gordon, 1995). Overall, these studies[25] unveiled some of the social structural issues pertaining to patriarchal values, their impact on society and, for example, how much influence they have on one's health, particularly regarding women's access to (structurally gendered) health services (Connell, 2002).

More generally, feminist and post-modern critiques sought to identify and challenge the patriarchal structures in society, which led to a growth in studies exploring how women's health is influenced by inequalities of gender (Sabo and Gordon, 1995). It also meant that early research on gender and health focused almost exclusively on women (van der Kwaak and Dasgupta, 2006). With the passage of time, however, there has been a broadening of perspective to embrace men and masculinities. As Giddens (2001) explained:

> sociologists have become increasingly interested in the positions and experience of men within the larger order that shapes them, [leading to] a new emphasis on the study of men and masculinity within the overarching context of gender relations, the societally patterned interaction between men and women. (Giddens, 2001, p.118)

It is now widely documented that, like women, men experience a range of health problems, some of which are linked to determinants that can affect anyone's health, whilst others are more closely related to masculinity specifically (Hearn and Kolga,

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[25] These days often referred to as "Women's studies".

2006; Gough and Robertson, 2010). In particular, in Western countries of which Portugal is an example, it is expected that young men engage in a number of harmful practices and behaviours (such as smoking, drinking, risky sex and substance use) that serve as a vehicle to demonstrate their masculinity (Vale de Almeida, 1996). Whilst there is some truth to this statement, this has been criticised for aggregating all men into the one group all of whose members behave in the same way (Robertson and Williams, 2010). Recent theoretical frameworks, such as the ones that will be explored in this chapter, allowed for a more sophisticated approach to the complex nature of men, masculinities and health.

Sex, gender and health

The notion of gender demarcates a distinction between what is commonly regarded as sex (biological) and what is social. The difference between the two concepts was explained by Oakley (1972) in the following way:

> sex is a biological term: gender a psychological and cultural one. Common sense suggests that they are merely two ways of looking at the same division and that someone who belongs to, say, the female sex will automatically belong to the corresponding (feminine) gender. In reality this is not so. To be a man or a woman, a boy or girl, is as much a function of dress, gesture, occupation, social network and personality as it is of possessing a particular set of genitals. (Oakley, 1972, p.158)

In social research, concepts of gender were initially used to replace the notion of sex role as hitherto used within the fields of social and developmental psychology. Sex role theories stressed the socialisation of individuals into typically masculine or feminine selves[26]. The shift from focusing on these characteristics to analysing gender in broader terms allowed for a clearer differentiation of what was masculine

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[26] For a comprehensive analysis of sex role theory see Eagly, Wood and Diekman (2000).

and what was feminine within a given culture. As a result, gender emerged as a

social category that facilitates the identification of similarities and differences that go

beyond the binary sexual division. This is exemplified in the following excerpt from

Standing (1998):

> men and women's different roles and perceptions of acceptable levels of
> discomfort lead to gender differences in willingness to accept that they are
> sick and to seek care. There is some evidence that women wait longer than
> men to seek care for illness partly due to their unwillingness to disrupt
> household functioning until they become incapacitated. However, fulfilling
> male roles such as that of the 'breadwinner' may also lead to pressure on
> men not to accept the sick role in certain contexts because of the economic
> implications of this. (Standing, 1998, section 2.2)

Nevertheless, as Petersen (2003) has pointed out, "if scholars are to effectively

challenge the power relations of gender, race and sexuality, it is important they

critically examine the discursive frameworks that shape the fabrication of concepts"

(Petersen, 2003, p.54). Notions of gender, as seen earlier, attempt to account for the

social realities of men and women. Gender is fluid, malleable and varies between

cultures and between people within the same culture. Notwithstanding this, much

research on gender seems to have focused largely on the fixed differences between

men and women, failing to acknowledge the diversity that exists within each

category. This may be due to the residual influence of the earlier psychological and

normative analysis of gender identity formation (Petersen, 2003).

When it comes to men and masculinity, one also needs to acknowledge the

differences between both concepts, for it is common for both terms to be used

interchangeably, when in fact they encompass rather different ideas. Flood (2002)

identified three clusters of phenomena to which masculinity usually refers: "beliefs,

ideals, images, representations and discourses; traits which differentiate men from

women and powerful men; or a strategy for maintaining power" (Flood, 2002, p.204).

This multidimensional conceptualisation of masculinity is useful in that it includes the

various complex structural hierarchies that exist among men, and between men and women. It also allows for a better understanding of diversity within men as a group, and of different forms of masculinity, or masculinities:

> There are diverse expressions of masculinity, not a singular one (...) Men interpret their experiences of masculinity in relation to their race, ethnicity, socio-economic status, age, ability, sexuality and geographical location (...) These interpretations and the values they express are not fixed and change over time. Some forms of masculinity are more dominant [and] the values of masculinities are evident in men's health behaviour, their social and cultural practices and in the social structure. (South Australian Health Commission, 1997, p.7)

The above quotation not only acknowledges the multifaceted nature of masculinity, but also stresses the role of other social factors in constructing men who, in turn, are a complex and diverse group. Notwithstanding this, much public health and social research on men's – and indeed women's – health still tends to look at men as a monolithic category, characterised by supposedly similar social practices that determine their health behaviours. In doing so, a loss of structured variation occurs, even when some research studies present different categories to describe different kinds of men.

Approaches to studying men, masculinities and health

Men worldwide suffer more ill health, engage in less healthy lifestyles and die at a younger age than women (WHO, 2000). What remains to be understood, though, is why men engage in less healthy lifestyles than women, and in fact why it is that there are such differences between genders (Courtenay, 2000).

Biological explanations for these differences such as the fact that men produce the health protecting hormone oestrogen in much smaller quantities than women[27] cannot solely justify all the observed differences. Busfield (2000) highlighted an interesting paradox in the data for the UK: despite men having higher mortality rates, these are not usually matched by higher rates of morbidity. This may be due to the fact that, even though men tend to adopt fewer health-promoting behaviours, men also engage more commonly in high-risk activities, or are employed in high risk jobs as well as being more exposed to hazards, which may have fatal consequences (Busfield, 2000; Courtenay, 2000).

Another explanation for gender differences in health links to the notion of sex roles, which were briefly discussed earlier. In short, sex role theory argues that men and women behave in certain sex-specific ways. Sex role theorists stress the importance of early (sexual) socialisation in determining subsequent behaviour. By age three, for example, most children will have developed aspects of their core gender identity. Thus, they will identify many characteristics that are specific to being a boy or a girl, and how these are performed by boys and girls, men and women (Butler, 1993; Luck, Bamford and Williamson, 2000).

For example, boys tend to be taught different types of play from girls (playing with cars, football are commonly regarded as boy's play). According to sex role theory, the construction of masculinity and femininity has its origins in this process of socialising boys and girls, through play and interaction but also through language and other non-linguistic tools – also known as the 'hidden curriculum' (Luck, Bamford and Williamson, 2000). Ultimately, and broadly put, sex role theory argues that being a man means obeying to a set of rules which will lead to conformity to an ideal type:

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[27] Despite oestrogen being linked to various forms of cancer in women, it has also been found to have a protective effect on the development of cardiovascular disease (Collins et al., 1993).

heterosexual, active and virile. This is not the opposite of being a woman, but rather an opposition to certain aspects of femininity such as weakness, passivity or subordination (Parker, 1991). This set of principles becomes part of most men's conception of being a man, which they may or may not aspire to or achieve.

The psychological approach, of which sex role theories are an example, also includes the study of masculinity and femininity traits. The most noted author of this area is Sandra Bem (1974) who developed the Bem Sex Role Inventory, a set of psychological scales that measure which traits are more or less masculine. The identification of traits that are more masculine or more feminine derives from what is commonly regarded in society as assigned to one gender or the other. So, for instance, aggression is often seen as a masculine trait whereas displaying affection is a feminine one. Subsequently, Bem and her colleagues correlated these traits with a range of other factors such as specific health-related behaviours (such as alcohol or drug use), cardiovascular stressors or the number of sexual partners (Robertson, 2007). These scales are organised around the notion of there being relatively fixed sex roles which can be regarded as limited, limiting the variability that exists within masculinity to one primary dimension (Hearn, 1996).

In order to respond to some of these limitations, sociological studies have explored the influence of the broader social context on masculinity, and how this inter-relates with notions of illness and health. According to Hearn (1996), social research has supported the definition of masculinity as "a generalisable, cultural phenomenon and a variety of culturally specific expressions of gender and gender identities" (Hearn, 1996, p. 206). Robertson (2007) added that the creation of a theoretical framework in which masculinities are conceptualised is important, and that that framework should recognise the wide diversity that exists amongst men and masculinities. Additionally, the notion of power, central to the study of gender and often at the core of many

sociological analyses, appears to have been neglected by more psychological approaches (Connell, 1987).

For instance, power is present in most masculine behaviours associated with health practices. As Robertson (2007) showed, there is a negotiated power that can be witnessed in the interactions between men and health professionals. This is particularly visible when men become resistant to receiving health care support. "Whereas women's resistance may be an active, but often hidden, ignoring of advice (...), men frequently and publicly use (rhetorical and/or actual) resistance to health advice as a way of demonstrating masculinity" (Robertson, 2007, p. 122). The same author also suggests that this desire to maintain control conflicts with the goals of surveillance medicine[28].

Men's resistance to accepting advice from health professionals may be due to their socialisation: there are strong social pressures on men not to show pain, suffering, vulnerability or sadness. Men are supposed to be in control of their emotions and their bodies, and should come across as strong and vigorous. As Courtenay (2000) puts it, "when a man brags – I haven't been to a doctor in years! – he is simultaneously describing a health practice and situating himself in a masculine arena" (Courtenay, 2000, p. 1389).

In certain contexts, though, values of dominant masculinity abandon this notion of stoicism to adopt one of complaint and sympathy seeking. Simultaneously, women who bring up boys tend to pass these same values onto their sons (Luck, Bramford and Williamson, 2000). This goes to show, once again, that concurrently fixed and

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[28] According to Armstrong (1995), surveillance medicine, which is characteristic of the twentieth century, is based on a problematisation of the normal, in that all individuals are likely to be at risk of developing illnesses.

fluid notions of masculinities are constructed in a dynamic interaction between men and women.

Important to this discussion is also the range of gender stereotypes that can be used to explain how people behave and what their behaviours signify. As Rivers and Aggleton (1999) explained, the variability that exists within society as a whole and within men as a group is not always acknowledged, leading to stereotypical and superficial analyses. By adhering to a certain gender stereotype, such as the fact that men are strong and women are weak, both men and women perpetuate their worth and place in discourse and action, contributing not solely as performers of stereotype, but also as agents of its spread (Courtenay, 2000; Robertson, 2007). Moreover, gender stereotypes consequently become rooted in every aspect of a man's behaviour, and can have serious implications for men's health and wellbeing. One example of this is the implicit notion that being a man includes resisting pain and being strong. Masculinity can, thus, facilitate or inhibit specific behaviours and practices within a health context (Robertson, 2007).

With this in mind, Connell (1995) proposed a model in which described different patterns of contemporary masculinity are described: hegemonic[29] masculinity, subordinated masculinity, marginalised masculinity and complicit masculinity[30]. Connell's theory suggests that men also demonstrate these different patterns of

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[29] Hegemonic masculinity refers to the dominant form of masculinity in a given society. For example, in Western society, hegemony is linked to notions of white, middle-class wealthy men.

[30] Connell believed that there are many expressions of masculinity and femininity, therefore introducing the notion of 'masculinities' instead of masculinity. In her study of masculinities, Connell used ideal types of masculinities in a hierarchical model. Hegemonic masculinity is at the top, and this refers to the dominant masculinity of a given society (which Connell associated with marriage and heterosexuality). Below hegemonic masculinity is complicit masculinity, or a form in which men benefit from certain hegemonic status but not in all its dimensions. Then there are those forms of masculinity that are more evidently subordinated to hegemonic forms, such as homosexual masculinity, emphasised femininity and resistant femininity (Connell, 1995; Giddens, 2001).

masculinity within discourses and practices of health-related behaviours. For example, hegemonic constructions of masculinity in the developed world perpetuate the image of men as resilient and tough, self-reliant and fearless. These characteristics can influence those men who adopt hegemonic masculine values to avoid seeking help concerning health matters, and can be used to explain some of the differences in mortality rates mentioned earlier. Moreover, as Robertson (2007) and Matthewson (2009) pointed out, when men displaying hegemonic masculine values do access health services, they can find it to be a difficult experience, as help-seeking may seem to compromise and limit individual agency and control.

The notion that hegemonic forms of masculinity may be harmful to health has been shown in various studies (see, for example Courtenay, 2000; Addis and Mahalik, 2003). However, while there has been considerable development in knowledge relating to men and masculinities, few studies can see beyond singular constructs of hegemonic masculinity. Matthewson (2009) added that cultural specificity is also not always taken into account in studies of men and health, so the notions of hegemonic masculinity that apply to the US or UK contexts are often generalised and used in studies of men living in quite different social and cultural settings. This was also highlighted in Connell's (1995) approach, when stressing the notion that hegemonic masculinity is the form of masculinity that is culturally dominant in a given context or setting. Therefore, as a number of anthropological studies have found, certain behaviours and values traditionally associated with masculinity in the Western world may not apply to other contexts.

Moreover, as notions of masculinity are so embedded in the cultural and social context, changes in societal approaches to health (as in the separation between sexual pleasure and sexual and reproductive health), improvements in reproductive technology, the fight for civil rights of gay men and lesbians and undoubtedly the

advent of HIV/AIDS, have all impacted on ways in which masculinity is currently portrayed, researched and understood (Haywood and Mac an Ghaill, 2003).

On the one hand, these factors have documented men's views and experiences of health and illness through more personal accounts. This has enabled an analysis of the extent to which men's experiences concur with current expectations and ideologies that are encouraged by hegemonic masculinities (White, 1997). However:

> there is still a dearth of health-related research in which gender is explicitly considered. While many studies do include sex as a variable, few explore how culturally dominant notions of masculinity and femininity might influence health practices. (Gough 2006, p. 2477)

Therefore, more research is needed into constructions of masculinity and health-related attitudes and behaviours within specific cultural contexts. Crucially, hegemonic masculinities do not need to be the most common or even most comfortable forms of masculinity, and men can find it difficult to balance the tensions generated by different forms of masculinity. Thus, the dominant character of hegemonic masculinity can assume varying forms of expression, from secluded to aggressive. It generally fosters sexual inequality and allows the hegemonic male to exert social control and influence over lower-status men and women.

Connell's hierarchy of masculinities is therefore not as fixed as sex role theories imply, for it allows flexibility amongst different forms of masculinities. In other words, men can demonstrate one type of masculinity within a certain setting that differs from the pattern shown in another. Or, as Robertson (2007) explained:

> what constitutes a hegemonic masculine ideal may alter through the life course (...), a hegemonic ideal for younger or single men [may] shift towards an ideal of 'controlling excess' when the responsibility of a stable relationship, and particularly fatherhood, are entered into. (Robertson, 2007, p. 56)

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Applying these ideas to the study of men and health can facilitate an understanding of why positive health behaviours are so often linked to what is not regarded as masculine[31]. Moreover, it can also highlight wider social structures that perpetuate these notions, sometimes unwittingly. Bourdieu (1977, 1990) observed that symbolic domination only happens when those in a subordinate position assimilate the structures that inform the way by which they are perceived by those in a dominant position. Therefore, generative dispositions (or habitus) need to change in order for men to think and behave differently (with regards to their health). Hegemonic masculine values are also entrenched within health services, which means that "it is [often] a (hegemonic) male gaze that undertakes observation and examination and a (hegemonic) male norm by which others (women, non-hegemonic men) are measured" (White, 2001, p. 131).

In other words, men and women construct health care systems that are organised around, and work with, these deeply ingrained notions of masculinity. That is why most men have fewer health services available to them, are given fewer explanations of their health conditions and receive less health promotion advice (Courtenay, 2000). Some authors have further analysed this question and concluded, for example, that: the physician's gender matters in the shaping of the patient-physician relationship (Roter and Hall, 1997); or, in a more macro-analytical approach, health systems are said to be constructed upon heterosexist values, which in practice may lead gay and lesbian patients to experience homophobia in health care settings (Fish, 2007).

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[31] Even if for certain models, notions of vigour and fitness can be regarded as masculine. This goes to show, once again, the spectrum of fluidity that can be applied to the study of masculinities.

Men, masculinities and HIV

As explained earlier, most early research on gender and health focused on women's health. This does not mean that men were entirely absent from research. Men have been at the centre of biomedical and social research for many years, including HIV research, with its early focus on gay men[32], for example. However, research has been deficient in teasing out meanings related to notions of masculinity in contexts of health care (Knauth and Machado, 2005; Schraiber, Gomes and Couto, 2005).

It has been well documented that gender is one of the most fundamental factors affecting vulnerability and impact of HIV infection worldwide (Mane and Aggleton, 2001; UNAIDS, 2009b). This has traditionally been associated with the dominant gender ideologies examined earlier that seem to place the subordinate gender at greater risk of ill-health. For example, in 1994 the International Conference on Population and Development in Cairo highlighted the notion of gender mainstreaming and, despite some reference to male involvement, women were placed at the centre of most discussions regarding gender and health. This in turn led to a significant increase in the number of studies looking at women's situation worldwide, with respect to their reproductive and sexual rights, issues and health needs (Zoll, 2006). As Mane and Aggleton (2001) explained:

> women's inability to negotiate sex, let alone safer sex, their economic and societal reliance on men, their lower positioning within family and social structures (…) make it next to impossible for most women to ensure protection from HIV (…). Women are thus disproportionately affected by the HIV epidemic in multiple ways due to the influence of gender. (Mane and Aggleton, 2001, p. 25)

It is important to recognise, however, that gender works to disadvantage both men and women. In the context of HIV, men play a key and multifaceted role in the control

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[32] Gay men were a focus also because they were (and are) a 'marked' masculinity.

and/or development of the epidemic, so it is as important for men as it is for women to be addressed by gender sensitive work, in HIV research and health studies in general.

But why have we not witnessed a greater breadth of focus on gender in biomedical and social programming so far? Zoll (2006) pointed out that funding programmes that are specific to work with men may also be regarded as detracting from the limited resources existing for programmes on women and girls. This contributes to perpetuating the notion of the role of men as agents of dramatic intervention (Zoll, 2006), for it highlights the perceived negative impact that conventional notions of masculinities traditionally have had on women and girls. There needs to be a shift in reassessing the pathways that link gender and health, as men have similar reproductive and sexual health needs as women, even though these are actually less addressed by services and policies (van der Kwaak and Dasgupta, 2006).

Over the last decade, this lack of visibility of men has started to be addressed. In 2000, UNAIDS commissioned a report for the World AIDS Day campaign on working with men for HIV prevention and care. This identified a set of priorities and actions needed with respect to policy, programming and project implementation. In a foreword to a report published at the time, it is argued that:

> work[ing] with men and boys should not seek to replace work with women and girls, but rather complement it. Parallel programmes for men and boys are crucial in ensuring that men protect not only their own health but also the health of their families (…) [and] rather than apportioning blame, it is hoped that men can finally begin to be seen as part of the solution rather than part of a problem. (Rivers and Aggleton, 1999, p. 5)

The authors also highlighted that working with men (and women) requires an understanding of the multifaceted nature of masculinities and the significant variability that exists between men:

> While some men display little interest in protecting themselves and their partners against disease, perhaps believing themselves to be 'invincible', others behave with the utmost responsibility and consideration for others. Moreover, while perhaps the majority of men prefer to have sex with women, a not insubstantial number of men have sex with members of both sexes or with other men alone. (...) Analysing the position of 'men' in relation to the HIV epidemic is therefore a complex and difficult task. (Rivers and Aggleton, 1999, p.7)

In the case of HIV infection, research and intervention should move on from discourses on hegemonic or subordinate masculinities to a new arena in which social practice is more deeply explored, and context-specific performances of manhood are examined in a more sophisticated way. In line with what was argued earlier, Dowsett (2003) has argued that, despite gender being such a crucial factor in the understanding of HIV infection, other variables must also be taken into account, including age, poverty and sexuality. So, studies of masculinities and HIV must address the influences that one of these factors may have over another, while being careful not to adopt an essentialist paradigm in which all issues related to men's health (and illness) are derived solely from the fact that they are men.

Masculinity and HIV in the Portuguese context

Portugal is a southern European country, often described as Mediterranean or Latin in character for sharing some of the cultural values of those countries located adjacent to the Mediterranean Sea or in Latin America. One of the core aspects related to masculinity in Portugal is that of 'machismo'. This term, that exists in most Latin languages, is usually associated with the belief or ideology that men are superior to women, and will not accept equal rights being given to women, for example (Porto Editora, 2009). Within majorly Catholic countries (of which Portugal is an example), there is also another relevant notion to bear in mind: marianismo, which

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Ary (2000, p.102) has dubbed as "the other face of machismo". This relates directly to a devotion to Virgin Mary, but indirectly encompasses certain stereotypical values associated with femininity and women, such as spirituality, humility, virginity and sexual passivity.

Notwithstanding this, according to Vale de Almeida (1997), Portugal has historical and social specificities, as well as a marked diversity – namely between the North and the South of the country – that influences notions of machismo in Portuguese society. One of these variations is that of 'marialvismo', which can be described as a form of hegemonic masculinity in which notions of power, nobility and honour translate into what it means to be a man. These values are often found reflected in music ('Fado'), in the practice of bull-fighting ('tourada') and in the political mythology associated with the 'national soul' linked with 'Sebastianismo'[33] and notions of 'saudade'[34] (Vale de Almeida, 1997).

Whilst marialvismo is somewhat restricted to specific areas in Portugal – namely areas where bullfighting is a known and respected tradition, such as the Alentejo in the South and Ribatejo in the Centre – it can be considered to be a form of hegemonic masculinity specific to Portugal. Traditionally, masculinity in Portugal tends to be depicted as the product of "a male chauvinist culture, with a strong sexual division" (Vale de Almeida, 1996, p.11). This same author also argues that masculinity is reflected in various social processes, particularly those surrounding

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[33] Sebastianismo relates to D. Sebastião, a Portuguese king of the 16th century who led the Portuguese Army and was defeated and killed in the battle of Alcacer-Quibir in Morocco, leaving no descendant. Despite the fact that the Cardinal D. Henrique replaced Sebastião in reigning the country, the Spanish King Filipe II took over ruling Portugal up until 1640. Sebastianismo was then fuelled by the fact that his body was never found. Sebastião was defeated whilst Portugal was one of the mightiest empires, and his death had significant consequences to the patriotic identity of Portugal. This has featured in the work of poets and scholars throughout the years, claiming that one day he will return to save Portugal and establish the Fifth Empire, in which Portugal will be the powerful nation it once was.

[34] Put simply, 'saudade' refers to feelings of longing, loss and painful desire to see someone dear again – usually someone who is absent, dead or missing.

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work and leisure. His ethnographic study of men in a Portuguese town explored how masculinity was performed and conceptualised. In particular, he applied Connell's framework to the study of masculinities to arrive at a characterisation of hegemonic masculinity in Portugal, which included:

> a) the dichotomy masculine – feminine is a symbolic asymmetry; b) sex and gender are compacted into one sole category in which body signs legitimise the social and symbolic divisions; c) masculinity is associated with the dichotomy active-passive, and therefore influences the public, political and social arenas; d) the hierarchical and divisive lines that separate masculine and feminine also separate men amongst themselves, i.e. 'higher' masculinity is often linked to higher social position; e) social division (of class, status) is understood in a discourse that is highly charged with higher or lower masculinity capital; and f) discourses accentuate the division between masculine and feminine, and the practice accentuates homosociability, in which the 'danger' of homosexuality is controlled by the exaggerated rhetoric of virility. (Vale de Almeida, 1997, p.1)

In other words, the marked distinction between men and women is extrapolated to other interactions, namely those between men. Those considered passive – through discourse or behaviour – and therefore feminine, will ultimately be disempowered within social contexts. Similarly to what was argued earlier with respect to Connell's interpretation of hegemonic masculinity, Vale de Almeida asserted that no man can experience or represent all of these concomitantly, as no man can be strong, a leader, brave or honoured at all times. Rather, these become nuances inflected in everyday practices, ways of talking, acting and thinking.

But how do these factors come to influence men's health and wellbeing? A study by White and Cash (2003) reviewed the state of men's health across seventeen Western European countries including Portugal, analysing subjective wellbeing and self-perception of health. Whilst there was an overall tendency for men to perceive their health as 'good' more frequently than women across the 17 countries, the Portuguese sample scored the lowest in all the study's dimensions, meaning that Portuguese men self-reported their health as being 'worse' than their European

counterparts. The authors did not offer any explanations for these discrepancies, even though it would be intriguing to understand why there were such differences.

In a relatively recent study looking at epidemiological evidence of gender disparities in Portugal, Prazeres (2004) pointed out that, as happens in other Western countries, mortality rates are higher for Portuguese men than they are for women, which may, at least in part, be due to men adopting traditionally hegemonic behaviours (risk-taking, sexual prowess, etc.). Additionally, Portuguese men suffer more ill-health related to alcohol or drug use than women, which can also be linked to dominant social expectations influencing the way men are socialised in Portugal: men start to engage in risk behaviours (unsafe sex, use of drugs and alcohol) earlier than women and more often throughout their lives.

When it comes to HIV, not only is there a clear and unusual disparity between the reported prevalence rates of HIV infection for men and women in Portugal (as of December 2011, a 73.6% of all HIV positive diagnosis are among men), mortality rates for deaths by an AIDS-related illness are five times higher for men than they are for women, with 83.9% of all AIDS-related deaths among men reported (Ministério da Saúde, 2009; UNAIDS, 2010; INSA, 2012). This discrepancy calls for approaches that aim to understand the role of gender and its impact on experiences of health and illness. In particular, it is important to adopt an approach that is connected to the symbolic asymmetry between men and women suggested earlier by Vale de Almeida (Amâncio, 2003; Prazeres, 2004). Similarly, and for the purpose of the present analysis, masculinities and femininities work as metaphors of power and ability to action; masculinity is asymmetrical[35] to femininity and also constituted by

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[35] According to Lohan (2010), gender power relations may be fluid and contradictory, but the relationships between men and women and indeed masculinity and femininity are asymmetrical in Western societies. This asymmetry relates mostly to the fact that the two

other asymmetries (namely, heterosexual/homosexual) and hierarchies (more or less masculine) (Vale de Almeida, 1996).

The diagnosis of a fatal or chronic illness that can present with distressing physical, social and psychological symptoms may also impact severely on the way in which men are seen and see themselves. If put in terms of the spectrum of masculinity-femininity alluded to earlier, a man living with HIV in Portugal may feel like a passive victim, and therefore more feminine. Being ill often means having less ability to work and be productive, less able to endure hard physical activities or risky behaviours, and that can operate as a divide from all the other boys/men.

Additionally, some men with HIV may have become infected through same-sex relations, which may be a (stigmatising) reason for their being viewed as less masculine than others. Men may seek to limit these effects by avoiding entering the social arenas in which disclosure of the diagnosis is likely to be required in order to preserve their position within the masculine hierarchy. This is particularly evident in work settings (such as having to disclose HIV status during occupational health screening), but may also present in private matters (such as when in enduring intimate relationships) or in health promoting behaviours (such as seeking help as soon as being diagnosed). This shows that HIV has important consequences for both private and public spheres.

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parts are interconnected even though they hold different powers: "Theorising men's lives does not and must not exclude women and femininities" (p.13).

Chapter summary

This chapter has aimed to shed some light on the complex range of medical, social, psychological and cultural factors that affect living with HIV. Whilst notions of hardship, stigma and discrimination have been recurring themes, the preceding section explored how certain responses to HIV may be empowering, engendering the potential for achievement and an improvement in wellbeing. The chapter has also aimed to provide an initial theoretical grounding for the current study.

In the latter part of this chapter I have explored some of the ways in which concepts of sex, gender and health inter-relate and offered a number of broader theoretical contributions to the understanding of masculinities and health. As the current study will explore the experiences of men living with HIV in Portugal, this chapter reviewed a number of relevant studies looking at the role of masculinities in Portugal. As research looking at masculinities and health in Portugal is very limited, the present study aims to shed some light on to this topic, in particular by analysing the experiences of men and the relationships between masculinities and health vis-à-vis HIV infection.

Chapter 3

Methodology

Introduction

This chapter will outline the methodology used to address the research questions identified in chapter one. Warwick and Overton (2003) identify three key aspects of research design: philosophical underpinnings, methodology and logistics/practice. The present chapter discusses each of these areas, but begins one-step slightly back with an initial description of the research context, as well as the role of the researcher in the research process. The chapter then discusses some of the key assumptions underpinning data collection and analysis. Finally, there follows a description of the various methods used for data collection, procedures for data analysis and ethics, together with a consideration of the study's methodological strengths and potential limitations, in terms of validity and reliability.

Researching men, masculinities and HIV in Portugal

Moving from the oldest dictatorship in Western Europe to a cosmopolitan and outward looking nation, Portugal has gone through major change in the last three decades. These changes, as Pinto (2004) has argued, have occurred at political, social and economic levels. Adding on to these historical changes in the organisation of Portuguese society, which occurred following the demise of the dictatorship in 1974, a significant number of other factors have also played a role in influencing Portugal today. The current recent economic recession (2008-12), which has greatly

affected Portugal, for example, has reignited a push for emigration to levels that have not been seen since the 1970s.

Gender relations have also been influenced as a consequence of changes in Portugal. Some examples include a gradual and stronger recognition of women's work, an increase in the State's responsibilities towards families, greater recognition of human rights and gender and sexual orientation equality, but also an increase in divorce rates, amongst others (Barreto, 2004; Aboim, 2010; 2011). At the same time, a recent report revealed that less than 10% of Portuguese people do not ascribe to religious beliefs, whereas 93% of those who self-identified as respecting and following a religious position are Catholic (Teixeira, 2012). Notwithstanding this high proportion, it is slightly lower than the 97%, which was previously reported in 1999. Taken together, these social changes place Portugal in a unique and challenging position. If one considers the concomitant fact that HIV remains a significant problem in the country, and has been so from the beginning of the epidemic, it is crucial to investigate how some of these social changes may have impacted on people's sexual practices or attitudes towards sex and, in turn, how these impact upon HIV epidemiology, and the experience of living with HIV in Portugal.

In parallel with the issues described, issues of men and masculinities have gradually become more explicit subjects within political, academic and social debates in most western countries (Connell, 2002; Hearn and Pringle, 2006). Growing social debate concerning men and masculinities is especially visible in modern Portugal, in particular at an academic level. Aboim (2011), for example, conducted a comprehensive study of multi-generational men in Portugal, in which she found that contemporary men's identities and practices are becoming more fluid, more hybrid and sometimes paradoxical in their nature and effects, when compared to previous generations. Despite focusing mostly on family relations and interactions, Aboim's

study offered a pivotal contribution to the understanding of Portuguese masculinities, which she portrayed as plural and dynamic. Yet, while her work has allowed for an insightful understanding of men and masculinity in contemporary Portugal, little is known about how gendered constructions of masculinity relate to men's health and their experience of living with a chronic illness such as HIV. This is where the current study seeks to provide new insights and perspectives, by examining the ways in which Portuguese men experience health and illness whilst focusing on personal identity to the experience of living with HIV.

The study

Using a number of ethnographically informed qualitative methods, the present study aimed at understanding men's various discourses, practices and experiences with respect to health in general and HIV in particular. Crucially, this study aimed to provide insight into changing conceptualisations of men and masculinities, and contextualise these in light of the social changes that have occurred in Portuguese society over the last few decades, for example, exploring how medicalisation is being reconstructed vis-à-vis the deep structural and social modifications that have occurred throughout the years, or how fluid and ever-changing social representations of HIV and AIDS (in Portugal) may or may not influence men's lives and experiences living with HIV.

From the outset, because I was particularly interested in exploring ways in which living with HIV is dealt with at a clinical level, I thought the study ought to take place in clinical settings only. There I would observe, interview, interact and, as far as

possible, aim to participate in the *patient*'s[36] trajectory from admission to discharge in the HIV ward or the outpatients' clinic. With this in mind, I contacted two hospitals with which I had key contacts (and in one of which I had undertaken my training as a nurse, and where I had subsequently worked).

As I reflected upon the notion of interviewing men in a clinical space, however, I started to doubt whether this was actually suitable or even feasible as a methodological approach. I conducted a few visits to one of the hospitals, visiting the various waiting areas and corridors, only to realise that, quite bluntly, most people who visit a hospital for a consultation may not be willing to allow a stranger to invade their space to elicit private information. Bearing in mind the fact that Portuguese hospitals sometimes have long waiting hours and equally long waiting lists for clinical procedures, it was also likely that health professionals might not be willing to give up their time either. This, of course, could have been a completely inaccurate initial assessment, but on discussion with a few colleagues who worked in the hospitals I visited, some of these worries made actual sense. I also wondered whether being in a clinical setting as a health professional myself might not encourage potential participants to focus more on specific clinical issues, such as blood test results and/or their therapeutic regime. This, of course, was useful information – yet I was hoping to elicit other types of information that individuals might not be used to sharing during their consultations within clinical staff.

Another option was to contact non-governmental organisations providing support to people living with HIV. These groups, which people access for a variety of reasons, are also sometimes providers of informal care. Working in such an environment would allow for a different perspective on the experience of care. Therefore, I might

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[36] The term 'patient' here is used loosely to refer to the user of health services. Throughout the thesis, however, I will opt by using the term 'man' or 'men' to refer to the participants of the study – if not by their aliases.

have been able to complement one, more biomedically informed perspective with views elicited in a different context more focused on men's social needs. Because of this, I recruited study participants from two rather different support settings (2 clinical and 2 social support units) in two urban centres in Portugal, but which provided support across the whole country. This meant that a number of participants were initially contacted in one institution, but then followed up in another place, sometimes another city altogether. In total, I visited men and carers across the country, as presented in Figure 1.

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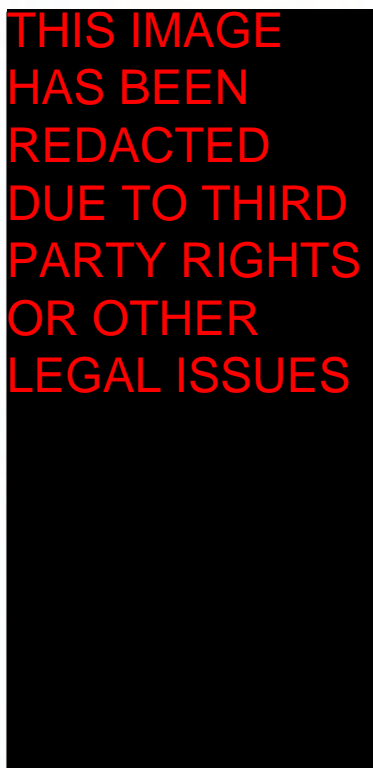
Fig.1 – Map of Portugal and research sites

Legend:

Research site where at least one contact took place

The reason for choosing particular institutions (both clinical and social support institutions) related to the fact that all of them offered a comprehensive range of health care, information and support specifically directed at people living with HIV and AIDS. In particular, the social support institutions offered a range of services aimed not only at improving the quality of life and wellbeing of people living with HIV, but also at improving professional development for health care workers. They also

provide workshops and events for clients to socialise and meet other people, including health care practitioners and other staff.

A stranger at home

The Chicago School of Sociology[37] pioneered the concept of 'ethnography at home', i.e. the extension of ethnography to the study of local communities, rather than 'exotic groups' or other cultures. This approach allowed data gathering by means of participation in the daily life of informants in their natural settings: watching, observing and talking to them in order to discover their interpretations, social meanings and activities (Giddens, 2001). The initial conceptualisation of the current study touched somewhat on these principles. I aimed to undertake a broadly ethnographic study of HIV-positive men in clinical and social support settings in Portugal. While I do not live in Portugal, I am Portuguese and returned to Portugal for the period of fieldwork. This allowed me to re-enter 'home', yet, analyse it as both an insider and an outsider. Because I share the same cultural background as many of the participants in the study, familiarity with the values and ideas pertaining to the experience of health and illness was of utmost importance. In fact, working 'at home' facilitated some of the knowledge gathering processes.

The reasons behind my choice of setting were not only linked to the fact that I am Portuguese and interested in undertaking some fieldwork in Portugal. My concern was more related to the fact that, despite the high incidence of HIV infection in the

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[37] Anthropology has traditionally sought to explore and interpret cultures and groups that are not particularly familiar. The most prominent example of an author from the British Social Anthropology School is Malinowski (see for example, Malinowski, 1913, 1922). He influenced the way fieldwork was done during his study of the Trobriand Islands between 1915 and 1918. Following World War II, several Chicago-based scholars decided to undertake fieldwork in the various communities in Chicago, switching the focus from the exotic to the familiar, and aimed at understanding how civilisation and urbanisation influence the sense of community and human behaviour, in an ecological way.

country, not much is known about the social construction of HIV, or even how a number of factors such as gender may or may not affect the way people in Portugal become HIV-positive, or live and experience HIV infection. The issue of being 'at home', or even returning home, was not particularly relevant at first. Once I started engaging with the notion of returning home and how that might influence me as a researcher, I realised that there was much more to 'being-native' than having a shared nationality.

As the structure of the study became clearer, I also realised that my return was not solely to home as my country, but to a setting in which I used to work. Similarly to Zaman (2008), my 'native-standpoint' was twofold, in that I was both returning to my country and to a clinical setting in which I had worked and studied, but which generally also represented an area of work from which I had been detached from for a while, and was sometimes challenging to understand:

> The tiger's experience of tigritude is different from those who hunt tigers and write about tigritude; the more tigers who write about being tigers the better we will understand both tigers and tigritude." (Bolton, 1995, p.1660, cited by Zaman)

And just like Zaman, despite considering myself to be a tiger (a health professional), being away from clinical nursing practice for a while depleted me of a certain degree of insider-perspective. Being removed from the hospital culture, meant that "I was more a tiger that had remained away from the jungle for several years and then returned to observe tigritude" (Zaman, 2008, p.145). As such, my viewpoints presented both subjective and objective opportunities for reflection on the social world that I was (re-)entering.

I was, then, both an insider and an outsider in the field. Beyond the clinical aspects of my standpoint, there was the fact that I returned to Portugal and to some very familiar

places. I did not make a selection of research settings based on familiarity or location that was most convenient for me, but I did try to research which institutions offered the most comprehensive kinds of support. Unsurprisingly, most of these were located in Portugal's major urban centres, so those were my starting points, but which eventually expanded to a quite extensive area, as show in Figure 1 on page 80, and as will be discussed later.

Returning to the issue of working at home, I shared some of the complex experiences that Vale de Almeida (1996) alluded to in his ethnographic study of masculinities in a Portuguese town:

> In the territorial space of the Portuguese national-state, cultural homogeneity and heterogeneity coexist. State structures and linguistic homogeneity have their counterpart in heterogeneity of forms of social reproduction. This can be perceived at a regional level (the stark differences between northern and southern Portugal), at a developmental level (the abyss between coastal urban areas and inland deserted areas), and also at broad social level." (p.10)

Despite being written in 1996, this observation still remains valid to some extent. In any case, one aspect that differed from Vale de Almeida's study was the fact that, unlike him, I had not lived in Portugal for a number of years up until the time I returned for data collection. This meant that on the one hand, I was somewhat detached from issues relating to the social organisation of health care, for example. On the other hand, I could look at some of these matters from the point of view of a 'foreigner' to that culture, but nonetheless as someone with an intimate history of the cultural setting. This fact, I believe, placed me in a unique position when it comes to making sense of the experiences, thoughts and ideas that some men shared with me during the course of data collection.

By way of context, it is important to offer some insight into what my status as a white, educated, urban, middle-class gay man may have meant for those I engaged with

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during the fieldwork. When working in community-support organisations I was frequently asked about my academic background. Saying I was a doctoral student in education or social science was never enough, as I felt that people required a 'proper' professional label in order to adjust their expectations about my engagement with men. I therefore introduced myself as a nurse and a researcher. Within clinical institutions, in contrast, I was very seldom asked any questions at all – which may be, in itself, a reflection of the fact that, for those men, I was simply just another member of the health team, going about their daily routine at work. I was thus, it seemed, part and parcel of their clinical trajectory on that particular visit. As the relationship between myself and the participants became more established, especially after the first contact, I noticed that some men were more prone to asking questions surrounding my interest in studying HIV in Portugal. Some wondered whether I was HIV positive. This resonated with previous working experiences I had had whilst working as a HIV research nurse in London, where there appeared to be an expectation that most nurses working in the area were also HIV positive.

Some men were also curious whether if it was my sexuality that was one of the reasons why I decided to study a disease that affects so many gay men worldwide. Despite never needing to explicitly disclose my sexual orientation, as I was never asked about it directly, I noticed that those men I interviewed who were also self-identified as gay seemed to know that we shared that same characteristic. I think that this allowed them to feel more comfortable in discussing a number of issues . This was reflected in the way certain events were described and the use of language – by using terms that are part of the 'gay lexicon', for example. As for those men who did not identify as gay or MSM, I do not think that my sexual orientation interfered with their ability or ease at discussing the issues that were explored during the research process. Despite not having that common ground with them, I still shared a whole set

of characteristics which allowed myself to be familiar with the range of issues that were discussed.

When entering the field, I sought to understand how men made sense of their lives in the midst of the fluid complexities that characterised their lived social realities. In this study, the field relates to all clinical and non-clinical spaces that I visited and where men received health and social care. While I was familiar with the clinical spaces and procedures with regards to patient care, I was less aware of how non-governmental organisations function, the scope of their activity and the logistics of individual care. Some of this uncertainty dissipated as I visited institutions on a regular basis and became more engaged in their routines and procedures.

There are a number of well documented issues in entering clinical fields for the purpose of social research (Matthews, 1987; van der Geest, 1989; Zaman, 2008). Atkinson (1997), for example, described some of the problems he faced when entering a medical education institution, as he followed a group of medical students, sometimes being mistaken for one of them. Other issues can relate to the hierarchy of the setting, the failure to adapt to local codes or even the adjustment to specific language or attitude, to name but a few. Long, Hunter and van der Geest (2008) have pointed out that hospitals, or clinical settings in general, can be difficult to access for the purposes of ethnographic research. Some reasons for this include: the excluding/exclusive nature of clinical spaces (Foucault, 1963); the difficulty for clinicians in welcoming ethnographic research without feeling that it might become a form of 'doctor bashing'; the patient-advocacy standpoint which is often used to justify the 'intrusive' presence of an ethnographer in a clinical setting (Long, Hunter and van der Geest, 2008); and the paradigmatic 'difference' of ethnography compared to surveys, for example, which means that some clinicians might not feel comfortable with the methodology (Atkinson, 1997). However, as Long, Hunter and

van der Geest (2008) asserted, ethnography is uniquely placed to interrogate the complexity associated with clinical environments.

I experienced a few of these tensions at an early stage of this study, in particular when seeking ethical approval for the study to be conducted. A research protocol was submitted to the ethics committees of all the institutions involved[38]. After a quite lengthy deliberation, the first hospital I contacted rejected the study based on alleged issues of patient protection and confidentiality. The official reply argued that no patients should be exposed to an outsider to the health team for whatever purpose. At that stage, the research proposal as submitted was premised on the development of an ethnographic study of clinical spaces for men living with HIV. Despite the fact that I had been granted a prestigious Portuguese Ministry of Science and Technology doctoral studentship[39], this situation highlighted the difficulty that some social researchers and ethnographers may have in entering the field, for example when the field is a hospital or clinic with stringent procedures concerning access to patients (Goodwin et al., 2003; Zaman, 2008). There is a very limited number of studies focusing on issues of access to clinical spaces for the purposes of research in Portugal. However, Carapinheiro (1991; 2005) has argued that the Portuguese hospital is the arena *par excellence* for the exercise of the medical power, which is generally considered to be a moral and socially unquestionable form of authority in the country.

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[38] These included Ethics Committees for hospitals, and the board of directors, or equivalent, to the non-governmental organisations.

[39] During the course of my doctoral studies, I was supported by a studentship which was awarded by the Fundação para a Ciência e Tecnologia, which is part of the Portuguese Ministry for Science and Technology and Higher Education. These studentships are very competitive and reputed amongst higher education students and academics in Portugal and abroad.

Given these challenges, I decided I would need to reformulate aspects of the research proposal if I wanted to secure the involvement of any clinical institution at all. Subsequent applications for ethical review were adapted in order to emphasise the fact that the data collection methods used were mostly interviews and observation, highlighting the qualitative nature of data collection, and lessening the focus on the more ethnographic work involved. Following the adoption of this approach, and the submission of a revised research proposal, each of the remaining institutions to which research applications were made granted ethical approval for the study. Both clinical settings, however, granted ethical approval only on the basis that I would not access patients' notes, nor would I (audio or video) record any clinical encounter. This was accepted and agreed to.

In practice, after these initial obstacles were overcome and I had gained access to the field, the process of accessing potential participants went very smoothly. I also found recruitment via the social support institutions to be less complex, as most men visited these institutions with a different frame of mind than when going for their consultation at the hospital, meaning that they were typically more open and receptive to my invitations to participate in the research. Similarly, as I familiarised myself with the space and the staff at the institutions, it became easier to participate in the daily routines of these institutions, and also strengthen the relationship with their gatekeepers[40].

The gatekeepers were generally interested in the goals of the study and were keen to help me find participants who were more theoretically valuable to the study, i.e. who had relevant stories to tell and were happy to share them with me. Often, I would be informed of a number of potential men who were to visit the institution and I was

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[40] The term gatekeeper refers to any individual with the power to grant or deny access to people for the purposes of research (Oliffe, 2010).

allowed to use a consultation room to speak to them in the first instance. The gatekeeper always introduced me as a researcher, who was studying towards a doctorate in London. So, from the outset, my insider/outsider role was overtly disclosed and I believe it certainly contributed to my field experience as it often encouraged me to see my own culture as a 'strange object'.

Reflexivity

A good qualitative researcher needs to provide a reflexive account for his/her perspective and involvement, since s/he can also be influenced by the conditions s/he faces during fieldwork, which can, and most certainly will, inform the research process (Hammersley and Atkinson, 1996). Flanagan (1981) has argued that reflexivity complicates all three of the traditional roles that are typically played by a classical (positivistic) science: description, prediction and control. From a positivistic perspective, including self-reflection and examination on the part of the researcher in the research process is likely to bias the process from the outset. A more interpretivist response to this issue would be "rather than engaging in futile attempts to eliminate the effects of the researcher completely, we should set about understanding them" (Hammersley and Atkinson, 1996, p.18). This perspective, in which the researcher is also a participant in the research process, allows for interpretation and, ultimately, contribution to the theoretical field.

During fieldwork, I kept a field diary in which I detailed some of my thoughts and reflections related to my involvement in the research process, as well as some more general thoughts on the data I collected. Some of these reflective notes have been alluded to in the previous section when describing my role as an insider/outsider, for example. More significantly, their contents are also incorporated into some of the findings. The field diary had an additional function too: when it was not possible to

audio record, I used my diary to jot down what had been shared in conversations or consultations. After each recorded interview, I also used the diary to write some ideas and/or thoughts that had occurred to me with regards to what the participant(s) had shared during the interview.

Overall, the field diary was populated with a collection of general observations, such as on the participant's engagement with the interview process, the flow of the conversation, or any relevant side-talk, for example. Sometimes my observations were initial starting points for further reflection: key themes that seemed to be recurrent in men's accounts and that I should bear in mind for future interviews. For instance, during one interview, one man disclosed a situation in which he had been abused as a child, as a way of supporting his argument that "certain things that happen to you as a kid, shape you for life, and it is hard to get back on track" – when asked about the circumstances in which he found out he was HIV positive. As this was quite early on in the first interview with this man, I decided not to probe into that particular episode, and continue with the more general questions. I did, however, keep some notes on the revelation, as well as the circumstance in which it was shared, which I revisited in another encounter with that man. This account, as described and analysed in the findings chapters, turned out to be theoretically very rich, as it offered some remarkable insights into ways in which men experience their identities in relation to past experiences. All of the data analysed in the results chapters (Chapters 4, 5 and 6) are thus the product of a continuous and reflexive engagement with the data I collected through interviews, observations, conversation and informal meetings.

Issues of ontology, epistemology and methodology

I shall now turn from the specifics of the study to some of the larger assumptions that framed the way in which it was conducted. As is conventional in social science research, these include questions of ontology, epistemology and methodology (Duncan, 2007; Blaikie, 2007; Cohen et al., 2007).

Ontological assumptions fall into two broad perspectives: realist or nominalist (Cohen et al., 2007). The first of these, realism, is associated with the idea that the social world is objective and external to the individual. The research process must therefore be objective and controlled, with the researcher assuming a non-involved role. Nominalist ontology, on the other hand, offers a different take on how the social world is perceived and constructed. The focus of this perspective is the individual processes of cognition, thought and language. Its concern, therefore, is for how individuals interpret and perceive reality in a variety of ways (Cohen et al., 2007).

Based on these broadly contrasting ontological positions, various epistemological approaches have been developed to advance knowledge of the social world. A distinction is often made between social scientific knowledge developed through the application of logics similar to those utilised in the natural sciences, or positivism, and those created through social interaction and meanings attached to the social world, or interpretivism. Positivistic and interpretivist paradigms have traditionally been conceived as opposing philosophical stances in research. Positivism has been criticised and questioned with regards to its application to some forms of social research, as its origins lie in the study of the natural world, which is significantly different from the social and cultural world. In particular, positivism does not easily account for the unpredictable and social nature of human life, and it tends to exclude

or downplay notions of choice, freedom and moral responsibility (Greene and Thorogood, 2004; Cohen et al., 2007).

According to Greene and Thorogood (2004), one of the key criticisms of positivism is that many aspects of reality may not be pre-existent and ready to be researched; they are in fact socially constructed. Sayer (1992), a realist, has argued that positivist approaches too easily force respondents into pre-defined conceptual categories with a focus on demonstrating causal relationships. Additionally, Cloke et al., (1991) pointed out that the use of a positivist approach to research separates the researcher from the researched.

The strongest supporters of arguments against the application of positivism to the social world, or anti-positivists, were led by Max Weber (1947). Weber and his followers rejected positivistic principles of description, control and prediction, as they were said to lack 'understanding' (Verstehen) of the phenomena studied. From this point of view, what matters to the researcher is not the 'reality' of the world, but how one interprets it. This is the core argument of interpretivism, which differs substantially from positivism in that it seeks to study people in their natural, social settings, and aims to understand the social world from the standpoint of individuals (Hammersley and Atkinson, 1996). Interpretivists argue that the researcher can and *should* get involved in the research environment, but should also seek to account for the effect their presence may have on the actions of the people being studied, and consequently on the validity of the study. An interpretivist account is, in sum, more concerned with personal and subjective perspectives and the experiences of individuals rather than the categorisation and measurement of more seemingly objective data.

Many qualitative approaches to research are concerned with narratives, focusing on people's understandings, feelings, beliefs and experiences. Such approaches usually follow an interpretivist epistemology, as data are collected using the subjects' own words and expressions to describe their own lives (Matthews and Ross, 2010). The study of phenomena in their natural environment is key to the interpretivist philosophy, which is also premised on the idea that there may be many interpretations of reality, but appreciating these varied interpretations is intrinsic to understanding social life (Berger and Luckman, 1966; Davidson, 2010).

The present study sought to elicit men's own understandings of health, illness and social needs, and enquire into how such meanings may be shaped and defined within the context of their everyday lives. The study thus explored the personal experiences of men living with HIV in contemporary Portugal and sought to link such knowledge to new insights into HIV-related health care. This approach took men's own ways of seeing and knowing as the starting point for examining and understanding their experiences. Through such a nominalist approach, the realities of the men who participated in the study were viewed as the products of several processes that were entangled within complex socially constructed meanings. Methodologically, an understanding of these varied realities was sought by close narrative exploration of the social worlds that the men were engaged in (through interviews), and via participation in some of the different institutions that the men attended (clinics, community-centres and so on).

Research Methods

One of the main aims of qualitative research is to gather naturally occurring data, or "an 'enactment' of social behaviour in its own social setting" (Ritchie, 2003, p. 34). This is usually achieved by employing a range of methods, including (participant or non-participant) observation and interviewing, for example. Data generated through these methods can be analysed using a variety of forms, including documentary and discourse analysis.

Participant observation involves the immersion of the researcher in what they wish to observe, allowing them to observe and participate in events as they occur (Ritchie, 2003). Non-participant observation, on the other hand, requires the researcher to look in on a particular event, without taking active part in it. Documentary and discourse analysis are both methods of analysing text, which can be derived from observation, interviews or publications, for example. Documentary analysis tends to focus on analysing existing public or private documents (e.g. government publications, media reports, personal diaries, emails or letters), in order to gain deeper meaning regarding the content in which they were written or published (Ritchie, 2003). As such, I used a number of published materials in order to contextualise the study, namely some legal documents which focus on the criminalisation of HIV infection, for example, or the protection of people from discrimination, which will be discussed in chapters 4, 5 and 6.

Discourse analysis, on the other hand, often focuses on text and transcripts originated in speech, i.e. arrived at from communication between people. In particular, discourse analysis is useful to analyse transcripts generated from interviews, which was the case for the current study.

Because of their ability to gather detailed data relating to individuals' personal experiences and perspectives, individual in-depth interviews were selected as the main form of data collection. Prior to interviews taking place, I undertook documentary analysis, as well as a critical review of existing theoretical and empirical literature on men, masculinities and HIV. I conducted several systematic searches on a number of databases: Medline, CINAHL, PUBMED, ScienceDirect, EMBASE, EBSCO and PsycINFO. Key words and combined terms included: 'masculinities', 'health', 'HIV/AIDS', 'men, 'health-seeking', 'Portugal', 'chronic illness', 'stigma' and 'discrimination', amongst others. A library search of relevant texts was also undertaken.

Subsequently, and once in Portugal, I engaged in observation of clinical spaces as well as social support institutions, and also used field notes as a form of data. This way, I ensured the study would cover data generated from a number of sources and thus I could engage in data analysis knowing that I had carefully considered data arrived at from different perspectives or in different situations. For example, had I only collected data generated through non-participant observation during consultations, it would not have been possible to gain information about men's experiences of receiving care, of living with HIV, and so on. Similarly, had I only conducted interviews without prior consultation of the current legislation, governmental guidelines and structural aspects of the organisation of care for people living with HIV in Portugal, I could make assumptions and misjudgements when contextualising the content of those interviews.

Sample and recruitment procedures

With regards to sampling and recruitment, a combination of methods was used, namely theoretical sampling and snowballing. Theoretical sampling, useful in

generating theory, involves the recruitment of comparison groups of participants, based on their theoretical relevance (i.e. characteristics that are expected to influence the type of statements made in relation to the topic) (Glaser and Strauss, 1967; Field and Morse, 1985; Corbin and Strauss, 2008). Snowballing was used to recruit new participants through links with those already recruited. Thus, the sampling frame followed social networks. This approach was particularly useful when recruiting participants from similar social groups, as often I was referred to other potential participants from informal conversations with staff or other participants. All institutions contacted had a point-of-call, a key informant, with whom I kept in touch with regards to my visits to each centre, as well as to familiarise myself with the range of services provided and the scope of support. Sometimes, these key informants also advised to contact a particular man (client) who they thought would be beneficial to the study. As happened with suggestions from snowballing, I contacted every person, by telephone or email, to try to arrange a preliminary meeting. When meeting for the first time, I was more interested in understanding something of the personal biography of each man, in particular in terms of how and when they were diagnosed with HIV and how they felt the support they were receiving might be making a difference in their circumstances, or otherwise. I always tried to select those men who were keen to offer in-depth knowledge with regards to living with HIV, based on their own experiences as shared in that first encounter. On a couple of occasions, it was not possible to pursue the contact, as it was not physically possible to arrange a time and place to meet. A total number of 20 men and 10 professionals made up the total sample of the study. A list of participants can be found in tables 1 (men) and 2 (professionals), and a short biography of each participant can be found in Appendix 3.

Alias	Age*	Ethnicity	Stated route of infection	Years since diagnosis*	Years since initiating ART*
Gaspar	44	White	IVDU	13	10
Valdemar	40	White	IVDU	12	6
Salvador	36	White	IVDU	16	16
Paco	42	White	IVDU	18	18
Patricio	29	White	MSM	1	--
Gabriel	52	White	MSM	6	6
Agostinho	43	White	MSM	3	--
Leonardo	31	White	MSM	1	--
Pedro	50	White	MSM	19	19
Vicente	54	White	Hetero	16	15
Luciano	37	White	MSM	6	--
Filipe	54	White	MSM	2	2
Pascoal	37	White	Hetero	1	<1
Martim	40	White	MSM	<1	--
Samuel	48	White	IVDU	18	16
Serafim	53	White	Transf	8	8
Cristiano	38	Black	IVDU	19	14
Leopoldo	35	White	MSM	6	5
Rodrigo	35	Black	Hetero	5	5
Mateus	39	White	MSM	4	--

*as of December 2011

Table 1: List of participants (men) by age, ethnicity, route of infection, years of diagnosis and treatment

Alias	Profession
Alice	Social Worker
Alfredo	Nurse
Romeu	Support worker
Maria	Psychologist
Roberto	Physician
Guilherme	Physician
Silvia	Nurse
Marcia	Nurse
Manuel	Social Worker
Paula	Nurse

Table 2: List of participants (professionals)

The criteria for inclusion included being a Portuguese man with a positive diagnosis for HIV. If not recruited via snowballing, men arriving for a visit to one of the settings were asked if they would like to discuss their current experiences of living with HIV. Consenting participants were then asked to take part in an informal discussion. Depending on the theoretical relevance of each participant's account, further formal and informal interviews took place. Throughout the process of data collection, I undertook regular visits to the research settings in order to undertake observation and to keep field notes updated. Field notes focused on a number of aspects that were picked up though observation, as well as any situation or information that was relevant to the study and/or any participant in the study.

Data Collection

Data were collected using a variety of techniques. As indicated earlier, official documents including local policies, laws and government documents were first analysed to understand contextual issues relevant to living with HIV in Portugal. Primary data collection then took place in the field. Once access had been negotiated and granted, field observations were initially undertaken. The aim was to examine the role of care providers and whether or not power relations affected men's apparent satisfaction with the provision of care and information, for example. Consent for observation was sought both from institutions and from individuals as appropriate, and confidentiality and anonymity were preserved at all times. Detailed field notes were prepared after each period of observation. Information gathered from field notes was used to determine the topics and issues to be explored in more depth during the interviews.

Semi-structured in-depth interviews then took place with HIV-positive men accessing the institutions of support and some of their carers. Interviews covered topics that had emerged from previous data collection, and included brief questions on demographic characteristics followed by open-ended questions on the impact of an HIV diagnosis, experiences of health care and social support, and information about HIV and AIDS. The interview guide was piloted prior to the main study with a sample of three men and two carers. A few adaptations to the guide were made, mostly in terms of its focus on masculinities and health. The initial interview guide gave relatively little emphasis to these issues, so new questions were added to it. A copy of the final initial interview guide can be found in Appendix 2. In the course of the study, no participants refused to be interviewed. Because of the broadly inductive and ethnographic character of the work, data were analysed reflexively throughout the study on an on-going basis.

Data analysis

With regards to the first phase of data collection – documents and policies – data was reviewed and critically analysed with a focus on implications for policy and practice. The framework for the discourse analysis was guided by the approach suggested by Fairclough (1995). The purpose of this analysis was to critically examine notions of masculinity and its relationship to health, illness and HIV. This process was used mainly in developing the theoretical framework of the study, particularly with regards to the structural and socio-political arena in which the study was taking place, which was used further in contextualising the findings of the study.

The second phase of work generated a considerable amount of data in different forms, namely field notes and transcripts. After a lengthy period of transcription, each interview was read thoroughly, sentence by sentence, a number of times to identify key ideas and themes relating to a similar topic. This theoretical comparison was useful in identifying potential relationships between concepts or experiences. Each interview was carefully coded in order to identify key themes and topics that emerge from each account. Later, the different codes were grouped together into broader thematic subcategories and categories using atlas.ti software. After this process was complete, I translated the data from Portuguese into English, and had it verified by another bilingual researcher. This ensured that most of the primary analysis occurred in Portuguese so as to remain as faithful as possible to original meanings. Translation was undertaken bearing in mind what Eco (2003) classified as 'negotiation', i.e.

> A process by virtue of which, in order to get something, each party renounces something else, and at the end everybody feels satisfied one cannot have everything. In this kind of negotiation [translation] there may be many parties: on one side, there is the original text, with its own rights, sometimes an author who claims right over the whole process, along with the cultural framework in

which the original text is born; on the other side, there is the destination text, the cultural milieu in which it is expected to be read, and even the publishing industry, which can recommend different translation criteria, according to whether the translated text is to be put in an academic context or in a popular one. (...) A translator is the negotiator between those parties, whose explicit assent is not mandatory. (...) [thus] the idea of translation as a process of negotiation (between author and text, between author and readers, as well as between the structure of two languages and the encyclopaedias of two cultures) is the only one that matches our experience (Eco, 2003, p. 6, 34).

As such, while translating the analysed content, I was involved in a process of negotiation between what had been shared by men and professionals, in Portuguese, the cultural context in which those accounts had been produced, and the purpose of such translation. In certain circumstances, as will be made explicit throughout the results chapters, some expressions were kept in the original language so as to maintain the specific value and meaning of what had been said. An approximate translation will be offered in footnote, as appropriate.

The type of analysis undertaken was mostly a theoretically informed thematic analysis, informed by a grounded approach to analysing data, i.e., "using theoretical coding, theoretical memos, the generation of core problems, processes and conditions, theoretical sorting, theoretical writing and generating theory" (Glaser, 1978, p.17). In other words, the data analysis process allowed me to identify key factors seen as influencing men's lives and experiences, from their own perspectives and those of significant others, with the goal of adding to existing understandings and generating new theory.

Ethical considerations

As Goodwin et al. (2003) explained, ethical issues surrounding research can be grouped into two categories: general issues such as informed consent, confidentiality, harm, exploitation; and issues that arise from the particular nature of

the study. Some ethical dilemmas may "develop unexpectedly and spontaneously, perhaps in situations where the researcher has little control over events" (Goodwin et al., 2003, p.567).

Most institutions (particularly medical institutions) have developed their own ethical codes of practice and, when working in them, researchers should also abide by governing laws and local cultural norms (Greene and Thorogood, 2004). In the present study, a research protocol was submitted to the ethics committees of all the local institutions involved. Ethical review was also conducted in line with the procedures agreed to by the Faculty Research Ethics Committee of the Institute of Education, University of London. Of particular concern were three major ethical issues that can arise in research with human participants, and which were pertinent to my own experience as a researcher. These involved informed consent, anonymity/confidentiality of data and the right to withdraw from the study without explanation (Greene and Thorogood, 2004).

The principle of informed consent lies at the heart of research with human participants, and has at least three main components: communication, comprehension and participation. Gaining consent aims to ensure voluntary participation in the study, i.e. there must not be any form of coercion or persuasion placed upon the participants (American Anthropological Association, 2006). The current study adhered to the principles set by the Helsinki Declaration on research with human participants (World Medical Association, 2000). Gaining informed consent involves informing participants (and institutions) what the study is about, in a comprehensive and clear way, allowing any doubts or questions to be answered in detail if need be. In pursuit of such a goal, throughout the study I constantly assessed whether or not the participant had understood the rationale for the study, and what was required from them. Even as the relationship between myself and each

participant became less formal (I interviewed a few participants on a number of occasions), I always started the conversation by highlighting what the goals of the study were and what was going to happen with whatever was being discussed or recorded. A copy of the consent form can be found in Appendix 1.

The second major ethical concern relates to confidentiality and anonymity. These terms tend to be used interchangeably, but they have different meanings. The Helsinki Declaration highlights the need for paramount concern regarding individual privacy and confidentiality. This means that the information on any particular participant that is gathered during the research process should be handled carefully so as not to be shared or divulged unwittingly. This process covers a range of data formats, from transcripts of interviews to field notes, participants' files or videotapes. Moreover, the researcher must bear these concerns in mind throughout the process. This includes publication of the study, whether in a thesis or otherwise, which should also ensure that the identity of the participants and institutions involved is protected where possible.

It may sometimes arise that a participant does not wish to be anonymous, or their identity is difficult to protect. Such issues were discussed with the participants involved so that their expectations upon publication of the study were realistic (Greene and Thorogood, 2004), and in order to minimise discomfort and maintain anonymity as far as possible. One man asked whether data would be published using his real name, as if that was the case, he would rather not take part as most people did not know about his HIV status. I reassured him that every participant was to be given a pseudonym and that identification would be very difficult to be made from it. This was not an issue for other men in the study, some of whom said they would happily consent to being identified in the study. However, I maintained the same procedure with all participants so as to retain their anonymity. Professionals

were given aliases as well, as can be seen in Table 2 above. However, as the study was ultimately focused on men's accounts, and except when it is otherwise made explicit, most of the data gathered from interviews and contacts with professionals were generally associated with professionals and not directly attributed to a specific individual, in order to protect that professional's identity.

Finally, every participant was informed about their right to withdraw from the study at any time, without the need to provide reasons, and without suffering negative consequences from withdrawal. This is a standard condition in most forms of research and is an integral part of any informed consent process. This right was repeatedly stressed throughout the research process. I also informed every participant that their involvement in the study was voluntary and that contributing to the study had no bearing on their admission to and treatment by the institution to which they were connected.

Reliability and validity

There are a number of criticisms that can be applied to research that adopts an interpretivist approach, some of which relate to broader questions of reliability and validity. As Sim and Wright (2000) put it:

> "data are said to be valid when they represent what they purport to represent, and meaningful inferences can therefore be drawn from them. In contrast, if data are reliable this means that they are reproducible or consistent, i.e. data gathered on a particular entity will be the same when gathered by different investigators, or by the same investigator on separate occasions". (Sim and Wright, 2000, p.123)

In other words, reliability refers to the consistency of the method of data collection, be it a scale, observation or other. Validity, on the other hand, relates to the extent to which measures indicate what they are intended to measure, or the degree to which

a study accurately reflects or assesses the specific concept(s) that the researcher is attempting to access. This means that reliability is a prerequisite for validity, i.e. a study can never be valid (reflecting what it is supposed to study) if it is not reliable (i.e. generating consistent and trustworthy results) (Cohen et al., 2007). The ways in which these two concepts are articulated is deeply related to the type of study and the choice of research paradigm. Within an interpretivist framework, the focus tends to be more on trustworthiness and consistency of data (Eisenhart and Howe, 1992; Daniel and Onwegbuzie, 2002). Because reliability is not an easy concept to apply in interpretivist research, which is less concerned with the use of the same method to gain the exact same result, and more focused on the trustworthiness of the data, Denzin and Lincoln (1994) have suggested instead the use of the term replicability, which concerns the stability of the observations.

An interpretivist study is valid if the data are gathered in an honest and deep way, and if appropriate forms of triangulation is used. Similarly to the notion of reliability, validity is a contested concept when applied to interpretivist research. The term *understanding* is seen by some as being a more suitable term than that of validity (Cohen et al., 2007). The reasons for this are linked to the fact that many interpretivist researchers eschew objectivity, claiming to aim for subjective insight and intersubjective understanding. The aim of an interpretivist account should thus be to generate often different but fundamentally subjective accounts of what it is that is being studied (Patton, 2002; Cohen et al., 2007).

Qualitative researchers have at their disposal a number of techniques to ensure that the study they are developing is reliable and valid. Some authors have suggested the use of triangulation (Cohen et al., 2007), theoretical sampling (Field and Morse, 1985), observation training and extended fieldwork (Homans, 1955) as strategies to improve validity. Mathison (1988) explained that:

triangulation has risen an important methodological issue in naturalistic and qualitative approaches to evaluation [in order to] control bias and establishing valid propositions because traditional scientific techniques are incompatible with this alternate epistemology. (Mathison, 1988, p. 13)

Triangulation may be particularly suitable when the study follows an interpretivist approach. As Golafshani (2003) put it:

> to acquire valid and reliable multiple and diverse realities, multiple methods of searching or gathering data are in order (...) Engaging multiple methods, such as, observation, interviews and recordings will lead to more valid, reliable and diverse construction of realities. (Golafshani, 2003, p.604)

In order to address some of these concerns, the current study used theoretical sampling, as well as a range of methods, from observation through in-depth interviews to field notes. Internal validity was sought in that participants' accounts were triangulated against observational findings and information in documents, including research findings from other studies. Another way of maximising validity occurred through my active and reflexive engagement with the data collection throughout the study.

Some study limitations

While a more detailed assessment of study limitations is offered throughout the main body of the thesis, it is appropriate at this stage to highlight some of the challenges that might be expected to arise in a close-focus, ethnographically informed study such as this. Broadly speaking, limitations can be envisaged with respect to data collection and analysis, and the role of the researcher in this, as well as the nature of the study itself.

With regard to the first set of concerns, interpretivist approaches have been criticised for relying on too subjective a set of data, and for allowing the researcher to be too active a participant in the research process. However, as was argued earlier, when well conducted this form of enquiry also allows for the generation of new knowledge and new theoretical insights. Reflexivity is important in this respect, and adopting a reflexive stance can open up avenues for exploring some of the dilemmas that research may present (Monaghan, 2007).

As a qualified nurse, I returned to a clinical environment in which my role as a nurse was substantially different to my role as a researcher. Nevertheless, I presented myself as a researcher at all times, even if I encountered situations where my immediate response might hitherto have been one of a professional involved in care. This kind of concern mirrors the ethical dilemma faced by Goodwin et al. (2003) during fieldwork in the operating theatre in which Goodwin used to work as a nurse. Here, she was faced with an ethical dilemma that inevitably influenced the course of her study. Whilst observing a patient (as a researcher), she overheard a conversation between the anaesthetist and the surgeon which pertained to the patient and would be useful to her study. While listening to this conversation, the patient's blood pressure began to drop and his intravenous fluids to run out. Goodwin was then faced with a double-dilemma: should she intervene as a qualified nurse or wait for the anaesthetist to take charge, maintaining her role as a researcher only? Similarly, should we report on the confidential conversation or ignore it, in the face of its potential usefulness? Similar issues were identified by Pool (2000) in an ethnographic study of euthanasia in a Dutch hospital:

> during the first weeks of participant observation I thought that I would be relatively inconspicuous in my white coat (...) I sat next to doctors during consultations [and] I was there when doctors informed patients of their diagnosis and prognosis. (...) Everyone knew, of course that I was there and what I was doing, but I assumed that they would soon get used to my presence and not, as far as their decision making was concerned, take any notice of me. Then one day, as I was browsing through a patient's file, I read:

'The patient has expressed the desire for euthanasia. Robert Pool will discuss this with him this afternoon. We await his findings.' I was shocked. (...) I could not refuse to contribute (and in some cases it would have been unethical to do so) and as a result I could not avoid influencing what I was studying."
(Pool, 2000, p.17)

Thus, the researcher may encounter ethical dilemmas that derive both from his/her professional background and her/his immersion in the group s/he is studying. The difficulties discussed above should not be regarded as methodological faults, but are instead an integral part of the research experience. Moreover, not only may the researcher in such a situation be potentially regarded as a member of the health care team, s/he can also serve as a catalyst for participants to reflect and understand themselves under new light. Social meaning is thereby gained through interaction with different actors, in a dialogical way.

In the case of the current study, issues concerning methodology were mostly related to obtaining ethical approval from a hospital, following my initial application to undertake an ethnographic study of that clinical space. These issues were alluded to earlier when discussing conducting research at home and other issues encountered when entering the field.

Then, mercifully, few issues arose regarding to my role as a researcher *vis-à-vis* my role as a health professional. Often, participants asked about my academic background as both a way to get to know more about myself, and my interest in the subject area, and to link me to a particular professional stance. As a health professional working and living outside of Portugal, I often felt that providing this information helped the level of detail and richness of contribution, as some men said they felt more comfortable speaking about their issues to someone who was not part of their immediate care team, for example.

This also related to limitations that may derive from the nature of the study *per se*. Dealing with complex concepts and lived experiences, such as those that were elicited from participants during the interview process, is not an easy task for some people. There is a risk that some participants may have felt shy or embarrassed disclosing some of the issues they did. On the other hand, and more commonly, some participants may have felt encouraged to talk more openly about issues associated with living with HIV, some of which may be going beyond the scope of the current study. In any case, in no circumstance did any participant indicate a desire to withdraw from the study, take back or delete information previously provided, or express discomfort with data collection. On the contrary, I was later contacted by a number of women living with HIV who also wanted to participate in the study, and who had heard about it from colleagues and friends. In fact, as the study was solely focussed on the experiences of men and their carers, later in the research process I found that, for some men, it would perhaps have been beneficial to have included accounts from partners or family members, so as to offer a richer picture of the realities of those men in the study.

Chapter Summary

Against the background of my concern to explore the experiences and the perspectives of HIV positive men in Portugal, this chapter has described the methods utilised to do this. It outlines the interpretivist approach I aimed to adopt and its underlying rationale. It describes the design of the current study, as well as the characteristics of the sample, context and forms of data collection, and analysis. Finally, it highlights key issues pertaining to ethics and field role, as well as potential study limitations – several of which will be returned in subsequent chapters.

Chapter 4

Homens com H[41]: making sense of Portuguese masculinities

Eu sou homem com H,
E com H sou muito home.
Se você quer duvidar
Olhe bem pelo meu nome.
Já tô quase namorando,
Namorando prá casar ...

Ah! Maria diz que eu sou,
Maria diz que eu sou,
Sou homem com H!
E como sou![42]

Ney Matogrosso

Introduction

According to the World Health Organisation (2011):

> gender norms related to masculinity can encourage men to have more sexual
> partners and older men to have sexual relations with much younger women.
> In some settings, this contributes to higher infection rates among young
> women (15-24 years) compared to young men. [Moreover], norms related to
> masculinity, i.e. homophobia, stigmatizes men having sex with men, and
> makes them and their partners vulnerable to HIV. (...) [Also], socialization of
> men may mean that they will not seek HIV services due to a fear of stigma
> and discrimination, losing their jobs and of being perceived as "weak" or
> "unmanly". (WHO, 2011)

From the beginning of the epidemic, Portugal has had some of the highest

prevalence rates and number of AIDS-related deaths in Western Europe, with an

uneven gender distribution of HIV infection compared to some other countries. In

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[41] "Men with capital M"

[42] "I am a man with (capital) M, I am a whole lot of man. If you want to doubt that, just look at
my name. I am almost dating, and soon will get married. Oh! Maria says I am, Maria says I
am a man with M. Oh yes, I am!"

2009, 70% of all people living with HIV in the country were men (UNAIDS, 2010), and at the same time, around 44% of young men aged 15-24 reported having had unprotected sex[43] (Amaro, Dantas and Teles, 1995). At the heart of such epidemiological data are issues surrounding gender norms. Masculinity is therefore a key attribute to explore when trying to understand the range of experiences of men living with HIV. In particular, it is essential to understand the ways in which dominant gender norms contribute toward the spread of sexually transmitted diseases such as HIV. Social norms of masculinity are particularly important in this regard, as the ways in which masculinities are defined (often through a number of risky practices and behaviours) may add to men's other vulnerabilities. This chapter will explore how findings from the present study shed light on contemporary Portuguese masculinities, focusing on how the men who participated in the study interpreted their notions of masculinity both as an abstract concept, as well as a factor influencing most aspects of their lives.

Machos and machistas: the Portuguese context

In a recent daily television talk-show on RTP2 (one of two Portuguese national channels), Isabel Freire, a Portuguese philosopher and writer, discussed what she described as a *shift* in the paradigm governing Portuguese masculinity. In short, she argued that modern-day Portuguese men have changed significantly when compared to the man of the 1950s and 1960s, the core years of the dictatorship period[44]. At that

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[43] For example, the Young People's Health in Context report by the WHO (2004) reported that Portuguese boys have the lowest rates of condom use in all of Europe (68.5% againts 80.2% of European average).

[44] The dictatorship period, commonly known in Portugal as Estado Novo (New State) or Salazarismo, refers to the period between 1933 and 1974. It was during this time that Portugal was under the dictatorship regime of Salazar. This era has been characterised as conservative, authoritarian, anti-communist, anti-liberal, colonialist and repressive of people's

time, gender codes required that every man had to be strong, domineering and able to form a family, to manage and lead it in a very effective way as the sole 'breadwinner'. At the same time, 'masculinity' was a relatively fixed concept that was *achieved* as early as during late childhood. Then, it was common practice for boys as young as 13 years to go through a sexual initiation that involved a visit to the local brothel, usually accompanied by their father (Freire, 2010). If not at that age, a few years later, boys would undergo this rite during the compulsory *inspecção*[45], which was the first stage of recruitment for boys to join the army. Some fathers would even require a 'performance report' from the woman with whom their son had met, in order to be sure that the boy was 'operational', i.e., sexually competent and therefore ready to 'become' a man. This was often the first step towards achieving a fully masculine status, which at that time meant being strong, capable and determined. Paradoxically, as Freire (2010) argued, there was also a concomitant belief that men were allowed to be fragile, permanently boyish in character and lacking in maturity or, as Isabel Freire put it, likely to act as "the unaccountable boy behind the strong man"[46].

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rights. Its motto was "God, Nation and Family", as those represented the three pillars on which the state should be built upon. Salazar was a very religious man, and was a devout Marianist. Censorship was heavily practised in all media, as well as in literature, music and advertising. Portugal was virtually closed up to any form of external support or exchange. The regime fell during the 1974 millitary coup which was popularly known as the Carnation Revolution (Saraiva, 2007).

[45] Inspecção (militar) was compulsory for all boys aged 18 in order to assess their physical and mental fitness to undergo military service. It usually required the boy to visit their nearest Army headquarters (located in a larger city, like Lisbon, Porto or Coimbra) with a requirement to stay overnight. Often, it involved villages coming together to celebrate their boys' departure and arrival from this inspection. Since this was the first time many boys had left their homes and headed for the big city, it was also common for boys to get together and go out to brothels in the evening, in what was the most common sexual initiation ritual there was. It was a moment for checking physical fitness for a dual purpose: for the State – which required fit young men to fight in the war – but also for their peers, evaluated through the ability to be sexually able, and to share news of this within the fraternal space of the army headquarters. Military service is no longer compulsory, and inspecção was replaced in 2006 by the "National Defence Day", which is a compluslory event for all boys and girls aged eighteen.

[46] At the same time, women were educated to be fragile and docile, devoted to family values. Yet, some specialised press in that same period also encouraged women to be strong and to stand by their husbands and their husbands' ideas, even if they disagreed with them or

The question that provoked Freire into discussing this topic came from the presenter of the show, a man in his late 30s. His initial question was specifically directed at finding out if, in Freire's opinion, machismo was no longer existent in Portuguese society. Indeed, just as Freire began contextualising the historical shifts in masculinity paradigms, the presenter began speaking over her, and jokingly added a few bold (and macho-charged) statements. In a way, by doing so, the presenter provided an answer to the question: machismo is alive in Portuguese society, and it is inherent within male and female interaction – just like the one that had just occurred between this man and this woman. By resorting to this "unaccountably boyish" behaviour while trying to exert some level of power over his guest, the TV presenter was, thus, an agent in the transmission of machismo. In fact, machismo is often and erroneously used as a synonym for masculinity, both in discourse and in practice (Vale de Almeida, 1997). One participant in the present study, for example, said:

> Masculinity is changing in Portugal, but there is still a lot of confusion between masculinity and machismo – it is a lot to do with 'quero, posso e mando'[47]. I live in a small village and I see that on a daily basis. Some men, just because they were born men, think they are superior to women or to some other men. (Pascoal, 37)

Another man, Leonardo (31), also felt that machismo was a synonym for Portuguese masculinity, and was still visible in the institutionalised process of bringing up and educating young boys:

> We still live in a society driven by machismo, in which there is a lot of attention being given to young boys (...) Their education takes place improperly, in a very generalised and sexist way. You are a man if you do

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foresaw that a particular course of action was not going to work out as successfully as their husband had envisaged.

[47] "Quero, posso e mando!" is a colloquial expression meaning "I want it, I can (do it) and I'm in charge!". It is used to describe an insensitive attitude of control and power over a person or a group.

what men do. You are a boy if you behave like other boys, otherwise people won't understand whether you are a boy or not. (...) There is a lot of this idea in Portugal, when it comes to bringing up children. This notion of being more or less one 'thing'... At work I experience this. I often see my fellow colleagues [teachers] saying things such as: you are less of a man because of this... or, 'hey boy, don't you wave that fan – boys aren't meant to wave fans.

As Pascoal pointed out, in Portugal, machismo and masculinity exist in close relationship but the shift that Freire alludes to in understanding masculinities means that we have now moved on from boys being taken to houses of prostitution: *inspecção* is no longer compulsory, nor does it require a sleepover, and Portugal is now open to a range of external influences. Essentially, older ways of understanding masculinity coexist with but are being challenged by other current and contemporary practices. As Luciano (37) put it:

> There are two generations: the one before ours, men who are older than 45, and then younger men. The majority think that domestic tasks are for women to do. Certain conversations are typical amongst older men. They don't have emotional conversations. Even if they have certain feelings, they don't show them or talk about them. This has a lot to do with machismo. I think our generation, those who are younger than 40 years is different. One can be manly and affectionate. I can hang my washing on the line; it doesn't make me less of a man. I can still have a brave attitude in life, face up to my challenges and support other people.

Practices have changed, some have been replaced by others and hopefully concepts such as machismo and masculinity are changing – ultimately, though, the underlying meanings associated with these practices may also change, even if at a slower pace.

Faz-te um homem![48]: the making of a man

After the Carnation Revolution of 1974, and with the fall of the dictatorship, a new set

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[48] "Be a man!"

of values emerged in Portugal which included changes in relation to women's rights, as well as access to education and health care for all. This reorganisation of Portuguese society, fuelled by values of freedom and equality, also allowed a number of groups to stake claim to their rights, including homosexual or same sex attracted men, who were virtually invisible in public up until then (Santos, 2005; Amâncio, 2007; Almeida, 2010[49]). Almost 40 years after the revolution, and influenced by Portugal's entry to the European Union, the rights of minorities have come a long way. Recent signs of such changes include the legalisation of abortion as well as gay marriage[50], as well as changes in the Constitution that protect all individuals from discrimination on the basis of sexual orientation, gender or ethnicity. Portugal has thus kept up with much of Western Europe in ensuring that there is a body of legislation in place to ensure people's equal rights and freedom.

One of the participants in the study, Vicente (54) was particularly vocal about the differences that exist in the way gay men are visible in society these days, even if he thought most homosexual men still remain 'in the closet' or live a double life:

> Nowadays it is different. It is common for boys to get together, to cruise and go [have sex], even if they have girlfriends. The man of that time [1960s, 1970s] is not the man of today. If you're gay, it's ok, there's no problem, as long as you don't mix up with them. WHO have forbidden it [homosexuality] to be considered an illness. People tolerate it. But tolerating is not the same as accepting!

Another participant, Filipe, also 54 and a gay man, shared the following notion of there being a double-standard of acceptance versus tolerance:

> We live in a racist and homophobic society. We're all that way, even if we say

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[49] São José Almeida published in 2010 a comprehensive analysis of homossexuality during the dictatorship period based on accounts of a number of people as well as offering a broad historical review.

[50] Law 9 of 2010, which was published on the 31st of May 2010, recognises civil marriage between two people of the same sex – yet, it does not allow for the newly formed couple to adopt.

the opposite thing. (...) Gay marriage? People don't know and don't want to know what that is. But as soon as it's related to someone, they know. It's all 'what a horrible thing, what is that all about?'... We're terrible as a society.

As can be discerned from both Vicente and Filipe's accounts, changes in society mostly worked towards guaranteeing that legal frameworks were in place to protect the rights of certain minority groups (tolerance), and not to ensure that these were accompanied by a change in the deeper social processes that undergird discrimination, ostracization or processes of othering (acceptance). Regrettably, social debate about such questions remains in an embryonic phase. On the one hand, this may be due to a difficulty in adjusting to these changes, as they have occurred in a relatively short period of time. On the other hand, it is due to the continued existence of deep-seated conservatism and strong religious values in Portuguese society. As Filipe put it:

> Religion is the main cause for non-acceptance of homosexuality in Portuguese society, mostly because of what the Pope says. For example, everyone loved Pope John Paul II. There has not been any Pope as homophobic as him, but anything he said, right or wrong, was accepted. This one [Pope Benedict XVI] says the exact same things but no one can stand him! Still, the Church does not follow society, which is decades ahead. And if I want to accept myself as I am [for being gay], I have to separate from the Catholic Church a little. (...) I find that the Church stands in the way of social development in general, and it has way too many privileges in Portuguese society; it interferes a lot in Portugal, in school, for example. If you're not Catholic in school, you're tied up. There are lessons for religious Catholic education[51], and there is nothing for other beliefs. Some say there are, but there isn't.

Thus, certain structural factors stand in the way of greater levels of acceptance of some of these changes. At the more micro levels of society (such as families and individuals), these tensions impact directly on the way people behave and interact. At a practical level, people may feel confused, with mixed messages coming from the

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[51] According to Law 329/98 (issued in 23/11/1998), the Portuguese public school curriculum offers optional attendance to the module of 'Religious, Moral and Catholic Education and Other Beliefs' to all students in year 5 through to year 12. Despite its name, the module refers to Catholic doctrine and associated beliefs. It is usually taught by Catholic priests and nuns, and focuses almost exclusively on Catholicism.

government, the Church and the people with whom they relate more directly. One example of this was what happened with Gabriel (52):

> After my ex-wife and I divorced, she took me to court in order to stop me from seeing my kids because I had HIV and that I then had a male partner. The court decided that, not only had I the right to visit my children, I could also have them stay at my place. (...) The judge said I lived a perfectly normal life and the fact that I had HIV and was homosexual did not interfere with educating my children correctly.

This quote highlights the complex nature of current Portuguese attitudes towards social issues such as sexual orientation and health status. On the one hand structural and legal foundations have changed, allowing Gabriel to gain custody of his children, despite being gay and HIV positive. On the other hand, these are the ideological principles that substantiated his wife's actions (present in the sole fact that his wife requested exclusive custody based on his sexual orientation and HIV status). Similarly, gender is prone to divergent interpretations in Portugal, and this is likely to influence men's own experiences as well as notions of masculinity.

Ar de homem[52]: defining masculinity

Masculinity, or masculinities as they are more commonly referred to in the specialist literature[53], imply notions that may seem relatively clear-cut but in fact encapsulate a wide range of meanings and interpretations. Masculinities (in the plural) is a more suitable term to adopt conceptually, since the attributes described are not unitary but diverse – cultural constructed and personally experienced (Flood, 2002). In the Portuguese language, the direct translation of the term masculinities is

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[52] "The air of a man."

[53] See, for example, Mac An Ghail (1996), Haywood and Mac An Ghail (2003) and Gough and Robertson (2010).

masculinidade(s), which, according to the Priberam online dictionary (2011) is defined as "the quality of what is masculine; manly; a baron; virility". This simplistic notion, that at first sight seems to ignore any social or psychological attributes, may actually epitomise some of the social aspects of what is regarded as masculinity in Portuguese society today. Dictionaries both define terms and offer insight into the social meanings that these terms carry in a specific social context. In this particular case, this definition offers a useful starting point for the analysis of masculinities amongst study participants. In fact, most participants came up with definitions of masculinity that were generally similar to conventional stereotypes. For example, Samuel (48) put it this way:

> Masculinity has to do with authority and identity. (...) Men are firmer; they have a greater ability to make decisions. (...) Masculinity is the act of being masculine, or liking himself with the sex that he has got, the phallus.

Luciano (37) added that:

> men are naturally protectors. (...) I associate masculinity with a man being in charge; not necessarily rough, but behaving in a way that is different than women, in the way he moves.

For example, Mateus (39) said:

> masculinity is what a man has that women don't have. It's a different way of being, more independent, more autonomous, more childish, more individualistic but also more comrade-like.

The masculine/feminine symbolic asymmetry is thus a common framework by which men interpret and also enact masculinities (Vale de Almeida, 1997). This is clear in the definition put forward by Martim (40):

> It is the opposite of what's feminine. They're different behaviours and what is masculine should not be feminine or vice-versa.

Thus, men in the study utilised a gender-based dichotomy in order to define

masculinity, enhancing the asymmetrical relationship between feminine and masculine. Agostinho (43) refers to this asymmetry in the following way:

> There are two types of people in the world: the masculine and the feminine. Feminine people behave in one way and masculine people in another. There are no commonalities. I think a man is masculine when he behaves like a man. For example, I don't like, and have a certain aversion to travestis. I don't like it because it's not masculine. (...) That's not masculinity to me. To me, masculinity is behaving like a man, having manly attitudes, because feminine is for women (...) [being masculine is not about] feather boas or sequins.

The above quote also suggests a particular social organisation of masculinity, in which a 'masculine attitude' may differentiate men from women as well as from each other. Differentiation between men, associated with masculine capital (understood as doing what is masculine and not behaving like a woman), occurs in a hierarchical structure: those who are 'more masculine' are at the top and those who are less masculine (here framed as in 'more feminine') are at the bottom. Or, as Agostinho continued:

> I don't blame feminine men... I can identify a certain level of masculinity in them but not all. There's a lot of femininity. (...) I don't fancy effeminate men. If I did, I think I'd rather be with a woman.

In the case of Agostinho, a self-identified gay man, interpreting masculinity as a continuum (that goes from being very masculine to very feminine) also allowed him to determine which men are more or less attractive, from a sexual point of view. So, not only is 'higher' masculinity linked to a higher social status, higher masculine capital[54] also equates to stronger sex appeal. This was a recurrent theme among other men who had sex with men in the study.

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[54] Here framed in terms of social capital, i.e. the way men organise and act collectively towards a common goal that will benefit men as a whole. For example, research has shown that men and women may have different types of social capital based on differences in their social networks, values of collaboration and capacity for conflict management. Women tend to depend more on informal relations established within social networks, leading to them establishing stronger relations than men. Men are more prone to establishing formal relationships instead (Moore, 1990; Molyneux, 2002).

Another point in Agostinho's earlier statement relates masculinity to self-presentation, i.e. the way men present themselves publicly, in part through the clothes they wear. Thus, masculinity:

> has to do with the way you look and the way you dress. (Leopoldo, 35)

> (…) is wearing like formal clothes, (…) wearing trousers. (Vicente, 54)

> (…) means dressing up in a more, say, sober way; not very extravagant … without wanting to have everyone looking. (Luciano, 37)

Paco (42) summed it up well when he said "masculinity is having *ar de homem*[55]".

If these statements associate masculinity with visible characteristics, another set of responses link masculinity to less tangible aspects. For a number of men, masculinities were more about personality traits than about physical expression:

> Beside the physical aspect, a man must have integrity, be coherent and know how to face up to challenges. This doesn't mean he needs to stop feeling or showing emotions. Like – not crying for being a man? That idea doesn't sit well with me. (Paco,42)

> Masculinity is to have correct attitudes in society. Do I think crying is a woman's thing? Of course not! However, men must have correct positions in society, as men. (Filipe, 54)

> "Masculinity is based on many parameters: respect, being delicate, having charm, loyalty and honesty. (Serafim, 54)

Honesty, intelligence, companionship, compassion and kindness were the most common characteristics used to describe the 'ideal man'. Such findings parallel those reported by Amâncio (1994) who analysed attributes and stereotypes that were linked to men and women in Portugal – and all of the above (honesty, intelligence, kindness) were associated with males, by both men and women.

Also associated with men was participation in a range of activities (leisure and/or

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[55] *Ar de homem* literally means 'the air of a man'.

professional) unsurprisingly different from those associated with women:

> A man will look after the car, the insurance, changing light bulbs; DIY... that is the image we're used to. A man who drinks beer, who reads sports newspapers. (Gabriel, 52)

This corroborates findings from a study by Amâncio (2007), in which she found that most men looked after 'small repairs and DIY' at home, whereas women did the others. Activity and occupation thereby lie at the core of gender construction. For some men, being professionally active was a key factor in being considered for a higher position within the masculinity hierarchy. This does not include, however, any kind of domestic work, as this was seen as an area reserved for women. Similar to changes in legislation protecting the rights of sexual minorities, significant changes in women's roles (in particular regarding employment) have not been accompanied by public debate on gender and equality within the family system, as happened in the neighbour Spain in the 1980s, for example (Amâncio, 2007).

In sum, the variety of meanings associated with masculinity offers a rich starting point for further analysis of how this complex concept influences a range of contexts, interactions and attitudes in men's lives.

Leonardo (31) offered a definition of masculinity that encapsulates some of these general aspects that men associated with masculinity thus far:

> The concept of masculinity or femininity is in itself sexist. Is it being stronger? To have testosterone ...? I don't know. Is it the idea that a man must work to bring money home, pays the bills, because that is his role ...? I don't think there should be such role difference between men and women. To me, it [being masculine] is having integrity, someone that does not make me feel intimidated because they're trying to be more of a man than I am.

Homens de família - **family men**

Family is a key factor to take into account when analysing interpretations of masculinity in Portugal. It provides a refuge for some men: a place of escape from the daily struggles and competition at work. As far as family dynamics are concerned, men tend to lead, setting a clear definition of tasks that each member is meant to complete within the hierarchy (Amâncio, 2004). Moreover, as Aboim (2010, p.61) argued:

> it is in the historically privatized contexts of reproduction and sexuality that key processes of domination occur materially and discursively. The gendered self is greatly formed and reconstructed in the space that modernity fallaciously constructed as private, and also through the tensions between the public and private.

For most men in the study, family is one important idea that is brought up in a number of contexts and which often lies at the core of various tensions that derive from their own role as men. Valdemar (44) explained:

> I always lived with my parents until I had to leave home [to get married]. I spent most of my childhood moving from place to place trying to find somewhere for my father to settle with work. We used to live around here [urban centre], then we moved to Angola but had to return to Portugal after the war started over there, and we settled around here again as my father managed to get a job here.

Thus, home was wherever Valdemar's father could find a job. This patriarchal notion of family was reported by most men in the study. In fact, the father figure was recurrently referred to as the *pilar* [pillar] (Cristiano, 38) of the family system, the "provider of control" (Valdemar, 44), in opposition to the role of the mother as "educator, carer" (Paco, 42), "[someone who] looks after the home" (Gabriel, 52). About half of the men in the study were part of the same generation, being older than 40 years. This defines some common ground for these men's experiences of family, as, historically, some of the aforementioned patriarchal values were more visible

before 1974 (when these men were young children). This is illustrated in Vicente's (55) words, who referred to two activities as examples of common practices of caring – which somehow reveals a level of patriarchal parenting in which soft demonstrations of care were not suitable for young men:

> In my youth, I was brought up under a different philosophy. (...) At home, we never celebrated birthdays; we didn't even brush our teeth. (...) All you were told was to be a 'macho' man. If you asked for a glass of milk, you were considered to be *maricas*, or *bicha*[56]. The man of that time is not the man of today's times.

Adding to the notion of the father as the pillar of the family system, the father figure also came up as a key element in determining some of the respondents' own interpretations of a patriarchal model. Surprisingly, most men did not like or did try not to adopt this model in their daily lives. Those men who had to bring up children of their own made particular mention of this idea, as in Valdemar's account below, for example:

> My father did not show emotions (...) he didn't encourage us. On the contrary, he would bring us down in order to teach us. He would tell us to do stuff and we had to obey. (...) I want to make sure I am different, but there is a part of me that is like him. All manifestations of fondness that I have towards my boy are nothing like those I have towards my daughter. [With my son] I'm more afraid of what he may think of me, that he might reject me. (...) when I see my daughter I run to her and hug her, I tell her I love her and miss her. With my boy, I also say that, but in a more masculine way. (...) I want him to be better in everything we do. For example, we play football with a group of friends. In football, as in tidying his bedroom, I am demanding. (...) I am as my father was with me – I don't want to, but it is here. It's part of me; rooted in me, and I fight against it.

Also clear in Valdemar's account is the idea of a different value system in bringing up a boy or a girl. In a way, Valdemar perpetuates in his relationship with his son the

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[56] The words *maricas* and *bicha* are common derogatory terms used to describe men who have sex with men. Both terms have a strong gendered connotation in that they exclusively target men who behave in feminine ways, or as the Priberam Dictionary of Portuguese describes "a man who engages in activities that women do" or someone "who is scared of things, who is weak and frightened, who is not brave and courageous to face their fears". *Bicha* is "the female species of any animal". Both terms are thus used to belitle the masculinity of effeminate men and, according to Carillo (2002), *maricas* (in Spanish '*maricón*') derives from Mary or Maria, the Catholic name for the mother of Jesus Christ.

hegemonic values of masculinity that he inherited from his father, even though he

does not agree with them or feel completely comfortable doing so.

Other men reported similar experiences regarding their upbringing, usually stressing

the idea of a "pai ausente e mãe castrante [absent father and a castrating[57] mother]"

(Gabriel, 52). Most men thus grew up in a home environment in which patriarchal

values meant living with a father who was domineering and violent. If these men

responded by being more timid and obedient, two men explained they often

misbehaved or acted in a rebellious way:

> I would act in a completely inappropriate way as a way of being myself. I
> would wear ridiculous outfits and have weird hairdos. (Paco, 42)

> I would wear boots like the Beatles, or anything that could annoy my father –
> but he was the one financing it all, which I now find quite funny! I would annoy
> him so much. Sometimes he would throw a dinner party, for which I had to be
> home at 8pm, but I would only get there at 9. Of course I was immediately
> reprimanded... but I had to show him that that was not what I wanted. (Filipe,
> 54)

Both instances here portray situations in which there is a fight against well-

established hegemonic norms of masculinity – particularly around self-presentation

and formal codes, as well as the distribution of power within the family. Father-son

relationships amongst the men in the study had remained the same throughout many

men's lives – taking the form of antagonistic or heated interactions, lack of affective

engagement or the establishment of more intimate relationships. As portrayed in

Valdemar's words, some men had the opportunity to pass on certain traits to their

children, whereas others fought back against these:

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[57] The concept of 'castrating' mothers is used here in a more popular way than that derived of
Freudian and Kleinian psychoanalysis – referring to mothers who adopt more domineering
styles of parenting. In a way, a castrating mother is an empowered woman who may
eventually take on a number of household-related responsibilities that are typically associated
with men. However, more commonly, they are fully responsible for educating and bringing up
their children. Sometimes they may be married to an 'absent father', a man who spends little
time at home, which helps her in defining the physical boundaries of her dominance. Despite
there being a certain level of matriarchal power, this tends to subside when the male partner
is present.

> That kind of talk [about affections/feelings] and sharing experiences between my father and I was absent. (...) I try to act differently with my children. I'd like them not to be scared of talking to me, to share whatever they feel. (Gabriel, 52)

Cristiano (38), who was not a father but was considering becoming one, described his experiences:

> I would never be like [my father], because there were things I don't like and things I don't agree with. My relationship with him was never good. He's got everything I dislike in a man: he's authoritarian, he can't hold a conversation, he acts like he is *dono da verdade*[58].

The emphasis so far has been on the role of the father, and even if quite often that was the main 'character' mentioned referred to in men's experiences of growing up, there were also some important accounts relating to the mother's role.

As discussed earlier, mothers were referred to as 'castrating/emasculating', 'passive' or 'domestic'. Whereas passive and domestic imply a more subaltern role, castrating on the other hand offers an impression of these mothers as emasculating, empowered women, usually in charge of a specific set of tasks. Notwithstanding this, they were also likely to resort to the same subaltern role when in presence of their husbands. These terms are therefore not fixed categories but may be utilised to describe the same woman as ultimately men's mothers had lived within a patriarchal micro-cosmos. Additionally, mothers (and wives) often had a very important role in perpetuating notions of hegemonic masculinity *per se*. Some men in the study referred to this quite openly. For example:

> If I had any health problem, I would just tell my mother and she would take care of it. (...) She would sort it all out. It was only in 2002 that I started to

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[58] 'Dono da verdade' is an expression that literally means 'owner of the truth'. A similar meaning in English would be the expression 'to have a chip on one's shoulder', as it refers to someone acting superior and self-righteous.

take some ownership of my life, pay my bills, find a place to live on my own …
(Paco, 42)

Aboim (2007) has written that both men and women in Portugal adopt a mixed position when it comes to family life. If, on the one hand they can be regarded as 'modern' when it comes to accepting divorce or civil unions as alternatives to marriage, on the other hand they are conservative when it comes to the division of labour within the home, children and parenting, which are almost exclusively part of the woman's remit. This, in turn, generates a tension for women's roles as they are pushed to and expected to divide their time between the public and the private spheres more so than men. An interesting point to emerge from Aboim's (2007) study was the shared agreement by both men and women that men should be more engaged in domestic work – even if this did not correspond to actual practice.

O corpo sexual[59]: masculinities, the body and sex

When it comes to the body, men commonly recognised that part of what it means to be a man relates to physical attributes. Watson (1993) explained that most practices that men engage in (working, going to the gym, excessive drinking) are made visible through the body, and that the physical body alerts men to all their 'wrong-doing', as men follow a 'if it works, don't fix it' approach to body maintenance and performance – almost as if the body is a piece of machinery.

Maria, one of the study participants who was recruited as part of the team of professionals working with people with HIV (a psychologist who worked for an HIV-charity but who had also developed some work in a men-only prison) alluded to the

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[59] "The sexual body"

idea of a well-kept body as a means of protection, by projecting the image of 'looking strong':

> They [prisoners] have a huge concern with their bodies. Not only it is a mental escape for them, there are some men who, when I met them initially, were quite frail and had to develop some muscle also as a way of protecting themselves. (...) It relates to the image they show to others, so for them the time they spend in the gym is sacred.

Along the same lines, Pedro (50) indicated how important it was for him to have a muscular body, even if this meant taking illicit drugs such as steroids[60] to aid muscle growth:

> I look after my body, my physical appearance means a lot to me. I do yoga and Pilates three times a week. (...) I have always exercised a lot, I used to compete as well. In the gym, sometimes I would do silly stuff in order to grow my muscles. It didn't quite go according to plan, though.

Agostinho (43) also stressed the importance of being fit, highlighting that a well-looked after body is more sexually appealing:

> I don't think it is futile to think that an ideal man has the perfect body, well looked after and muscular. Whoever is with that man will have much more pleasure, and that is important for a man.

Thus, the body encapsulates overlapping concerns with health, image, strength, protection and sexuality, all of which relate to the dominant notions of masculinity analysed earlier. That said, men are caught up in a tension between having a good body and showing that they do not really pay any real attention to their appearance. This fact, allied to the notion that a stronger body is regarded as healthier and more masculine, can trigger a number of concerns for men who are ill, such as men who are living with a chronic illness (HIV included). Not only are these men more likely to

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[60] Pedro had used deca-durabolin, a steroid-based substance that is commonly used among body-builders. However, because it interacted with the ART he was taking, Pedro had to stop using it.

experience bodily changes as a consequence of certain treatment options, they may also experience a number of secondary conditions and symptoms – including cardiovascular problems – that may impact on taking up exercise, for example.

The body has particular importance as men also define masculinity based on what others see, be it physical appearance and fitness or choice of clothing. Intimately related to an analysis of masculinity and the body is the way in which men express their sexuality – both in terms of sexual practices and the values and principles that define their sexual behaviour.

In the introduction to this chapter it was noted that men in Portugal used to go through a ritual of sexual initiation that involved a visit to a house of prostitution. Serafim (54) explained that his sexual debut took place within this context:

> While I was there [boarding school], as soon as we got to 5th grade, we were pranked which consisted in the group escaping the school and going to visit *tias*[61], who were prostitutes. That is how I had my first experience, but shortly after my father also took me to one of these houses [brothels] so that I would know what sex was all about.

These practices, even if not as common nowadays, have been replaced by others that carry similar meanings in terms of understanding masculinity. The advent of the World Wide Web and information technology, allied to a number of societal changes that have radically revolutionised the way sex is understood and portrayed, mean that it has become easier for younger people to access sex-related information, without necessarily resorting to their parents or peers. This does not mean, however, that parents have abandoned their role as sex educators altogether:

> When I was 18 my father came up to me to talk about condoms. I felt quite uncomfortable … At that time I knew it all, he came a little late… (Luciano, 37)

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[61] *Tia*, meaning an aunt, may refer to an older woman, or a woman of upper social status. In this context, it refers to an older woman whose role was to 'educate' and provide sexual initiation to younger men.

Serafim's and Luciano's quotes reveal two issues that seem to play an important role in descriptions of sexual initiation among the participants in the study. First, both accounts allude to the role of the father as a leader, the power holder and the decider of the right time to initiate sexual activity. Second, particularly in Serafim's account, emphasis is placed on the role of peers in defining and encouraging sexual initiation by pressure or through organised play. The latter was more commonly described, maybe due to the fact that most participants are slightly younger than Serafim. Martim (40) for example described his sexual initiation as follows:

> I was 16. At that time, there were no lessons on Friday afternoons so me and my friends used to organise parties in each other's homes, and sometimes those things [having sex] used to happen.

Paco (42) had a similar experience:

> My first time was organised by friends, and it was like doing the chores … It wasn't nice or pleasant, even if it was with one of my (girl) friends. But it didn't go well at all.

These last two accounts were provided by men who, despite initiating their sexual activity with girls, now self-identify as men who have sex with men. Interestingly, out of all men who have sex with men in the study, only two had their sexual debut with men. There was a combination of experimentation, curiosity and social pressure in some of the reasons used to describe sexual debut with women:

> I always had girlfriends that I had to keep because of social image, but I always knew what I was. (Filipe, 54)

> I had the advantage that I did not differentiate between girl and boy. It sounds weird today but at the time it didn't. (…) So I could fall in love with a boy or with a girl. I suffered a lot of bullying in school because of that, from age 10, and when I realised it would be useful for me to hide this, because people were quite cruel if they knew. (…) I had my sexual debut with a girl, but my relationship with her didn't last long. The longest relationship I had was then with the woman I ended up marrying when I was 20, and divorced 5 years later. (Leonardo, 31)

When it came to describing their sexual debut (or first sexual relationship) with other men, these tended to occur later in life, even if there had been some sexual initial experimentation with other boys during childhood and adolescence. For example, Paco (42) said he:

> (...) experimented with this other boy from school. We used to tell each other that we were doing that because we didn't have girlfriends, because as soon as we did, that would stop. (...) I thought that was something I would do but then eventually end up having a normal life like all the other men I knew.

Paco's homosexual debut was with a much older man, one of his cousins, during summer break:

> He used to come over to our place in the summer and I started having sex with him. I had the idea that I shouldn't tell people about it (...) but my mother knew he was gay and once warned me that if ever he tried to do anything to me – she wouldn't say what – then I should tell her about it. I agreed but never told her.

Initiating sexual experience with an older person – be it a woman (as happened in the rituals involving prostitutes) or a man (as Paco described above) – seemed to be a common practice. Another participant described his own sexual debut with another older man he himself seduced, resulting in him being sexually abused:

> I had the idea that I was attracted to boys, since I was 9. And I liked older men... so I have no idea whether or not the abuse was caused by me. I was creating situations that would lead to what I wanted sexually. But it left a mark, no doubt about that. However, it helped me to grow up as a man, as it was an experience that my friends did not have. I was already a step ahead ... I already had had that relationship. (...) I didn't do anything against my will, I just didn't expect it to be like that. I had more of a magical idea... but it hurt, it physically hurt. (...) I could not continue doing that [receptive anal sex], and it is one of the few things I've not still resolved in my head, because when I am penetrated, I feel that my masculinity is affected. That is why I will never have sex with an effeminate guy, but I feel very attracted to a masculine man who I can dominate. (...) I now seek sex with married men. (...) If I am ever to be penetrated, the guy doing it must be more masculine that I am; that is the only way he'll get the license to do that. (Pedro, 50)

This account contains several ideas that are worth analysing. On the one hand, for

Pedro, masculinity carries strongly sexualised connotations, as *something* a man has that makes him more or less sexually appealing. The more masculine a man is, the more domineering he can be, i.e. he is given the lead in any sexual activities he wants to pursue. Penetrative anal intercourse thus symbolises the epitome of masculine practice within sex. Pedro thus aimed to be the more masculine man in whatever sexual relationship he was involved in, so he could eventually penetrate his partner. Not only that, he would aim at penetrating 'macho' men, or men whose masculinity *levels* were similar or greater than his own.

This was also visible in other accounts:

> I enjoy talking to men who are straight because that is what I would like to be. (…) A macho wants to possess, to own. So I never quite understood where is the pleasure in being possessed [anally receptive]. (Vicente, 54)

One participant also highlighted the idea of dominating the (hetero) sexual relationship, but in regards to his sexual experiences with women:

> In the past I was incapable of stopping the pleasure I got [from unprotected sex], by putting on a condom. (…) But if I find a girl today, I may just use a condom and not tell her about that [HIV status](…) It depends on my choice at that moment. If I feel like talking about it, I will. It's my call. (Valdemar, 40)

Dominance is present here in the fact that preventive decisions are based solely on Valdemar's choices; there seems to be no place for his partner(s) to have a say in decisions involving sex. Despite disclosure coming only from Valdemar, he could have negotiated safer sex rather than choosing to wear a condom and expecting his partner to agree. He adopted a macho approach to (safer) sex which reduces the threat of disclosure but also impedes open communication. He adopted a similar approach when describing his relationship at the time of interview:

> This is not a relationship as such. I have been having sex with the same

person for about a year. And this is how I'd like it to continue to be. (…) She has complained before that this is not the type of relationship she wants, I've said this is what I want and she is free to decide based on that. (…) I'm only attracted to her on a sexual basis, though.

In a strongly Catholic country such as Portugal[62], virginity is sometimes regarded as something to be protected until the moment of matrimony, particularly for girls and young women. It contrasts with the notion of sexual prowess that is expected from boys and young men as a performative expression of their virility. Both account for a cultural construction of pre-marital virginity and pre-marital sex as normal, even if contradictory in principle. Often, virginity is interpreted as a valuable 'item' that one keeps and then may give away to someone special, or under very special circumstances – such as marriage, or to consolidate a solid and long-term relationship. Some men related to this, as follows:

> I had a few dates in school until I met a girl with whom I had a proper relationship. It was a bit more solid and stable so we decided to have sex. We were both virgins, so it was the first time for both, which was good. It made our relationship stronger (Pascoal, 37).

> I never had any sexual experiences during adolescence. I only had sex when I was 29 or 30, because I was in a relationship for nine years with this girl whose dream it was to be a virgin until we got married. We would go on holiday together, but her parents were there as well. (…) Even though we'd spend a lot of time together, there wasn't any kind of sexual activity between us … It only happened later with another girlfriend. But when I was 12, I remember this time I was in the locker room at school and I was looking at the older boys – they were 18 or so – and I was looking at them naked and I had an erection, and that lit up a big issue in my head… so since that time until I was 30 or so, I always repressed that … (Agostinho, 43)

'Losing' one's virginity is usually conceptualised as a magical and unique experience, tangled up in symbolism and representing the definitive rite of passage from childhood to adulthood. Moreover, this last account stresses a level of repression of both heterosexual and homosexual desires. In a way, sex was interpreted here as something forbidden and only allowed after marriage, despite a physical impulse and

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[62] The website catholichierarchy.org described Portugal as the 12th most Catholic county in the world and 6th in Europe, with a percentage of 90.41% of Catholics living in the country.

the manifestation of sexual readiness (erection). Similarly, sexuality is connected with a level of desire that is not straightforwardly acted upon.

Chapter summary

Historically, Portugal has been a country in which performances of machismo often juxtapose those of plural masculinities. Recent history attests to Portugal's attempt to transform itself from a rural, conventional and religious country to a modern European and secular nation. This is not without its consequences – at both the micro and macro levels of society. In this chapter, historical shifts have been interpreted in light of their potential to contribute to new conceptualisations of men and masculinities in Portugal. This analysis has focused on a number of different arenas in which masculinities are likely to play a crucial role, such as the family, the body and sex.

Overall, recent changes in Portuguese society have generated a number of tensions that affect understandings and performances of masculinity. In particular, cultural constructions of both premarital virginity and premarital sex are framed as somehow both normal and viable, social pressure associated with being macho and being restrained and thoughtful as equally masculine, and the hegemonic male and the 'castrated' male as parallel psycho-social models of gender and sexuality.

Chapter 5

Saúde de ferro[63]: masculinities, health and chronic illness

Não tenho inveja da maternidade
nem da lactação,
não tenho inveja da adiposidade
nem da menstruação.

Não tenho inveja da sagacidade
nem da intuição
não tenho inveja da fidelidade
nem da dissimulação.

Só tenho inveja da longevidade,
e dos orgasmos múltiplos
e dos orgasmos múltiplos
Eu sou homem,
pele solta sobre o músculo.
Eu sou homem
pêlo grosso no nariz[64]

Caetano Veloso

Introduction

Concepts of masculinity, health and illness are important in analysing the

experiences of men with HIV. Lay understandings of health and illness are culturally

and contextually-specific and, as pointed out in chapter 2, there have been few

attempts to define what these might mean for Portuguese people in general (Duarte,

2002), and Portuguese men in particular. As the current study deals with these two

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[63] 'Iron constitution'

[64] "I am not envious of maternity or of lactation. I am not envious of adiposity nor am I of menstruation. I am not envious of sagacity or of intuition. I am not envious of fidelity or dissimulation. I am only envious of longevity and multiple orgasms, and multiple orgasms. I am a man. Loose skin over muscle – I am a man, thick hair in my nose."

concepts, it is important to clarify what health and illness may refer to for the men in the study. Some of the notions are in fact intertwined with discussion of masculinity. Coincidently, as is the case with masculinities (see literature review), there is also a level of hegemonic power (associated with medicine) influencing health and illness in Western societies (Pringle, 1998).

As Riessman (1993, p.5) argues, "culture speaks itself through an individual's story [and] it is possible to examine gender inequalities, racial oppression and other practices of power (…) using narrative analysis". As the current study aims to understand the meanings men attribute to HIV, its trajectories and consequences, and how these intersect with men's biographies, I will adopt the chronic illness framework suggested by Bury (1982, 1988, 1991, 2001) to analyse narratives of men's experiences of living with HIV. In particular, and to aid the flow of argument, the current chapter will follow the sequence adopted by Bury (1982) in analysing the processes and trajectories adopted by people living with a chronic illness[65].

Beyond *mazelas*[66]: defining health and illness

Health as a concept carries with it a range of interpretations and meanings. Even when examining formal definitions of health (see Aggleton, 1990, Seedhouse, 2001 or Bury, 2005, for example), one finds a variability that is anything but objective or

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[65] Bury (1982) links three aspects of disruption that occur during chronic illness processes as follows: "First, there is the disruption of taken for-granted assumptions and behaviours; the breaching of commonsense boundaries. (…)This 'what is going on here' stage involves attention to bodily states not usually brought into consciousness and decisions about seeking help. Second, there are more profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved. Third, there is the response to disruption involving the mobilisation of resources, in facing an altered situation (pp. 169-170)".

[66] *Mazela* is a Portuguese colloquial term for illness, deriving from the Latin word *macula* (wound).

clear-cut. Within the current study, there were a number of accounts in the data that pertained to varying notions of health. In fact, one of the professional interviewees – a psychologist – referred to health in a broader sense as a useful vehicle by which to engage with other themes in consultation, in particular issues of sexuality. This comment denotes a perspective that is twofold: on the one hand, health is both fluid and broad as a concept *per se*. On the other hand, health is a concept that people generally seem to be comfortable with; indeed it is a term that professionals may use to engage with other, more delicate and sensitive notions – such as sex or sexuality as in noted the psychologist's account above. Moreover, as the same informant explained, when health is framed utilising symbols such as strong bodies and physical fitness, men may be more likely to relate to this conceptualisation, as it fosters a normative masculine ideal of strength and vitality.

Most of the participants in the study, however, seemed to define health as a non-concept, i.e. something that was taken for granted, and difficult to define as such. In his study of men and health, Robertson (2007) found similar results and related his findings to Bourdieu's (1990) claim that many everyday practices are not consciously organised but are, instead, organised through a 'practical consciousness', which develops from the individual's habitus. One example of this can be found in Filipe's (54) account:

> I've always been healthy. Never had any health issues … I mean, I had those *mazelas* that we all have, like chickenpox and mumps … the most serious was hepatitis A, but never really had any issues.

So, despite actually experiencing a number of different illnesses, including hepatitis A, Filipe's underrating conceptualisation of his experience was fuelled by a desire to come across as generally healthy. The episodes he dubs *mazelas* were but slight bumps on the otherwise smooth health road.

Health is often defined in relation to illness, be it the absence of the latter or opposite to the latter (health as diametrically contrasted to illness). Moreover, as can be seen in Filipe's comment above, underestimating a common *mazela* may add to the notion of health as a 'normal' state – a somewhat fixed balance that is only disrupted by serious illness. The notion of health as balance[67] is, according to Bury (2005), back in vogue, potentially fuelled by an increased focus on health promotion and sustainable wellbeing. By underestimating *mazelas*, Filipe addresses the imbalance they may cause and presents himself as an all-round healthy individual.

A similar strategy was used by Serafim (54), who explained that he:

> (..) had a *saúde de ferro*[68]. I was 20 years without setting foot in the doctor's office. When my doctor saw me 20 years after asked me: what are you doing here? Because he knew that I was very strong physically. It was common for me to break a leg or an arm but that was from sports ... it was part of the deal, it wasn't anything clinical, as such.

Other participants agreed with this conceptualization, which sees health not in terms of absence of disease but in terms of the number of times one visits a hospital or a doctor. In short, the more one visits a hospital, the less healthy you are:

> I would usually stay well away from hospitals (…) and the less I go there now, the better. (Patricio, 29)

The study also explored how a definition of health may become entangled in notions of masculinity. For example, Serafim's account of his doctor's reaction, as well as that of Leonardo's (31) below, allude to specific cultural values which relate to men, masculinities and health. Leonardo's doctor, upon discovering he was HIV positive, became:

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[67] Herzlich (1973) identified three different conceptions of health, including 'real health' which Herzlich considers to be health as a sense of equilibrium.

[68] *Saúde de ferro* literally means 'health as strong as iron' and could be translated as having an iron constitution.

very anxious… he kept saying it wasn't right that such a young man was involved in a situation like that so soon.

Specifically, these accounts suggest that the medical profession reinforces and perpetuates prevailing notions of health and illness, in particular when patients are male – as there is an expectation that (younger) men are meant to be more resistant to illness. Moreover, younger men must be strong in order to secure a job and maintain a family. This expectation is intimately related to other notions of health, particularly when participants spoke of health in terms of "not taking any medication" (Luciano, 37), being "autonomous" (Samuel, 48), "being fortunate" (Salvador, 36) or "being productive to society" (Gaspar, 44).

When it comes to defining illness, a few accounts were clearer in defining it as something that was limiting, degrading and incapacitating:

> everybody thinks this [illness] is one thing and it is not. It's a few limitations, emotional and psychological limitations instead of a practical issue. (Valdemar, 40)

> No one likes to be ill. No one likes to have something that can mean that at any given moment they're totally dependent on others. (Paco, 42)

The literature is replete with differing conceptualisations of health and illness. Herzlich (1973), for example, conceptualised illness in three ways[69] as being destructive, liberating or an occupation. From a different perspective, Parsons coined the term 'sick role' to encompass the set of rights and responsibilities pertaining to patients' and doctors' behaviours within society. Both examples, despite being widely recognised and to some extent useful in understanding health and illness, are

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[69] See footnote 67.

somewhat abstract and imply a level of generalisability which is questionable. Also, in these conceptualisations, health and illness do not appear to be fluid and flexible concepts, but fixed entities. Crucially, concepts of health or illness can change, depending on age, context, and so forth.

For example, Luciano's (37) notions of health and illness were altered by his diagnosis of HIV. There was a significant adjustment to what health and illness meant in the light of his being in closer touch with his own mortality:

> I did not use to care at all with my health. I wasn't bothered at all. I always thought my body would sort it [minor illness] out. (…) [After HIV diagnosis] In the initial phase if I had a cold or something really light, I used to get all worked up and worried. Thankfully my doctor helps me deal with my dramas, even if this worry is now constant.

In this particular situation, there was a shift in ownership of health. Initially, health was a taken-for-granted state of wellbeing that was shattered by an HIV-positive diagnosis. Luciano reacted by taking ownership of his illness and managing his concerns, doubts and anxieties through getting support and attention. This process, which is not as straightforward as it may seem, was accompanied by a re-interpretation of himself in the light of the new reality. Other men, after being diagnosed with a life-long illness, may never reach a state of ownership (which is sometimes revealed in the form of acceptance of their condition). For example, a long-term partner who kept a secret 'double life' allegedly infected Filipe, and that was one of the reasons he found it hard to adapt and accept this new reality. Filipe explained how painful it was finding out he was HIV positive, mostly because:

> [I] did not do anything to get this, but he [my ex-partner] did. (…) I will die with this angst inside me.

When someone is diagnosed with HIV – or in fact any chronic illness – a process of adaptation to their new condition is initiated. Examples of this can be found in the

models suggested by Karsl and Cobb (1966) and Dingwall (1976). Both models focus on behavioural responses to illness, and highlight the fact that adapting to a new illness is mostly an individual experience. Nevertheless, as no one exists in isolation, other people's responses[70] have an essential role to play in adapting to a new condition. Thus, attention must be given to the ways in which others respond to an individual's new diagnosis.

In the current study, other people's responses varied greatly and carried meanings that impacted on the ways in which respondents experience health and illness. More frequently, it was through discourse that people expressed their feelings about and understanding of this new illness – HIV infection, in this case. This could occur by avoiding direct reference to the particular illness or, most commonly, utilising codes to tone down its negativity. For example, Valdemar's (40) parents knew about his HIV status but avoided talking to him about it at the beginning. More recently, though, they made reference to HIV at their Sunday family lunch:

> Sometimes they ask me how my cholesterol is. At first I was caught off guard as I didn't know what they were on about. Then I realised that they meant HIV. They ask me if I've been going to check my cholesterol, and if everything is ok …

This statement implies that Valdemar's parents conceive of HIV in a similar way to cholesterol: both are identifiable through the blood. Valdemar's parents used one characteristic to redefine their notion of HIV, as if to say there is something wrong with Valdemar's blood, but are not sure what it is. This process of redefinition can be seen either as a form of denial, as a simple misconception or potentially a genuine attempt to engage supportively. Likewise, Paco's (42) parents referred to his "going to hospital" as a way of implicitly referring to his health status. In other words, if he

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[70] Other people here refer to those in close contact with the respondent, as in family members, friends and partners.

attended his hospital consultations, he was being looked after – which translated into his illness being under control.

Finally, as happened in relation to notions of masculinity, health and illness were sometimes framed in relation to sex. In particular, stemming from an interpretation of health as a reserve of vitality and strength, men seem to frame health in terms of being sexually able. Illness corresponds to its counterpart, i.e. the inability to perform sexually due to physical or psychological impairment:

> Living with this illness means I'm limited in terms of sex ... I can't do everything as I used to (...) then there are some side effects too, that affect [sexual] performance (Pedro, 50).

Specifically among those who self-identify as gay, sexual health seemed to be more commonly brought up than among the other men who took part in the research. This may be because men who have sex with men have been widely researched concerning their sexual health as a consequence of HIV. There is an underlying association for these men with a medicalised discourse to which they can relate more closely. Similarly, gay men referred to notions of (sexual) risk more often, which provides for a useful indication of health in terms of risk.

Semper tutis[71]: negotiating risk

Courtenay (2000) has argued that men tend to be less worried about their health and that they seek care less often than women. Men are also known to be more likely to adopt risk behaviours, and are therefore more likely to suffer ill health as a consequence. Most participants in the study reported a level of detachment from risk

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[71] 'Always protected' (Latin)

behaviours such as unprotected sex or the use of dirty needles for injecting drugs. In more than half of their accounts, the notion of 'it will only happen to others' featured as a detachment from a real assessment of risk. It is unclear though as to what extent this detachment was cultural or gender-based. People's motives are multidimensional and complex, allowing for a range of interpretations that may go beyond simplistic ideas of detachment. Some people may flirt with danger, perhaps because they feel immune or because they genuinely seek risks and their consequences (Halkitis and Parsons, 2003; Wolitski, 2005; Balán et al., 2012).

When the notion of risk is engaged with in health-related studies, there is often a compulsory moral agenda attached to it, for example, through the idea that someone should not engage in certain behaviours because they are not morally acceptable. Men are often expected to take risks in society. In doing so, they correspond to social expectations. Notwithstanding this, sometimes conceptualisations of risk fail to recognise that men may take certain risks in order to avoid others. For example, when describing how he thought he might have been infected with HIV, Leonardo explained:

> I had cancer, (…) which left my body really weak. I was quite depressed as well, and I think that the risk behaviour I had was almost like an acknowledged irresponsibility, which was like a leftover from the other situation [cancer]. I was so taken by the feeling that life wasn't worth living, and so physically low, that I decided to go and do that stupid thing [having unprotected sexual intercourse]. I knew it was not right, but at least it would make me feel a bit better about myself, being liked and all.

This highlights something of the complexity of motivation suggested above. Here, Leonardo did not seek risk because he felt immune, but because he was vulnerable and confused – and the engagement with risk acted as a sort of safeguard for his own self-confidence, shown through expression of "being liked" by others, or being sexually appealing.

For Paco, his experience of dealing with his diagnosis led him to engage in different risk behaviours, such as the use of stronger drugs:

> When I knew I was HIV positive, I started using heavier drugs ... I would tell people that I was fine and under control, but I wasn't. In a way I knew I was taking drugs not to feel a thing, not to go back to having careless sex with people. (...) I just stopped having sex altogether.

Additionally, Paco was driven to adopt a risky behaviour in order to overcome the temptation of another greater risk, based on his own assessment. The use of stronger drugs meant a lower libido, and therefore a lower likelihood of engaging in (unprotected) sex. His actions also revealed a concern to protect others: he stopped having sex as he knew whenever he would engage in sex again, it was likely that it would be risky. In a way, some form of ulterior health protecting behaviour that had a risky practice at its foundation.

Despite both examples focusing on individual experiences of risk, they sometimes involved more than one person, either because one of the actors took into account the perspective of the other as an active participant in the risk taking or because there was a shared desire for risk. In the study, some participants related to the first of these ideas:

> There was this guy I was dating and at our first time [having sex] I said, I am going to get some condoms, and he said, 'Do you really think it is necessary?' I was like, 'I'm not sure, I'm conscious of what I am, or what I've done ...' And he said he was too, so we decided it wasn't necessary. This was the only time we did it unprotected from the beginning. In all others there was some discussion and a mutual agreement in that at certain times we would no longer use condoms. (Agostinho, 43)

In this quotation, negotiation leads to an engagement with risk. However, negotiating risk can also act as a formative experience, adding to knowledge and providing insight which may lead to the adoption of safer and healthier behaviours:

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> Until I met my ex, who was HIV-positive, and so we had to use condoms, I had no idea that there was such thing as a condom. Until that time, I couldn't care less about condoms in any situation, be it in sex with men or with women. (Pedro, 50)

As happened with Pedro's partner, most HIV-positive men in the study reported a strong practical sense of prevention, by adopting safer sex practices regardless of what their partners wanted. This practice encapsulates a triad of meanings: it is concomitantly an altruistic, a self-protective and a disclosure-reducing measure. It is altruistic because often it has the other person's best interest at heart and the desire not to put him at risk of becoming infected with HIV. It is self-protective because sometimes men did not know the health status of their partners, and therefore whether they might be placing themselves at risk too. Finally, it reduces disclosure because by being self-protective, men were also able to avoid discussing safer sex, and thus disclosure of HIV status and the potential of being shunned by their sexual partners.

This analysis has shed some light on the complex notions of health, illness and risk among a group of HIV-positive Portuguese men. Men tend to conceptualise health and illness in various ways: as a non-concept; as the absence of illness; or as a measure of productivity and fitness. However, all participants in the study were living with HIV, and therefore had to reassess their interpretations of health and illness in the light of this. These reassessments provide useful insight into their attempts at maintaining a hegemonic male identity, and this is what this chapter will subsequently focus on.

Living with a chronic illness: a narrative analysis

By definition, a chronic illness is "any disease or disorder that continues over an extended period and causes continuous episodic periods of incapacity" (Russell, 2009, p.165). Both acute and chronic are culturally defined categories of illness, which differ in more than just their time spectrum. In fact, as Scandlyn (2000) explains:

> metaphors for acute illness arise from the arena of war (…) [whereas] metaphors for chronic illness are drawn from the language of business: symptoms are managed, support systems are organised and regimens are designed. (p. 131)

HIV infection, initially considered to be a fatal acute disease, is increasingly regarded as a chronic illness in Western countries, yet it is still framed metaphorically using war terms[72] ('fighting the virus'). Highly active anti-retroviral therapy has allowed people living with HIV to experience less ill-health as a consequence of their infection, it reduces the progression to AIDS and has led to healthier lives with increased life expectancy. Nevertheless, HIV is still a condition that requires personal adjustments and a certain level of dependency. Moving from an acute and fatal infection to a chronic illness has an impact on the way people understand, approach and live with HIV. However, HIV has encountered a 'crisis of identity'[73] as remnants of its earlier representation remain and interact with aspects of a new and emergent identity.

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[72] Bastos (2002) also added that a bellic terminology is common in the biomedical discourses in infectiology. She argued that Sontag (1979)'s argument, who wrote extensively on war metaphors and its use in illness discourses and called for a cessation in using metaphors in all medical situations, required a significant paradigmatic shift in understanding of illness as we do it now. (War) metaphors are ingrained in the current scientific and social understanding of illness, and have been so for years.

[73] I will use this term to describe a period of complex analysis and exploration of distinct and different ways of interpreting HIV at social, political, cultural and individual levels.When referring to the 'identity' of HIV, I am referring to the complex make-up of both the social and clinical representations and individual experiences of living with HIV.

Strauss and Glaser (1975) were among the first sociologists to study chronic illness, focusing on how there is more to chronic illness than its associated biological dysfunctions. Chronic illness represents a process of negotiated reality in which individuals engage in whilst adapting to it. Their interactionist focus was shared by Bury (1982) who, through analysing narratives from a number of people with rheumatoid arthritis, concluded that chronic illness constituted a form of 'biographical disruption', which differed significantly from the relatively fixed Parsonian notion of sick role[74]. Bury highlighted how chronic illness affects daily living, the establishment of relationships and notions of self, and the coping strategies and styles[75] that are needed to manage chronic illness.

Upon being diagnosed with a chronic illness, individuals initiate a process of recognition, self-analysis, adaptation and restructuring of their disrupted self. Bury's proposed framework for understanding chronic illness focuses on a set of three time-specific stages, which he named in relation to the segments of biography most disrupted: (i) disruption of taken-for-granted assumptions, (ii) disruptions in explanatory systems and (iii) disruption in mobilising resources. As these three aspects usually relate to specific (and often opposite) tensions that may occur during the different stages of adapting to chronic illness, I propose an alternative framing of this approach in order to facilitate current analysis and understating of events as they

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[74] Parsons (1951) asserted that, in adopting the sick role, patients are under a social obligation to get better and as soon as possible, which is virtually impossible in some types of chronic illnesses.

[75] Bury (1991) suggested that adaptation to chronic illnesses includes the assumption of a number of strategies and styles as well as a variable level of coping. He distinguishes between these terms, and alerts us to the fact that often coping is referred to as being a strategy, when in fact it is merely a range of cognitive processes "whereby the individual learns how to tolerate or put up with the effects of the illness" (Bury, 1991, p.460). Strategy relates to actions, i.e. what is done by chronic illness sufferers in order to carry on – and not the attitudes people develop. Finally, style is, in Bury's terms, "the way people respond to, and present important features of their illnesses or treatment regimens (...) which involves considering the cultural repertoires that people can draw upon and fashion in presenting their altered physical appearance and social circumstances" (p. 462).

occur. Bearing in mind that stage theories like Bury's often emphasise a somewhat fixed and static notion of the different phases, they do not allow for the necessary degree of flexibility that should be in place when studying people. Therefore, the following analysis will focus on the processes of adaptation to chronic illness in relation to three stages of tension: (i) discovering/concealing; (ii) developing/declining; and (iii) settling/disarranging.

Discovering/concealing

It is well documented that an HIV-positive diagnosis can initiate a complex and troublesome journey affecting possibly all aspects of one's life. As was argued in chapter 2, HIV has always carried with it a range of negative and stigmatising connotations, which have informed discriminating practices all over the world, at personal, community and national levels (Ogden and Nyblade, 2005). The development of ART has meant that HIV is now a more manageable condition for those who can access treatment. This is the single most important factor contributing to HIV infection no longer being considered the fatal infectious disease it once was. However, HIV does not necessarily share commonalities with other, more mainstream chronic illness like arthritis or diabetes.

The first reason for this relates to the way it is usually diagnosed:

> One of the most important features of chronic illness is its insidious onset. Non-communicable diseases do not break out; they creep up. (Bury, 1982, p.170)

In fact, as insidious as HIV can be – certainly when taking into account the way

people can find out about it when least expecting it – it does not *creep up*[76] as such,

nor does it *break out*: it is diagnosed upon going for an HIV antibody test. Its initial

symptoms, which tend to occur within the so-called period of seroconversion, or

Primary HIV Infection (PHI), are often overlooked or mistaken for a common cold or

associated with other conditions. This may be at least one important reason why

many men in the study reacted with shock and surprise upon discovering their HIV

status:

> I used to go for annual check-ups and at that time I was not expecting it at
> all... When I got the letter from the clinic, as I usually got after those exams, I
> did not open it for thinking it was all ok. It was only after a few days that I
> opened it and could not believe it. Initially I thought that was not mine. That I
> was reading it wrongly. Positive means not having it, and negative means
> having it... you know... but when I came to my senses I rang the clinic to
> confirm. And then I felt really angry and upset. (Agostinho, 43)

Similarly to rheumatoid arthritis in Bury's (1982) study, the initial process of HIV

diagnosis may not involve any other person apart from the one being diagnosed and

the one diagnosing. This may vary[77] but when in a one-to-one context, it allows for

the person being diagnosed to be the sole manager of that piece of information, and

thus reveal or conceal their status in a variety of settings and contexts. Additionally,

reacting with shock and anxiety may also relate to a level of difficulty in

understanding exactly what living with HIV may mean, including attempts at

positioning oneself within pre-conceived notions of those 'who get HIV'. These

notions are often (and indeed unfortunately) related to early conceptualisations of the

epidemic in terms of risk groups (Dawson et al., 1991). This is particularly important

when considering how studies in Portugal have shown that, despite engaging in risky

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[76] It may indeed "creep up" in a different way, though. For example, when it refers to the
newly diagnosed to think back of past risk behaviours – but it does not creep up in the same
way as most other chronic illnesses, and certainly not in the same way as Bury has referred
to.

[77] For example, Cristiano (38) was diagnosed after being admitted to hospital for another
severe illness. As he was admitted in a coma, and stayed in that state for a while, his family
and close friends were informed of his HIV status at that time.

sex, people still think they are not at risk of contracting HIV because they are not members of particular risk groups (Amaro, Dantas and Teles, 1995).

In Portugal, as in other contexts, HIV infection is socially constructed as a disease of those who take risks, namely injecting drugs and unprotected sex. But even those who engage in these practices sometimes fail to understand that they may be at risk, adding extra layers of complexity not only to the social representation of HIV but also to the ways in which these representations directly influence each and every individual. Most men in the study, some of whom had injected drugs as well as engaged in unprotected sex before being diagnosed, found it difficult to accept that they might eventually become infected. This reveals a tough barrier for health promotion – people who are more at risk of HIV may seem less capable of understanding or consciously denying the risks they are exposed to. This was perhaps more true in the early days of the epidemic, when most men in the study were diagnosed – than it is now. Yet, in Portugal, infection has always been increasingly found among heterosexual men and women, who have paradoxically been seen as 'outsiders' in HIV prevention discourses and practices.

In addition, during the initial phase of finding out about HIV, the individual is faced with the challenging decision to disclose or not, to significant others and outsiders. As previous research (Chaudoir, Fisher and Simoni, 2011; Serovich, 2001) has shown, disclosure is more likely to occur either later in the development of the disease or when individuals understand the positive outcomes of disclosing, namely the possibility of gaining support and/or access to treatment.

Men in the study acknowledged the difficulty in dealing with disclosure right from the moment of diagnosis. For some, their HIV status was a *secret* that should be kept from most people, and one that needed to remain so. A few men said they still kept it

as a secret that only a very limited number of people knew. There was a clear distinction between disclosure to formal support structures – seen as acceptable albeit not compulsory – and disclosure to others – seen as extremely exceptional. Possibly one of the most significant situations in which disclosure could occur was when establishing new sexual relationships. Some men had experienced rejection following disclosure; others did not want to go through that, and therefore chose not to disclose. One of the most striking quotes came from Gaspar (44), who decided to disclose to his partner in the early days of their relationship, with the following outcome:

> She came to talk to me and said, like, things were over. She said we weren't compatible. I found the whole thing very odd, very strange ... Why then? Why not before?

This sole episode traumatized Gaspar into adopting a strategy whereby he only had sex with HIV positive people thereafter. Others chose not to become emotionally or sexually involved with anyone, thereby avoiding being in a position in which the need for disclosure would emerge. But, more commonly, men would engage in casual sex only, which had the advantage of allowing a certain level of detachment and anonymity, as well as making condom use easier.

Non-disclosure was sometimes understood in terms of potential health gains:

> I don't feel unwell, and have not been unwell – so I can live my life normally. There is no need to tell anything to anyone as I hardly remember I have this. If I was to be ill or to be admitted to hospital and so on, then I would have to explain that to people. As I am, healthy and feeling good so far, I don't feel that need to tell. (Paco, 42)

Bury (1988) might call this a situation of 'meanings at risk', i.e. when responding to chronic illness, people examine the meanings attributed to their particular situation in relation to their everyday experiences. Apparently, HIV did not affect Paco's identity,

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and would only do so in the case of him being admitted to hospital. In a way, this reveals Paco's need to justify disclosure as acceptable only in the face of appearance of symptoms, which, in a medicalised society, is a socially accepted way of adopting the sick role.

Developing/declining

Following the initial phase in which individuals are faced with a HIV diagnosis, and tensions appear surrounding disclosure, people tend to search for information about their condition, and try to answer the questions Why me? Why now? (Bury, 1991). In short, people may go through a re-evaluation of the self in relation to a new identity, and, in order to do so, "medical knowledge takes on particular importance" (Bury, 1982, p. 172), even if that is not the only form of knowledge that is sought or even relevant.

It is by using medical knowledge, as well as other conceptual tools, such as spiritual, philosophical or alternative forms of support, that individuals construct notions of their illness. In doing so, some may come to look at their illness as something external or foreign, that has taken over their bodies and does not belong there; others acknowledge their illness as just another aspect of their identity, and an intimate part of their being. More commonly, though, the narratives of the men in this study oscillated between both interpretations: a feeling that HIV was not quite an essential aspect of their lives, in spite of having taken on most of its dimensions.

Additionally, and despite most men agreeing that in the initial phases after diagnosis they avidly sought all the information they could access, this incessant search for insight faded away – sometimes completely – as the disease progressed and the relationship with the diagnosis was altered. Seeking information is one of the most

common strategies of dealing with the anxiety caused by diagnosis. The purpose is not to become an expert but to find suitable advice, anything that will put the mind at ease. Agostinho (43) said that at the beginning, he "would devour anything about HIV that he would find! (...) nowadays, I don't really mind".

Samuel (48), on the other hand, had an extensive knowledge of the different treatment regimens available and said he would often make his doctor search for specialist information to answer some of his questions. He was also keen on supporting other people and empowering them to be more proactive, as he himself found that most people living with HIV were paradoxically a mixture of passive receptors of medical care and unsatisfied people with their heads full of questions.

This opinion was shared by Leonardo (31) who thought "most doctors are not ready to deal with a patient who wants to know about their illness". He said he adopted a strategy of getting as much as possible from each consultation, so as to make the most of it. This is a classic example of one of Bury's (1991) so-called 'strategies' in adapting to chronic illness, i.e. as one of the actions or processes that people can use to better manage their condition[78].

As well as gathering information, it is usually during this phase that individuals seek specialised support and care, and thus establish client-provider relationships within clinical or social support institutions. All men in the study reported receiving care from a specialist physician within a hospital, and some also accessed social support from non-governmental organisations. In general, men were satisfied with the level of support and care they received from both sectors, with some of them feeling lucky and thankful to have such good level of care.

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[78] See footnote 75 on page 144.

As far as health care support was concerned, all narratives were focused around one person: the specialist physician. The medical profession, representing science and knowledge, holds a great deal of power within the various institutions in which men sought care. This also highlights the high level of medicalisation in Portuguese society, and the power of medicine in society more generally (Carapinheiro, 2005). Men in the study respected this power and very seldom challenged or even questioned any of their doctor's decisions. "I will do whatever my doctor wants ..." was a recurring refrain. However, some men were keen on broadening their own knowledge of the disease and treatment options so as to, together with their doctors, make informed decisions.

As pointed out earlier, it is also during this phase that individuals often question why they are the ones affected by a chronic illness, and why did this occur at that specific time in their lives. When it comes to HIV infection, the responses to these questions may differ from other chronic illnesses. Often, people may be aware of what situation in particular was responsible for causing infection, and when it occurred. In Bury's (1982, p.175) study, some participants explained that rheumatoid arthritis was the result of "shocks to the system", or being exposed to a series of difficult events that would eventually trigger the onset of symptoms. Similar narratives were found in the current study, particularly Leonardo's earlier account of how he got infected after engaging in risky sex as a way of overcoming the effects that cancer had on his body and mind.

In this case, the perceived trigger for engaging in risk behaviour was a low level of self-esteem allied to lethargy and debilitation due to other health issues. A certain level of vulnerability and confusion led Leonardo to engage in risky sexual behaviour, but, despite this, there is a resemblance to the notion of "shock to the system" described by Bury (1982).

A similar explanation was given by Gabriel (52) to explain a significant drop in his CD4 levels. According to him, the drop occurred because of all the stressful events he went through in a particular period of time, including divorce, a judicial action, unemployment and poverty. In any case, the acquistion of HIV is a far more morally loaded sitation compared to arthritis, so narratives of blame and responsibility in acquiring HIV are especially complex.

Settling/disarranging

In his analysis, Bury (1982) considered the third phase of adapting to chronic illness to pertain to disruptions in the mobilisation of resources. These include, but are not limited to, the array and networks of support that people have in place before living with a chronic condition, and how they manage to keep, change or remove these after that disruption.

During this phase, there is a tension between settlement and disarrangement as this is the phase in which the individual, while not at the very early stage of living with a chronic illness, initiates a process of adapting (settling), using a range of strategies and coping mechanisms to overcome some of the difficulties that may arise. It is also during this phase that s/he will typically mobilise resources and engage with support networks. Failing to do so may result in difficulty in accepting the diagnosis and failing to receive the right support, leading to further issues and even ill-health. While one must acknowledge that any stage model like Bury's may appear to be prescriptive of people's behaviours and practices, it is still useful to explore the different disruptions that tend to occur with people living with a chronic illness.

Of particular importance with respect to adaptation is the disruption that may occur

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within family or friends' networks, as well as other activities (including employment) that are crucial to one's role in society. At the time of the study, managing to maintain a similar quality of life after diagnosis was the goal of most participants. Some had endured difficult times, in which withdrawal from social activities, unemployment and rejection in interpersonal relationships were common. Reasons for this were varied but often included the side effects of ART. One man mentioned the time when his medication had such a strong effect on his body he could not leave the house as he had to use the toilet many times throughout the day. Others described suffering from depression and isolation, derived from an anticipated fear of rejection when trying to establish new relationships. More visible side effects, such as lipodystrophy, can cause individuals suffering from them to engage in radical changes such as remaining in the house for fear of being stigmatised in public, or exposed to the gaze of others. Some men pointed out that they were happy with the fact that their treatment regimens had never caused them the "wasting of the face and cheeks", regarded widely as a visible sign of being HIV positive.

Similar to the analysis by Bury (1982), one must bear in mind that managing a life with chronic illness is deeply variable according to a range of social factors such as social class, age or gender. Some men in the study endured severe financial difficulties after being diagnosed, and failed to return to paid employment until they accessed social support from some of the organisations that collaborated in the study. Others, though, such as Luciano (37) and Filipe (54), were from higher social strata, and were able to access medical support privately whenever convenient for them. One of them (Filipe) chose to take early retirement as he could not face the idea of having to work whilst living with a chronic illness. These were well thought through decisions that people made in dealing with the impact of living with HIV. In other words, men engaged in a number of coping mechanisms and strategies to adapt to their condition.

One example of coping is what is commonly known as 'normalisation', which refers to incorporating all aspects of the illness within the person's normal routine, so as to have as little negative impact as possible. Some men in the study had similar coping mechanisms, and some have even referred to normalisation as an essential process to overcome the initial difficulties in living with HIV. "[HIV] needs to be normalised, (…) [despite it being] less severe these days than it used to be", mentioned Mateus (39), even if normalisation in this quotation is more directly related to the social representation of HIV than to the individual processes that take place in adapting to an HIV-positive diagnosis.

Additionally, Leonardo (31) said that:

> people that live with HIV for a long time have naturally gained a sense of defence, I mean, they know how to deal with difficulties better and to react to life's adversities.

In other words, adapting to a life with HIV involves engaging and developing a range of coping mechanisms and strategies that help those affected by HIV to manage in the long term. And it is when focusing on coping mechanisms and adapting strategies that narratives gain a 'progressive' tone (Robinson, 1990)[79]. For example, some men who had been living with HIV for over ten years described their experience as not "being the end of the world" (Agostinho, 43). Gabriel (52), who described his initial reaction to diagnosis as feeling that his whole body was "toxic", added that nowadays, he would:

> see this disease in a whole new light, as we have to readjust to it, and learn how to live with it… I feel less toxic now, as I feel more at ease with what it is

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[79] Robinson (1990) studied patients with multiple sclerosis and found that those suffering from it for a long time would more often engage in a more positive response to illness, which was visible in discourse and narrative analysis. This is in line with the notion of finding a positive side to a disrupted identity, which as seen before, is also common for people living with HIV.

like having HIV.

Despite an apparent sense of accommodating to the diagnosis, which is in fact achievable and well documented in the data collected for this study, the apparent smoothness of trajectory is often interrupted by particular situations that affect adaptation to living with HIV in a positive and constructive way. Distinctly, what some men termed "the waiting area syndrome" was both upsetting and difficult to cope with. This syndrome refers to the fact that some men, while waiting for a consultation in the hospital, would fail to acknowledge others within that setting, despite having previously been acquainted. Patrício (29) was particularly annoyed with this, probably due to only recently being diagnosed at the time of data collection, and already had experienced it a few times. Others would mention it in conversation, as being a taken-for-granted aspect of their health care experience – which was heavily frowned upon, but unlikely to change. The causes for this syndrome were often linked to feelings of shame, drawn essentially from a process of 'othering': if I do not acknowledge you, I am not like you, I will not look like I am like you to others, and I will not be able to be so labelled.

Finally, living with HIV could also be characterised as a positive and enriching experience. Some men were keen to explain that HIV did not currently play a central role in their lives, as it certainly had in the past. Salvador (36) explained this as follows:

> I have had many types of attitudes towards HIV. When I was using drugs, HIV was a reason for victimisation. Today I don't think it is. I didn't want to shock you when I say this, but today it is more of a good thing than a bad thing. It is more a reason for inspiration to continue living my life the best I can. I rather have a positive attitude now.

A similar view was expressed by Gaspar (44):

This is a situation no one would like to be in. No one likes to have a disease that can be fatal (...), I would rather not need all the support I receive. (...) But despite being a bad thing, there are always positive things to take out of those bad things. There are a lot of things that I now know about myself, feelings, emotions, that I only know because I went through the experience of using and stopping drugs. That has allowed me to understand much better some of the things that I wasn't aware before, so, to an extent, this path was not that bad.

By weighing both negative and positive aspects of living with a chronic illness, most men managed to reach a stage in which their condition is more or less incorporated into their daily activities. As most had lived with HIV for some time (the majority were diagnosed in the 1990s), this allowed them not only to have passed through a number of phases in dealing with their illness, but also to engage in some level of introspective thinking which, like in Gaspar's quote, emphasised the positive aspects of living with HIV. The balance between the sufferer and the survivor is therefore visible in some of these accounts.

Chapter summary

Health and illness, as well as risk, are social constructs that influence behaviours, attitudes and practices and therefore may impact on the way each individual responds to a diagnosis of a chronic illness like HIV. Being ill is, to most people, ideally a relatively temporary situation that requires some level of adaptation in order to regain an optimum sense of wellbeing. However, chronic illness, which is permanent rather than temporary, can initiate a process of self-discovery and adaptation, in which strategies and coping play a central role in managing anxieties and expectations. In this chapter, a number of narratives pertaining to notions of health and illness have been explored. HIV currently holds a unique status in that it is concomitantly regarded as a fatal infectious disease for some – which makes some

sense in certain parts of the developing world – and as a chronic illness for others –

in particular in the West. Bury's framework, even if potentially static and inflexible at

times, proved useful in delineating potential routes that men living with HIV may

navigate in the path to adapting to their disrupted biography. Finally, this chapter

also focused on the fact that chronic illness gives the person experiencing it a regular

presence in strongly medicalised arenas – which in turn may generate power

struggles and/or motivate the pursuit of better understanding of disease through

expert knowledge and specialist information.

Chapter 6

Uma nova côr[80]: men living with HIV in Portugal

Prometo não falar de amor, de gostar e mentir
Portanto não vou lidar com amar e sentir
Joga-se pelo prazer de jogar e até perder
Escolhem-se poros, trocam-se beijos sem escolher

Até são retratos de solidão interior
Não há qualquer tragédia, mas um vinho a beber
Partidas, regressos, conquistas por fazer

Homens sempre sós são bolas de ténis no ar
Muito abatidos saltam, acabam por enganar

Tudo apostado numa memória que quer esquecer
Homens sempre, sempre sós preferem perder.[81]

Rui Reininho

Introduction

Having focused on men, masculinities and health as well as understandings of chronic illness, the analysis will now turn to the experience of living with HIV for the men involved in this study. The chapter will focus first on dominant social representations of AIDS, arguing that these impact on men's experiences of living with HIV. In particular, men's varied and sometimes contradictory experiences of stigma and discrimination link closely to tensions that exist in conceptualising HIV at

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[80] "A new colour"

[81] "I promise not to talk about love, about liking and lying. I won't deal with loving and feeling. We play just for the pleasure of it and until we lose, we pick at the skin, exchange unchosen kisses. They are pictures of an interior aloneness. Not one of drama, just of wine to be drunk. Departures, arrivals, new conquests to be made. Men always alone are like tennis balls in the air. When beaten, they bounce, and sometimes they dodge. All of this rests on a memory that we want to forget. Men who are always always alone, prefer to lose."

a broader social level in Portugal today. This chapter will then move on to analysing how the 'HIV careers' of different men are affected by the intersection of these tensions, demonstrating in particular how men in the study actively seek a level of social recognition, while at the same time experience pressures to non-disclose and hide.

Do medo à invisibilidade[82]: social representations of HIV in Portugal

In general, most men in the study perceived HIV as a serious condition still shrouded in myths, misconceptions and ignorance. Society's general lack of information regarding HIV was a major concern for all men, as this affected the ways in which they were able to go about their lives. For Gaspar (44), for example, this severely affected the way he behaved at work:

> It is very hard to manage sometimes. I work in a team of men and it is very common for them to joke – Look at that one over there, dying of AIDS! – and they have no idea that I have that kind of problem too. I can only think it is ignorance. (...) And this ignorance is not only amongst uneducated people, which is part of the problem.

Valdemar felt the same way, perceiving HIV as similar to other little known about illnesses, such as avian flu:

> Everyone is alarmed because they know nothing about it. Until there is a bit more information everyone will be frightened about it... and that is what has always happened with HIV. (Valdemar, 40)

He went on to explain how HIV positive people were often seen as *coitados*[83], a derogatory term applied to vulnerable people who have brought misfortune upon

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[82] 'From fear to invisibility'

themselves. Another man considered HIV to be the "bogeyman of illnesses", with people in society being:

> ignorant and hypocritical. I see many TV shows where they talk about HIV, making it all sound very nice but when it comes to the day-to-day, and when the situations affect them personally, their reactions aren't consistent with what they say. (Salvador, 36)

The mass media were regarded as responsible for propagating outdated ideas about HIV still being the fatal and highly infectious disease of the 1980s. This portrayal was, according to Martim (40):

> the main cause why I dealt with my diagnosis in the beginning in such a bad way. When there was any mention of HIV in the media, all I saw were images of really ill people, in bed and very frail. I didn't see images of healthy looking people; people working!

For Pascoal, in speaking about society at large, HIV has:

> lost momentum and is no longer in the spotlight, which is both a good and bad thing. The overall perception was frozen in time, so all people know is that they need to wear a condom – but still, only if you're in a 'risk group'.

He felt "revolted" by constantly seeing sensational headlines and bad press for HIV. According to him:

> HIV has changed but not the approach of the media and society in general. I find that media are useful in alerting people to the fact that HIV exists, but they also fill people's heads with idiotic ideas.

Respondents made frequent reference to the fact that:

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[83] The term "coitado" originally derives from the term "coitus" or sexual intercourse, and refers to the passive subject of coitus. Its use in the Portuguese language is usually associated with the man who has been cheated by his wife, or with someone unfortunate, pitiful and miserable (Porto Editora, 2009).

they [the mass media] just mention HIV on December 1st [World AIDS day], and then it is ignored for the rest of the year. Sometimes prevention comes up, yet still in reference to 'risk groups'. (Samuel, 48)

Samuel alluded to risk groups still featuring in contemporary discourses, despite much HIV work having shifted its conceptualisation to focus on risk behaviours.[84] Mention of risk groups, an enduring leftover from the early days of the epidemic, has negative consequences both for people's representations of the disease itself and for individual perceptions of risk, as pointed out earlier. In practice, notions of risk groups in Portugal are still charged with prejudice.

Among all men interviewed, the general opinion was that HIV is still regarded as a "gay disease" in Portugal, even if the country's epidemiological data have always shown that most infections were acquired via injecting drugs. One of the professionals interviewed referred to this as follows:

HIV in Portugal is still a disease of certain groups. If the person is white, heterosexual, with a stable partner and a so-called normal life, it's hard for them to think they too are at risk. (Alice, social worker)

The fact that HIV is so strongly associated with sex between men is especially problematic for people living with HIV who do not belong to such category. Cristiano (38), for example, said that it was only recently that he had started to come across media images of heterosexual or African people living with HIV, both groups which had traditionally not been associated with the epidemic in Portugal. He felt that it is important to let people know that this is a "global disease that can affect anyone". As a Black heterosexual man, he felt there was little societal visibility for people like him

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[84] Risk groups have been and remain one of the most enduring and widely used analytical tropes in HIV prevention, even when there are subtle changes of emphasis. For example, recent work talks more of most at-risk populations (MARPS) (see, for example, Kurth et al., 2011) or structurally vulnerable populations (see Rhodes et al, 2012 but also Lambert, 2011 for a critical review of this approach). Similarly, in relation to other epidemics, the notion of risk group is still widely utilised (e.g. WHO, in relation to malaria) (WHO, 2012).

living with HIV in Portugal. Initially, this had been a barrier to seeking support, as he did not fit the pre-conceived idea of a typical HIV positive person in Portugal; the same notion he then was forced to challenge in order to fully engage with services. A similar concern was expressed by Serafim (58), a heterosexual man who, after being infected through a blood transfusion, felt he was part of "a minority within the minority (…), like a lonely wolf (*lobo solitário*), who is hardly part of the bigger picture".

This notion of membership of a wider group of people living with HIV can, however, be useful for health promotion and health education purposes. As seen earlier, a sense of belonging, tied into notions of empowerment, self-understanding and self-efficacy, can derive from accepting and adapting to a new (yet disrupted) identity as a person living with a chronic illness. Part of the adaptive process however requires some level of understanding of the disease, its symptoms and effects on everyday life. When this is not present, the person may become an outcast within his or her own existence – as a potentially significant attribute of health and well-being may not be well integrated into practical, day-to-day life experiences. This, in turn, may lead to self-stigmatisation and isolation. The practical implications of such processes, like difficulty in adhering to treatment or seeking help, may have a detrimental effect on health status.

Social representations of people living with HIV have traditionally been negatively charged. However, when asked whether there have been any changes in how HIV is perceived by Portuguese society, most men agreed that there had been significant change, particularly with respect to treatment options and clinical management. Notwithstanding this, respondents were quick to emphasise how slow these changes had been, and how these had occurred only after the wider availability of treatment options:

In 6 years of living with HIV I have not seen many changes. Apart from the fact that we can now live longer thanks to new treatments, I don't think much else has changed. (Luciano, 37)

Things are evolving, and people are evolving a bit too, because they notice that the person next door died of AIDS or is suffering with AIDS and that person was cool or still is a cool person, and after all they were the ones being a bit silly with the attitude they were having. (Gaspar, 44)

I think there is a greater acceptance, and there is much more information available, even though I think there is a lot of resistance. All is well as long it doesn't impact on them personally. (Paco, 42)

With respect to social representations of HIV, Samuel (48) said that these seemed to have gone from being driven by fear to a state of invisibility. In other words, when the epidemic first began, it was wrapped in uncertainty and everyone who was diagnosed was given very little hope for survival. Fear was thus explicitly dealt with in every context pertaining to people's health career, be it at clinical, emotional or family levels. As the epidemic evolved, however, the quality of live for people living with HIV improved, Samuel thought that stigma related to HIV infection started to lose momentum and eventually became a non-issue, which in practice meant that reference to HIV was now more absent (something which he called 'invisibility'). Invisibility generated more fear – this time in the form of an implicit, repressed fear, rather than an explicit sense of anxiety. Invisibility was also regarded as an unfortunate consequence of (lack of) HIV prevention activities, which encouraged the idea that HIV had been eradicated. This had caused people living with HIV to enter into a state of social inexistence, and had evoked once again – albeit it in a new way – the notion of *social death*, which was so strongly associated with HIV in the early days of the epidemic (Daniel, 1993).

The concept of social death, or 'civil death' as suggested by Daniel in the early 1990s, originated in his own experiences of living with HIV in Brazil:

> AIDS is an illness like other illnesses and one loaded with taboos and prejudices. (…) AIDS can kill, but prejudice and discrimination are much more deadly. (…) Prejudice kills during life, causing civil death, which is the worst kind. They want to kill people with AIDS condemning us to a civil death. (Daniel, 1993, p.131)

Earlier representations of people living with HIV – often characterised by the prejudice and discrimination Daniel described above – have attenuated in Western societies, to the point of reaching "a state of invisibility", that Samuel referred to. This can be understood as a new form of social or civil death, if we were to borrow Daniel's concept, because the attention given to HIV and AIDS has radically decreased, and people living with HIV have progressively 'disappeared' from the bigger picture.

In the 1980s, enormous sums of money were spent campaigning against the transmission of HIV, often using shock and scare tactics to ensure everyone was aware of the new epidemic, and how to avoid being infected. These messages had mixed results, but ultimately contributed, to some extent, in the observed reduction in new cases that occurred in the early 1990s. In Portugal, the annual numbers of new infections have remained roughly steady since then. However, this has coincided with significant improvements in treatment options, which means that a diagnosis of HIV no longer carries a 'death sentence'. These facts together contributed to a new social representation of HIV as a less fatal and more manageable condition – which it is – but failed to acknowledge that the epidemic is still widespread and assuming new contours, such as an increase in undiagnosed cases, and a generalised sense of complacency towards testing and the consistent practice of safer sex.

There is a reciprocal dynamic here between society and the individual – as changes at the macro level affect individual (micro) practices. The impact these social changes have at a micro level contributes to the social invisibility of people living with

HIV. Similarly, those living with HIV also contribute to overall changes in how HIV is regarded in society. As Samuel (48) argued:

> positive people need to come out like gay men do. Neighbours need to see the healthy neighbour has HIV. (…) But no … because I am a target to discrimination, I protect myself from it, by hiding, by not disclosing. That needs to change, if we want to be seen differently.

In sum, men living with HIV in Portugal described becoming more personally invisible, which in turn compounded their social invisibility. This carried advantages, as living in "hiding", according to Samuel, may offer a sense of protection against popular prejudicial stereotypes of HIV. However, it may also reduce the visibility of people living with HIV outside the clinical spaces they inhabit. This in turn may lead to a general lack of awareness of the needs of people living with HIV – and a subsequent failure to address these. This is a new form of social death.

The above tensions in social representations of HIV also have an impact on the way some men wanted to be perceived – as a patient with one of the most dreadful and fatal diseases ever known, as a chronic disease sufferer trying to go about their lives the best way possible, or even someone who simply does not want to be 'defined' by their diagnosis. Thus, at the individual level, the issue is what to make of living with HIV nowadays – do I want to be recognised as having this virus, and in some ways defined by it? Or do I want the significance of the virus to recede? This dilemma reflects uncertainty and mixed portrayals of HIV at the macro level. As one man said:

> People say that HIV-positive people these days just have to take their medication, be followed up and that's that. But they forget that in the battlefield it is not like that. HIV positive people still have to go through a lot of very complicated problems. (Gaspar, 44)

Successfully negotiating this terrain is complicated. Echoing some of the points made earlier by Samuel (in which he stressed the need for an HIV "coming out"),

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men felt it was important to try to claim back some of the initial attention that had

been given to HIV back in the 1980s and the 1990s, but to show the condition in a

new light – which needs to be realistic[85] and non-judgemental – thereby bringing HIV

back into social life. According to these men, newer representations of HIV should

focus on the difficulties of living with it as well as how living with HIV can be

normalised:

> it is not a disease with *all* that [much] stigma ... There are some limitations,
> but it is more of an emotional and psychological thing rather than practical. I
> mean, what does it matter having to use a condom? Those *are* the limitations.
> And I can't give blood. Sometimes I wish I could, but I can't. So what is the
> big deal? Having to take one pill a day? I don't think that is that big a deal.
> (Valdemar, 40)

For Salvador (36), a major change in perception was only possible if normalisation

took place on a broader scale:

> HIV [should be] dealt with as with any other chronic disease, so that people
> [could] start going to the hospital and get tested. If people can speak
> openly about it, they are more likely to go to the hospital and seek
> help.

Other suggestions included making HIV a more frequent topic in the media (beyond

World AIDS Day) and emphasising the fact that some people had found new and

enriching meanings in living with HIV that helped them see their lives in a more

constructive and hopeful way. Other men felt it was important to have more

prevention work, covering all types of risk, and also more programmes in which

health educators go "into schools, trying to inform people about their behaviours, as

early as possible" (Valdemar, 40). This reflects what most men said in relation to

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[85] Samuel talked of the importance of showing people that the neighbour with HIV is healthy, and can live a healthy life, whereas Gaspar alluded to the fact that HIV is actually a complex disease which can carry a number of symptoms. These two realities co-exist for people living with HIV, and should both be part of a new approach to making HIV more visible socially.

present-day government campaigns, which tended to be "rare, and superficial, created only to justify the funding and without any visible effects" (Paco, 42).

Among respondents, there also tended to be a sense of discontent and lack of hope. One man in particular found it hard to envisage whether it would ever be possible to achieve an optimum level of satisfaction regarding the way others perceive HIV:

> Without wanting to be prejudiced myself, I think people will never understand, even if I try to explain... I will always know it is a different situation because they don't know what is like, or feel what is like. The fact they show interest and want to talk about it, though, is very positive" (Salvador, 36)

One area that was highlighted as needing major attention was HIV-related stigma and discrimination. The majority of men thought that not enough was being done to deal with these issues, particularly through educating people about living with HIV in Portugal. Leonardo (31) explained:

> I find it odd to think that there are so many people living with HIV in Portugal yet I hardly see any campaign or ad on TV and such, like there used to be before. That can make people think there is no more HIV, which is wrong. And this is also a form of stigma, I think. And stigma must be dealt with, otherwise we will never get those rates down.

These ideas link closely to earlier discussion of the invisibility of HIV and the emergence of a new form of social death. According to respondents, invisibility is government-led, in the way that little is being done to make HIV infection visible at the political and therefore social levels. For Leonardo, this invisibility of HIV is itself a form of stigma. However, as explained earlier, for others it is a form of denial or even a form of normalisation of the epidemic. This means that the Portuguese epidemic is currently caught up in an intriguing configuration of all three factors, which in turn affect men directly, in their individual experiences of living with HIV.

"You're not wearing my shoes!": **HIV-related stigma and discrimination**

In spite of changes in the ways in which HIV is represented, lived through and understood, men in this study still made reference to concepts of stigma and discrimination when referring to their HIV status. In fact, these terms appear to have become part of the HIV lexicon to reflect the impact society has upon those living with HIV.

Most chronic illnesses carry some form of stigma (Scandlyn, 2000). And yet, as Millen and Walker (2001, p.90) note:

> the manifest symptoms of any illness can still be at once the triggers for stigmatization for both sufferers and public observers alike. While there is still a stigma associated with individual illnesses such as epilepsy and AIDS (which still carry stigma by association with perceptions surrounding homosexuality) there has been a shift away from wholesale, overt public stigmatisation of chronic diseases and associated conditions in the West.

As these same authors point out, stigmatising processes have been associated with HIV from the outset of the epidemic, not simply when it 'became' a chronic illness. But stigmatizing processes are not fixed and stable, and overall changes in the ways HIV is socially perceived intimately re-shape HIV-related stigma and discrimination. This re-shaping calls for a properly nuanced approach to the study of stigma – one that acknowledges stigmatisation as a complex and multifaceted social process, that can take place in a variety of settings, and indeed assume a plethora of 'forms'.

When analysing men's narratives, one realises just that the experience of stigma is not straightforward. Most frequently, it is reported as discrimination or discriminatory practice. These were reported as pertaining to a range of contexts, but those that seemed to be most relevant to the men in the study took place in two different

arenas: when accessing health care and when establishing emotional and intimate relationships.

With respect to health care settings, and despite having a sense that discrimination occurred frequently, most men actually found it difficult to think of situations in which they personally had been discriminated against due to their HIV status. In general, the most obvious and blatant experiences of discrimination tended to have taken place earlier in the epidemic, for those who have been diagnosed the longest. When situations were described (most of which pertained to incidents in health care settings some time ago), these tended to be relatively serious, having a major impact on the man's life: for example, the episode that occurred during the birth of one of Valdemar's children. While in the maternity ward, one of the nurses who had been looking after Valdemar's wife who was HIV negative but who had a history of substance misuse, allegedly expressed her disapproval towards Valdemar and his wife's decision to have children. Valdemar described this event thus:

> I used to visit my wife every day at the maternity ward, and there was a nurse there that wouldn't miss an opportunity to tell us – you guys, with your life, with your problems … why would you want to have kids? – and all I wanted to do was to throw her out of the window. Someone with a degree shouldn't say things like that.

Pedro (50) mentioned that, despite some changes in the pattern and form of discrimination – less frequent and subtler nowadays – health professionals sometimes felt they need to provide some sort of moral advice, which may come from a genuine concern, but ultimately appears judgmental. For example, when professionals reinforce any advice on reducing the number of sexual partners, or when they ensure patients adopt safer sex strategies, after years of conveying the same messages, Pedro felt he could sometimes do without them, as he has lived

with HIV for many years and therefore is aware of the precautions and adaptations involved.

Other examples that have also been experienced by men in the past included being called in last for a general appointment, the nurse or doctor using two pairs of gloves for examinations, being refused treatment, or being asked to wear a mask. Samuel (48) sued a health trust for circulating HIV-positive people's clinical notes with a visible reference to HIV on the cover sheet. He felt that he had to resort to judicial action on a second occasion to deal with the fact that in some hospitals the names of people living with HIV were called out loud in communal waiting areas – in which there were people waiting to be seen by other specialities. Other patients in such areas commented negatively on the fact that they were obliged to wait next to the sidosos[86]. He said that when he approached the officer responsible for the ward, she did not understand why calling people out by their names was a problem. This particular issue was resolved in that ward, but other men reported this was an ongoing problem in other hospitals. This reveals a clear link between the lack of national) regulatory practices in clinical settings and patients' needs, rights and experiences.

Another example came from Pedro (50), who described once visiting a different hospital to that he routinely attended:

> I was waiting to be called for an examination and I noticed at the bottom of the waiting area there was a board with everyone's names in it, and next to mine it read 'positive serology'. I didn't feel comfortable with that, but kept quiet. After a while, a nurse came to see another waiting patient and tried to put a drip on him right there in the waiting area, but she couldn't so there was blood everywhere. This patient started saying that she should be careful as he had hepatitis C. I looked back at the board and there was no mention of

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[86] The term sidoso (aidetic) is a compound noun derived from sida (AIDS) and the suffix –oso (similar to -ese, -etic). It is used derogatorily to refer to anyone who has AIDS. It was more commonly used in the early days of the epidemic.

that in front of his name, and that was when I felt discriminated against. I asked to be seen by the nurse in charge who I spoke to and who then deleted that note and apologised.

This particular experience of discrimination derived from a feeling of inequity – the initial practice of highlighting one's private information was incorrect all along, yet it was only when that did not apply to another patient that Pedro felt personally affected by it. A similar situation was described by Paco. It concerned a particular routine that was institutionalised within one specific hospital, regarding the drawing of blood for routine check-ups:

> Whenever we had to draw blood we had to go to a specific room where there was a specific order in which patients were received first, the pregnant women, then those who were HIV positive and then all the remaining patients. Those who had to use the service on a regular basis knew that order and that made it all really awkward and tense. They all knew that, after the pregnant women, the AIDS patients would follow.

Paco (42) highlighted that the procedure had been changed since but, at the time, it used to upset him having to go through it. Paco (42) also expressed discontent with another aspect of his health care experience:

> I live in the same area where the hospital is, so sometimes I bump into people that work there. Sometimes, they are with other people … it is complicated … That person is out of duty and the confidentiality is broken. I say 'Hi' to one of the staff, and if there is someone else with them, they'll ask where they know me from, and they'll say I'm one of the patients, so that always makes it hard.

On this occasion, Paco described a degree of suspicion towards professional codes of conduct and those who supposedly must follow them. He assumed that there had been information sharing between those people, yet he did not have enough information to be able to assess whether or not this in fact occurred. In any case, the events caused some distress to Paco, who said he did not fully engage with his health care provider as a result. Despite a certain level of passivity in tackling this

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issue, on another occasion Paco addressed an instance of HIV-related discrimination, which resulted with the issue being dealt with:

> When I had a gallbladder surgery, I had to go to another hospital, so they sorted it all out, but then there was an appointment before that and when I went, the doctor asked me for lots of details, and two days later I got a phone call saying my surgery had been cancelled. They didn't give any reasons why. I was furious and sent a load of emails to the Ministry of Health asking if it was normal to schedule a surgery and then cancel it. I sent copies of these emails to the hospital and after a few days they called back saying it was all ok, that my surgery was back on. I don't know if I hadn't done anything, if I was just going to be put aside?

Significantly, the fact that Paco could voice his concerns taught him how to identify malpractice and defend his own rights. Importantly, all of the situations described are not clear and blatant manifestations of stigma. Whilst practices within them may be regarded as discriminatory, these may be as much stem from lack of information, be linked to the utilisation of a standard procedure or simply lack of thought. This is reflected in the way these situations were described, as both men were not clear as to what drove health professionals to act in that way. In addition, when challenged, apologies did seem to be forthcoming, and practices were changed, which reveals a process of adjustment and awareness raising going on at service level. Despite this, many men felt there was a major gap in training for health care workers, particularly those who did not work with HIV on a daily basis.

Overall, within the clinical arena there appears to have been some changes in forms and patterns of discrimination. Most of the issues reported related to health care professionals whose area of work does not involve direct and continued contact with people living with HIV. This was also reported by the professionals who took part in the study. Most were aware of situations of discrimination that involved health professionals, despite acknowledging a slight change in professional culture – towards one that is less tolerant of discrimination and prejudice.

The other area that was commonly reported to be affected by stigma was the establishment of intimate and emotional bonds with others, i.e. how HIV affected the way men established personal relationships. Often, after disclosing their HIV status, men were rejected. The consequences of such experiences led to isolation, fear and depression. Samuel (48) summed it up as follows:

> If I meet someone for a one-night-stand and I tell them my status, the affair ends there. If there is already some kind of relationship developing, and then I decide to tell, it's an 'anti-charm'. Very rarely it goes beyond that point. Then others seem to find it really cool – I was once approached by a bug-chaser[87] – but in that case I was the one who wasn't interested.

Samuel eventually resorted to a form of 'sero-sorting' – choosing sexual partners based on the basis of the same sero-status as himself, as a way of avoiding the awkwardness and complexity of disclosure. Others, like Luciano (37), still found it difficult to try to initiate a relationship with someone, as he did not have the courage to disclose and did not feel at ease with himself for fear of infecting his partner, or being rejected as a consequence of disclosure. He also mentioned that he did not wish to disclose to his family, as that would be a significant burden for his parents to deal with, and potentially they too might end up rejecting him in some way.

The anticipated rejection that some men expected did not always materialise, however. For instance, Pascoal (37), who had become infected through extra-marital sexual intercourse, was surprised when his in-laws were accepting and supportive and on learning his sero-status. In his words: "How could they have accepted me, after I put their daughter's life at risk?".

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[87] 'Bug chaser' is a slang term for those who pursue sexual intercourse with people with HIV in order to contract the virus. This may be due to a variety of reasons, from excitement to wanting to maintain a relationship with someone who is HIV-positive, or even being able to access welfare support through being HIV-positive.

Leonardo (31) described a particular incident that reveals an underlying sense of self-exclusion:

> I only told a couple of friends and once I was with one of them, and I was complaining about some symptoms. I was losing weight and then I said that even my feet had become smaller. I had dropped two shoe sizes. [My friend] did not believe me and asked me if he could put on my shoes. I was surprised and shocked at the same time, and you can see how prejudiced I was – because I thought somehow he could get infected by wearing my shoes. I shared that thought with him afterwards, and he responded saying that that is what friends are for, wearing each other's shoes.

Most of these accounts point to nuanced forms of self-stigma. People with HIV learn that with a positive diagnosis comes the potential for discrimination. As seen in the previous chapter, people develop a set of protective actions, which range from self-isolation (as in Samuel's account) to non-disclosure (in Luciano's) or even feeling guilty (Leonardo's). Thus, by engaging in one form of stigmatisation (self-stigma) they avoid another (enacted stigma).

As people experience a certain degree of abjection, becoming outcasts in their own reality, they may find it difficult to differentiate real situations of stigma from behaviours and practices that are not actually discriminatory. As in Leonardo's shoe narrative, it may be difficult for him to dissociate a friend's well-meaning request to wear his shoes from an idea of potential risk of passing on HIV – despite the very unlikely association between that practice and risk of HIV infection. Leonardo may have expected his friend to discriminate against him – yet that was not the case.

Similar expectations were expressed when referring to the need to disclose. As Filipe (54) explained, referring to establishing a new relationship:

> disclosing is putting part of me in someone else's hands. But a decision to have a relationship or not should not be based on what I have or have not. It

should be based in what I feel and what they feel. And often I think they will not want to be with me as soon as I talk about this [HIV].

This interpretation of disclosure reveals a genuine wish to be accepted regardless of HIV status. What is not yet clear is whether a restricted form of disclosure may be beneficial or not in tackling stigma and discrimination. In a different context, Gray, Doan and Church (1991) have claimed that cancer has historically become less stigmatised, perhaps because people are more willing to speak out about their illness, investing cancer within a kind of heroic discourse.

In the present study, disclosure was complex, meaning different things to different men, and often being seen as the likely precursor to failure and exclusion, even if some men reported never being discriminated against or excluded after they had disclosed. Others felt that part of living with HIV involved embracing the virus and not being afraid to talk about it. Pedro (50) who had set up some HIV workshops for a charity, explained how he always encouraged people to avoid feeling discriminated against:

> This diagnosis does not limit or impair one's identity. So people must react normally as they did before, be it in hospital, in a coffee shop or in church! (...) It is common for people to feel that they are less than others, as soon as they get their positive result. As soon as that happens they become submissive. That does impact on the treatment they receive, because they have no voice and instead of being able to get more help instead they get more issues.

Fear of discrimination may be greater when there is a visible sign of illness, such as lipodystrophy or jaundice. For Luciano (37), his fear of these physical effects was such that he hoped not to have to take any medication for any length of time. Both Pedro (50) and Filipe (54) said that they could tell if someone was HIV-positive by these signs, and thus hoped others would not recognise them. Pedro (50) said that people had "recognised" signs of HIV-related illness in him on a number of

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occasions, which had been very difficult to deal with. Samuel (48) also went through a difficult time in the beginning of his illness, when some of his family members started to notice the side effects of medication, including lipodystrophy, skin rashes and diarrhoea, which led to a lot of stress. He said he felt "dirty", and it took a long time to overcome that feeling.

This notion of feeling "dirty", similarly to Gabriel's (52) metaphoric idea of feeling "toxic" (see chapter 5), alludes to the idea of HIV as an embodied difference, which in theory may lay the foundation for enacted stigma. Cristiano (38) explained that being HIV-positive was the same as being black, as both were potential triggers to discrimination. Samuel (48), a white man who had supported a number of people living with HIV in Portugal, some from minority ethnic groups, interpreted this as follows:

> People don't know what HIV is all about. They think it's a disease that kills automatically. They think that a latex barrier is a barrier for feelings and affections, you know. HIV is a new colour, and with it comes a new racism, a new xenophobia, with one difference: this one is still very invisible.

Importantly, the fact that men were able to identify factors positioning HIV in relation to other social factors such as race points to the possibility of a new way of conceptualising HIV-related stigma and discrimination.

Some studies have looked at the juxtaposition between the processes of adapting to an HIV identity, or HIV career, and those pertaining to adapting to other (stigmatising) conditions. In particular, Glaser and Strauss' (1971) notion of 'status passages' may be useful in understanding movement within and between social structures, and corresponding changes in power. This was the framework used by Lewis (1999) in studying status passages for gay men living with HIV. She concluded that when (gay) men were first diagnosed with HIV, they began a movement towards a new identity,

one that reflected living with a chronic illness and which prescribed the adoption of the sick-role. Lewis referred to living with HIV as a *master identity*, one that colours any other role or feature of the self. Lewis also suggested that gay men were, in a way, better positioned to deal with a highly stigmatised identity such as living with HIV, for having previous experience of having done just that (by being gay). Men in her study sought to engage with other "people living with HIV and AIDS community" in order to prevent feeling isolated and "fight stigma [through] coming out as a person with AIDS" (p. 111).

Unlike Lewis' study, the current study did not focus solely on gay men, and therefore is better placed to understand how processes of adapting to new identities work for men who have traditionally been associated with more hegemonic performances of masculinity[88]. The idea of coming out, which usually refers to the process of identifying as lesbian, gay, bisexual or transgender (LGBT) and disclosing this to other people (Savin-Williams, 1995), may be a useful concept to borrow and adapt to (another) disrupted identity: HIV status.

Lewis' findings may have been informed by what Plummer (1975) has described as the process of sexual stigma. At a time when there was little sociological enquiry into the topic, and clinical research tended to focus on the medicalisation of sexual difference, the interactionist theory of deviance that Plummer developed to interpret sexual stigma paved the way for new understandings of sexuality. This stressed that any study of deviance should focus on the causes, characteristics and consequences of the actions (the process of becoming different), the reactions (the process of

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[88] Lewis's study was developed in a time in which developments in ART had not been as successful as they are today. This means that, so far as living with a chronic illness like HIV is concerned, ART has facilitated and improved health conditions for most people who take them, and allowed for a reduction in visible signs of illness and thus reduced chances of enacted stigma. In practice, this may contribute to a change in pre-determined notions of status passage in HIV, a phased framework for adapting to chronic illness, or even health-related stigma.

sexual problem definition) and the interactions ("the interplay between sexual experiences in society and the reactions towards them as deviant" – Plummer, 1975, p. 45). In adapting to 'being gay', men must negotiate meanings and experiences associated with their own identity as different. This is potentially what happens to anyone who is diagnosed with HIV, too. Similarly, both being gay and living with HIV trigger a number of social responses, both positive and negative. By focusing on the relationship between the ways in which people adapt to their sexual orientation (or HIV positive status) and the societal responses this generates, and by engaging in a "situated analysis of negotiated meanings" (p. 46), one may be better positioned to understand the aspects underlying the process of sexual stigma.

What this means in practice is that gay men living with HIV may feel more at ease when dealing with situations of stigma and discrimination, as they are more likely to have had previous experiences of these with regards to their sexual orientation. This may be so much so that, when describing situations of (HIV-related) discrimination, reference is made to similar experiences in respect of sexuality. Similarly, for Cristiano, who belonged to a minority ethnic group, there were links between his experiences of racism and of HIV-related discrimination. This may, however, mean that heterosexual men who live with HIV may find it harder to adapt to their condition as they may not have had previous experience of going through a process in which they may have gone "from a whole person to a tainted, discounted one" (Goffman, 1963, p. 3), particularly if they have assumed hegemonic masculinity behaviours.

Lavando as mãos e descalçando as luvas[89]: professionals' accounts

Some of the thoughts and concerns expressed by the men in the study mirrored those of the group of professionals interviewed. Most of them worked in the field of HIV, sexual health and infectious diseases for more than 5 years, which allowed them to highlight a number of aspects pertaining to the clinical and social evolution of HIV in Portugal. The most commonly expressed idea about the evolution of HIV at a social level in Portugal can be summed up by this account from Maria (psychologist):

> There have been a number of improvements and changes, an evolution. I noticed that HIV is now closer to people. This may sound odd but what I mean is that, in the beginning, the epidemic was seen as something that happened far way, to other people in other countries, and gradually it started to get closer to those we know ... we hear about someone being HIV positive within our group of friends. (...) It stopped being something that happened only to very specific groups, or certain neighbourhoods even, to everyone. And then we hear more people talking about discrimination, and it makes us think about the idea of being in the other person's position. I think more people are now aware of where they stand in regards to HIV, be it in terms of risk, or how they feel in relating to people living with HIV.

ART was the most common example of improvement in HIV management. Very often, and particularly nurses and physicians alluded to the early days in which a lot of people would die shortly after being admitted to hospital. There was a sense of impotence and inability to deal with the infection, which can be summed up by a quote from Paula (nurse):

> We would try and fight every single infection using all possible antibiotics, yet sometimes that was not enough. At one point, we had mortality rates of over 70%, and even when we had AZT, that still did not make a big difference. It was a dark period!

Intimately related to ART are issues of adherence and initiating treatment. As has been reported previously, some men, and indeed anyone who is diagnosed with HIV,

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[89] 'Hand-washing and removing the gloves'

may have issues in initiating a treatment protocol, and subsequently maintaining it. Complete adherence is of utmost importance for ART to work to its maximum efficiency. Nevertheless, a number of professionals have explained how that is such a complex aspect of patients' adaptation to living with HIV. Romeu (support worker), for example, said adherence was "the biggest challenge of working with people living with HIV". Alice (social worker) described this challenge as such:

> We try to explain that we can do a lot for each person that we work with, as long as they keep taking their medication as required. We constantly review their medication schedule and ensure that they are following it accordingly, but that is a big struggle at times. I think it is a national issue, actually. I think Portuguese people are not very concerned with following a therapeutic regime, regardless of the condition they are being treated for. And when it comes to HIV, there is a disadvantage, as most people won't have symptoms for a while, so some patients come to see us and ask 'Why should I take this when I feel fine?'. That often means that people stop medication, which is sad, especially after all the effort we invest into making sure they take their medication.

While the focus tended to be mainly on improvements to therapeutic options for people living with HIV, and how that tied into improvements in quality of life and life expectancy, some professionals also suggested other changes. In particular, those referring to professional conduct in dealing with such a charged condition as HIV infection. As Marcia (nurse) put it:

> We learnt how to leave our own fears aside. That constant fear that we can get infected if we do anything wrong, if we don't protect ourselves when doing a procedure on a patient. But that has somewhat dissipated. To be honest, I sometimes do not even remember to wear gloves to do some basic procedures. In my head, I'm not as frightened as I used to be, so that tends to influence my practice.

This account expresses a sense of comfort and adaptation to working with people living with HIV, as well as a loosening of professional conducts. According to other professionals, that has been accompanied by an increase in very knowledgeable patients, or expert patients (see Chapter 2) who have

Pushed [them] to be better at [their] job, to learn more and to be ready for some questions, as sometimes they can be quite tricky. I think it is an exercise in humility, to admit that we do not have all the answers all the time. But that is hard for some to do, as it goes against some of the ideas that some of my colleagues have about being a doctor. (Guilherme, physician)

As has been argued before, a strong influence of medicalisation in Portugal sometimes can create barriers for patients to access relevant care and information. HIV infection is, very possibly, one of few conditions in which some of the influence of the expert patient has been noted in Portugal. The widely acknowledged chronicity of HIV infection may also potentiate an increase in expert patients. For one professional, who occasionally worked with non-governmental organisations (NGOs), that was becoming more common, and partly it was due to the empowering role of some of these NGOs.

In fact, most professionals referred to NGOs and how they were pivotal in providing some of the support, in a complementary way to that received within a clinical institution. However, Marcia, a nurse who did not work in any of the main metropolitan areas in the country, said that there was a centralised distribution of these organisations. This in turn impacted on those living with HIV who did not reside anywhere near a major urban centre, to lack that kind of support, or having to make long journeys to access it.

The evolution of HIV has, according to those interviewed, revealed a number of challenges to which they had to adapt. One of the key issues that also featured when describing the evolution of HIV was discrimination. While most professionals recognised that discrimination was not as hostile as it used to be, some highlighted that, in certain situations, it was just as bad. Maria (psychologist) mentioned how often she would encounter people who still had inaccurate ideas about HIV and how

that would inform their discriminatory practices. Another side to discrimination was highlighted by Alice (social worker):

> One intriguing aspect is the discrimination that [people living with HIV] exert upon themselves. There are many situations, especially in terms of work and employment. When we try to help them in finding a job, for example, there are many people who come over here and say things like 'I went to a job interview and they asked me to do some blood tests, and I knew what that was for ...', as if all blood tests were HIV tests. This reveals some lack of knowledge and information, ignorance even!

Ignorance was a common issue presented by professionals and men when describing the social responses to HIV in Portugal. Not only was it commonly reported in association with people living with HIV themselves, as Alice's quote above reflects, it was also mentioned in regards to health professionals and society in general:

> I had a colleague who didn't know that the issue of vertical transmission was no longer a big issue, and that there were effective ways of dealing with it. And he works in the field and he is a health professional. I think it is interesting to think about our friends, who we think are well educated people, and then we come across situations like that (Maria).

Other challenges that were pointed out relate to the logistical side of keeping up to date with HIV, such as the obligatory professional continuous development required by professional bodies – information about the most recent treatments or trends in the distribution of the disease, for example. Yet, a number of professionals indicated that there was limited HIV-specific training being provided at undergraduate level. This occurred across the board of professionals, from nursing to medicine, social work and psychology. As Maria (psychologist) explained:

> As far as I remember, there was not much [training] on HIV as part of my undergraduate studies. (...) What regards HIV in Portugal, in Europe even, I

don't think there is much information on that. There isn't enough information being shared at an academic level, which is a shame.

Most professionals had to select alternatives at a post-graduate level, often having to support the costs of additional training themselves. Manuel, a social worker, explained how little training on HIV he received during his undergraduate studies, and thus had to enrol in other courses after he graduated so that he could learn how to best support his clients. But, as he highlighted,

> … this was a personal choice. I heard there was a course on HIV care, and decided to enrol. I received little support work-wise to do this, and had to pay for it myself. It is not always possible to do as much training as possible, which means that some of my colleagues have received very limited training after graduation. That can become a problem.

Along the same lines, Alfredo (nurse) pointed out that, even though he had graduated only 6 years ago, he had received very superficial HIV training during his degree. He was aware that, in the early days of the epidemic, student nurses were discouraged from undertaking their practical training in infectious diseases wards, as HIV-positive patients were meant to be isolated from other wards. Access to these patients was exclusively granted to the multidisciplinary team looking after them, and the patients' families. So, regarding that aspect, Alfredo noticed a considerable change. However, as he continued to explain,

> HIV patients are now chronic patients. The chronicity of the disease means that they will be living longer and also needing to access other services, not just because of their HIV status but because of their age and potential issues that come up with ageing. So there is no justification as to why there should not be a stronger focus on training health professionals on HIV. I know us [HIV health care workers] have constant dealings with people living with HIV, and we are used to it, but the more other professionals become used to it, the best it is for patients and for continuity of care.

The need for a better articulation of care was also highlighted by other professionals. In particular, as Alfredo stressed, the chronicity of HIV infection influenced the

traditional patient pathways and altered them: from a secretive and regular contact with infectious disease specialists only, to a less frequent and often multidisciplinary consultation. As the previous results have shown, this is a concern for most patients as well – so it becomes apparent that the articulation between specialist services and other, more general, types of support is not always as strong as it could possibly be. Many professionals explained they frequently heard patients mentioning the disparate level of support between the HIV-specialist institution and other (general) wards/services.

Beyond these issues of articulation of care and levels of support, some professionals focused on the interaction between themselves and the person living with HIV. While discussing some of the challenges that they faced throughout the years, one particular topic featured in a number of accounts: talking about sex and sexuality. For some, it took a lot of adjusting to being able to advise on sexual practices and listening to clients sharing some of their intimate details. Maria, for example, said that

> When I deliver some training sessions, I have to talk about sexuality and sex. Often this is done right at the beginning, which can be difficult to tackle. Afterwards, it tends to get a bit easier, but the beginning is always a bit complex. It also depends a lot on the relationship I establish with the group.

For Romeu (support worker), the issue was addressing issues of sex and sexuality with older men:

> It is quite difficult to talk to older men about sexuality, how to use a condom, for example. Most men tend not to be very open to condom use, and older men in particular are not keen on condoms at all.

Silvia, a nurse who has worked in the field of HIV since the very beginning of the epidemic, recalled how she used to avoid some topics as it was not easy for her to discuss sex with anyone, let alone 'her' patients:

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I was educated according to very conservative principles, so it took some adjusting. I won't deny it. It wasn't always easy. In particular when homosexual men would come to me for support and would describe some of the issues they had. But then I realised that the best way to become comfortable with it was to talk to them about it, rather than seek information elsewhere that could cloud my judgments.

She also highlighted that, in the early days, part of the stigma that surrounded HIV was due to the fact that, like her, everyone had issues talking about sex and sexuality. There was a "repressive environment", which did little for people living with HIV to talk openly about HIV, sex and sexuality; and for professionals to address their issues in a competent and non-judgemental manner:

There were many issues with dealing with homosexuals. Often I would hear colleagues making, you know, derogatory comments. That would cause patients to be a bit more quiet and avoid talking about their lives to us. And that is one of the reasons for HIV-related stigma. That repression, that difficulty of talking about what goes on, be it in terms of sex, drugs or life in general. Patients knew that that was what most people associated with being HIV-positive, so they would not talk about sex, or avoid coming to hospital. I think, as a country, we are very homogeneous, and we become strange when we see something strange.

Silvia explained that a lot has changed when it comes to these particular issues. Even if, according to her, there are still a number of issues to tackle, she says professionals have come a long way since the early days, and so did patients. This mirrors what Roberto, a physician, described:

Patients share more with us these days. It is more common for them to want to talk about their relationships, when things go wrong, or when they have a sero-discordant partner, for example. We also are better prepared to deal with those cases, as we have a well organised network of support, with psychologists and psychiatrists that we can refer patients to.

It is in the climate of better communication and dialogue between professionals and patients that these become close to their carers and feel more comfortable in sharing more information. People living with HIV became gradually less "blocked"

(entupidas), as Silvia put it, in sharing their concerns. However, every so often they would come across people who were still struggling with living with HIV, mostly because they were incapable of overcoming their diagnosis and adapting to it. From the number of examples I could quote, I will use one by Marcia (nurse), who had recently come across a nursery nurse who, upon being diagnosed, quit her job in fears of being fired. Another case was shared by Silvia, who had organised an event with a number of patients and it was only when some of them arrived to the venue and started talking to each other that she realised that most of those patients had never talked about their diagnosis with anyone else but the health care team.

Fear of rejection and the regulation of disclosure seem to be a key aspect of living with HIV for the men in the study. In fact, words such as 'fear' (medo) and 'dread' (receio) featured prominently in most interviewees' accounts. Within the professionals' interviews, I came across a reflection upon these fears felt by those they cared for, but also a new form of fear, an 'occupational fear' of becoming infected. While there has been some evolution in terms of acceptance and tolerance, some people still find it difficult to live with HIV, and care for someone who is HIV-positive. For example, as Roberto (physician) explained,

> I have seen some of my colleagues shaking a patient's hand and then wash their hands immediately after. It used to be very common and it is not so common these days, but sometimes you come across colleagues who struggle.

Notwithstanding this, when asked about their own experiences of stigma or discrimination for working in the field of HIV, most professionals agreed that, more often, people would react with admiration ("I don't know how you can do it ... I certainly could not! But I'm glad you enjoy it." Silvia) rather than aversion. In any case, Romeu described one situation in which he felt discriminated by another health professional:

I was discriminated once by a nurse. She asked me what I was doing there [in the hospital accompanying a patient], and when I explained, she said I was a young man and shouldn't be there ... I had better things to do instead of putting myself at risk like that. I was a bit shocked with her comments.

Overall, most professional accounts emphasised some of the issues that had already been highlighted by men in the study. Additionally, having the professional perspective on some of the issues faced by men living with HIV is useful to contextualise and understanding how HIV in represented and interpreted in clinical and support settings.

A number of suggestions were made by professionals in order to improve the levels of care and support received by people living with HIV, and also contribute to a more accurate representation of HIV in society at large. Thus, these suggestions could be grouped into three areas pertaining to the three key actors involved in HIV care and support:

(i) Government

Most professionals thought government efforts were suitable to meet most needs of people living with HIV, yet there were a few issues that needed to be addressed. Alice explained it as follows:

> The government needs to devise a number of strategies in order to intervene more effectively, and reduce the number of new cases. In Portugal we have had an increase in numbers, and we continue to be the country in Europe with the highest incidence of HIV. This obviously makes us wonder ... I know that all ART is subsidised by the government, and that is a positive measure. However, shouldn't we be working in order to prevent people from becoming infected in the first place? The government doesn't utilise prevention as it should. Most prevention work is badly planned and monitored, which means that there are many obstacles for it to be developed effectively.

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So, not only there should be a stronger input in terms of prevention work, other professionals argued that there should be a stronger articulation between primary care and hospital care, as well as government funded specific interventions (such as dermatologic fillers for people with lipodistrophy).

(ii) Professionals

There should be a stronger focus on HIV in health-based academic curricula, and continuous professional development courses on HIV and sexuality awareness for health professionals that work in other medical specialities.

(iii) People living with HIV/AIDS

Professionals suggested that, while some of the work that needs to be done is certainly at a macro-level (governmental action), there is a lot of scope for people living with HIV to help themselves in making their condition more widely respected as a chronic illness. Therefore, most agreed that people living with HIV should work at normalising their condition, by talking to people about it, including other people living with HIV, and hence avoiding isolation and self-deprecation. This may also involve a change in the way people present themselves within clinical settings. As Alice noted,

> there is not a spirit of *claiming* in Portugal, the idea of complaining is foreign to most of us. If someone has HIV, they already carry a lot of prejudice and therefore will feel even less inclined to complain if anything goes wrong. Most people think that by complaining they are setting themselves up for public humiliation and recognition.

Finally, as Maria explained:

> There should be a greater investment in education, in clarifying what HIV is and what it is not. People should be supported in their own personal and

cognitive development. One aspect, for example, is how everyone should work towards living a healthier lifestyle. That would ensure a reduction in new infections and also a greater quality of life for those living with HIV.

Chapter summary

In Portugal, whilst HIV is still regarded as a socially disabling disease, with a certain degree of stigma associated with it, there appears to have been some evolution in relation to the way people refer to and understand stigmatising and discriminatory behaviours and practices. Perceptions of HIV in contemporary Portugal suggest that AIDS may be understood as currently going through a crisis of identity.

Differing representations of HIV exist in complex relation to one another, with perceptions and experiences of stigma, normalisation and the social invisibility of HIV combining in subtle and unexpected ways. This may be one of the reasons why not all men in this study could identify specific instances of having been discriminated against, while still feeling marginalised and disempowered in certain ways. Additionally, their descriptions and responses reveal a number of tensions in their interpretations of living with HIV. On the one hand, men sought a level of social recognition that included an awareness of their needs and a certain degree of visibility. On the other hand, practices that ran contrary to these desires were also observed, including conscious efforts not to disclose, as well as seeking invisibility within clinical spaces. Some of these tensions were also visible in professionals' accounts. In particular, there was an agreement that, while HIV is now dealt in a very different manner than it used to be in the early days of the epidemic, there is still a number of issues that need to be addressed. For example, some professionals referred to situations of stigma, difficulty in talking about sex and sexuality with their clients, and about their own adaptation to working within the field. In the end, a number of suggestions from professionals were drawn. These focused on ideas for

improvement of the social representation and health care and support for those living

with HIV.

Chapter 7

Discussion

Introduction

The previous three chapters explored different aspects of what it means to be a man living with HIV in Portugal today. Together, they highlighted the importance of contemporary beliefs about health and illness, images of masculinity, and changing processes of societal response to HIV and AIDS. Building upon these findings, the present chapter aims to bring together and synthesise these results so as to offer a new and more contemporary perspective on living with HIV in Portugal today

Despite the increasing invisibility of HIV – which translates into a decrease in global concern for HIV at both policy and programme levels – the current study highlights the fact that HIV remains a significant problem, with associated impacts on health and wellbeing, for those living with it. However, with the passage of time some older issues have gained new connotations which call for a more nuanced understanding of what these experiences mean. As a result, this chapter aims to engage with broader questions about HIV against the social, cultural and moral backdrop of Portuguese society. It also seeks to examine the relevance of men's experiences to wider perspectives on contemporary experiences of living with HIV globally.

The argument is divided into three sub-sections. The first of these looks in more detail at how the social organisation of HIV in Portugal and the apparent crisis of identity surrounding HIV affects the 'social death' experienced by men in the study. This sub-section analyses how different social factors contribute to this idea of crisis

of identity and its effects. The second sub-section suggests that the present identity crisis affecting HIV may be the product of something of a 'disrupted biography' in the epidemic in Portugal. HIV in Portugal has had a troubled course, with strong social, political and moral discourses influencing its development. In turn, this disrupted biography impacts on those who live with it. The final section builds on both previous sections to analyse in more detail notions of stigma and discrimination. It argues that existing notions of HIV-related stigma may require re-thinking if we are to fully understand the individual and societal consequences of HIV on men's lives today.

Revisiting 'social death': HIV in Portugal

Despite Portugal having been severely affected by HIV from early in the epidemic, the Portuguese government's response to it has triggered mixed responses, both from people living with HIV and those working in the field. When UNAIDS unveiled its report on the state of the epidemic on World AIDS Day 2011, it showed that Portugal remained the country with the highest incidence of HIV infection in Western Europe, as well as having the highest rates of AIDS-related mortality. Despite this, and more positively, the report highlighted that Portugal was one of the few countries to demonstrate a marked reduction in new cases of HIV infection acquired via injecting drug use – which had been the most common route of infection in the country from the beginning of the epidemic up until the end of the 1990s.

In response to the high levels of infection acquired through injecting drug use, the Portuguese government passed legislation to decriminalise the possession and use of all illicit drugs in 2001. This had a knock-on effect on the reduction of new cases of HIV as well as drug-related criminal offences (Teles and Amaro, 2006; Hughes and Stephens, 2010). At the time, this was a pioneering strategy to curb drug use, and

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one that initially received fervent criticism from different sections of Portuguese society and world leaders alike. At a societal level, the introduction of 'shooting galleries' at various sites in the larger metropolitan areas was not welcomed by local residents and some political leaders, who claimed that attracting drug users to these areas would increase feelings of insecurity and foster criminality (Jornal da Noite, 2006). Ten years later, after the programme proved to be successful in dealing with drug use both as a social and a public health issue, Portugal's response is now regarded as an instance of best-practice worldwide (see Hughes and Stephens, 2010, for example), inspiring new strategies that have already been implemented or are currently under scrutiny for application in other contexts.

While overall rates of injection-related HIV infection have dropped thanks to this new approach, the same did not occur with rates of infection through other routes such as heterosexual sex. In 2011, as well as throughout the 2000s, heterosexually acquired HIV was the most commonly reported route of transmission – accounting for 45.8% of all reported cases since 1983 (UNAIDS, 2011; INSA, 2012). Homosexually acquired infection has remained stable in Portugal since the late 1990s. In 2011 alone, for example, homosexually acquired HIV remained lower (26.2%) compared to heterosexually acquired (61.7%) - these figure refer to both genders, nevertheless (INSA, 2012). Looking beyond the epidemiological data, however, it is important to realise that many homosexually acquired HIV infections may remain undiagnosed, hidden or may even be reported as having been heterosexually acquired, as happened with some men in this study.

Despite an apparent decrease in new cases overall, and success in curbing infection through injecting drug use, other HIV prevention activities have been only modest in scale, particularly in addressing the heterosexual risk of HIV. In the only publication mapping the socio-political aspects of HIV in Portugal to date, Teles and Amaro

(2006) explained how many HIV prevention campaigns developed in the country have lacked robustness, as well as proper integration into the social context in which they were implemented.

For example, in 1986, the very first campaigning efforts were based on the assumption that asking people to change their lifestyles was sufficient to prevent infection. The view was that the provision of information and advice would translate straightforwardly into a change in behaviour. One year later, a larger mass media campaign was implemented, which involved television adverts and postal leaflets[90]. In the 1990s, other campaigns were then implemented following the creation of a number of non-governmental organisations focusing specifically on HIV. In general, however, there has been little systematic evaluation of these efforts to assess whether or not they had been effective. To this day, it is unclear whether they contributed to (and to what extent they did contribute to) behavioural change, knowledge gain or even reduction in the incidence rates of HIV (Teles and Amaro, 2006).

Other difficulties related to the lack of scientific enquiry into the values, needs and motivations of target audiences and those considered to be most at risk. There was no evidence of groundwork identifying the motives, experiences and feelings involved in risk behaviour, for example. Similarly, there has been a lack of leadership and accountability in managing HIV prevention efforts. In short, it appears that most HIV prevention work was simply devised to fill a gap (Teles and Amaro, 2006).

The various changes in the political context, as well as the introduction of ART, meant that, with time, HIV prevention received considerably less attention (and

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[90] This campaign used a similar dissemination strategy as the UK's *Don't Die of Ignorance* campaign (Department of Health and Social Security, 1986) even if it was milder in its approach.

financial resources) from policymakers. Public taxes supported the cost of ART, estimated in year 2009 to be around €200M per year (Barros, 2009). Additionally, the decriminalisation of drug use in 2001 – and the associated costs in setting up support and outreach services – meant that fewer resources were available for other forms of HIV prevention. A number of NGOs carried on working in HIV prevention, but the government's own HIV regulatory body[91] devised only smaller initiatives, with little or no impact at a larger scale.

Such a disparate response engendered varied opinions among the present study's participants. Gaspar (44) considered himself thankful for the fact that he had never been refused health care after relapsing back into drug use a number of times. Like Gaspar, men who had accessed specific services for injecting drug users welcomed the measures that had been put in place. Firstly, they felt that these measures showed that the government cared for the welfare of people who used drugs. Secondly, they provided a platform to access other types of support, including rehabilitation services and signposting to relevant NGOs. And thirdly, they also allowed services to access this vulnerable population through outreach, and hence they were in a better position to assess specific health and social needs of injecting drug users. All of the men who were infected through injecting drug use in this study eventually ceased injecting, often due to the support of these services. Valdemar (40), for example, explained that the support he received from a NGO was only granted on the condition he "remained clear". Yet, once they stopped using drugs, men struggled to identify other government HIV prevention strategies that did not involve support for those who used drugs. As their membership of one risk group 'expired', men no longer felt there was a prevention agenda which encompassed their 'new' needs.

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[91] The National Commission for the Fight against AIDS, which was later replaced by the National Coordinating Agency for HIV and AIDS, was eventually closed down in 2011 as part of the various measures to rescue the country from serious financial difficulties.

As well as having a history of drug use, some of the men in the study self-identified as gay (and had sex with other men), while others had been infected via heterosexual intercourse rather than through injecting drugs[92]. Importantly, however, not all of the men who had sex with men self-identified as being gay, and not all of those had had injected drugs saw themselves as injecting drug users. This highlights some of the difficulty that can be found in trying to conceptualise risk of HIV infection in terms of risk behaviours or overly simple risk groups. Membership of one group is often not exclusive, as the sample for this study shows. HIV prevention efforts may have been hindered by this fact, and constant attempts to target members of particular groups, although effective in certain contexts, may also create a sense of social division that leaves people uncertain or unaware as to whether or not they are at risk.

According to Teles and Amaro (2006), this is one of the key socio-political aspects of the epidemic in Portugal. From the outset, the sole focus on risk groups diverted some of people's attention from HIV. In other words, the invisibility of those who did not belong to any risk group could be interpreted as an indication that they did not need to worry. Indeed, and despite the 16-year gap between two general population in-depth studies looking at risk perception for HIV in Portugal (in 1988 and in 2004) little difference was shown regarding levels of knowledge and risk perception. In both studies, risk was framed narrowly in terms of engaging in homosexual intercourse or drug use, triggering a sense of false safety among heterosexuals (Ayres et al., 1988; Amaro et al., 2004). This disconnection between HIV infection and heterosexual risk is further encountered in recent government HIV prevention efforts.

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[92] A detailed description of each participant's reported route of infection, as well as a short biographical note of each participant can be found in appendix 3.

For example, a 2010 campaign by the National Coordinating Agency for HIV/AIDS entitled 'Sometimes the unexpected happens!' depicted two men engaging in safer sex in different contexts. The campaign used two video clips to raise awareness of condom use: the first one applied to casual relationships and the second in more regular and stable relationships. Because the videos featured two men, it appeared that the campaign solely targeted men who have sex with men. However, the rationale for this campaign, written by the National Coordinating Agency for HIV and AIDS (2010), read:

> [this campaign] aims to raise awareness of the risks involved in transmitting HIV through sexual intercourse, regardless of the sexual orientation of those involved, or whether the relationship is stable or occasional (CNHA, 2010).

By depicting same-sex encounters, there was the naive expectation that heterosexuals would identify with the underlying message and adopt it. Bearing in mind that evidence has consistently shown that many people consider themselves not to be at risk when engaging in sexual risk behaviours, and that a large number of people in Portugal still think that only sex workers, injecting drug users and gay men are at risk of getting HIV (Ayres et al., 1988; Amaro et al., 2004; Maia, 2009; Maia, 2010), one would hope that present-day HIV prevention campaigns were broader in their scope. On the other hand, and given the current climate of financial restraint, to focus solely on a vulnerable population, may have been an attempt to reinforce some key HIV prevention messages to men who have sex with other men – whereas the rationale was but an attempt to promote a 'one size fits all' approach. This shows a certain degree of inconsistency, which in turn contributes to the overall disrupted organisation of support and care for people living with HIV, as well as the social representation of the virus.

Focusing on risk (groups) was perhaps initially a necessary, and in a way more convenient and generalised way of alluding to the fact that people who engaged in risky behaviours could genuinely be at a higher risk of infection. However, the enhanced visibility of risk groups also increased their marginal status, fuelling prejudice and stereotyping, and stigmatising those social actors who belonged to those groups. This occurred in various contexts and it became a deep-rooted response to the epidemic, both in Portugal (Victorino, 2003; Dias, Matos and Gonçalves, 2006) and worldwide (Spears et al., 1992).

To mark World AIDS Day 2011, the Government of Portugal launched a new national HIV prevention programme for 2011 to 2015. Key measures included: the promotion of generic medication so as to reduce the current amount spent on ARTs (estimated at €200m per year); economic evaluation to ensure cost-effectiveness of available resources; an enhancement of prevention by promoting treatment; and the development of a new plan of action that includes the creation of a centralised surveillance system for HIV (Freitas, 2011).

Despite abolishing the National Coordinating Agency for HIV and AIDS and the National AIDS Line (a free helpline providing information and advice about HIV and AIDS), the programme claimed to be responding to the World AIDS Day 2011 motto of 'Zero New Infections, Zero Deaths from AIDS, Zero Discrimination'. The following were identified as priorities for action: information systems and epidemiological surveillance; prevention; vulnerable populations; diagnosis and treatment, support and care; stigma, discrimination and human rights; research; cooperation and international relations.

The programme is a useful instrument in that is allows for some light to be shed into the way HIV is organised and represented from a policymaker perspective. In order

to better understand the current social context surrounding HIV it is helpful to look

briefly at the manner in which the following issues are characterised within it:

vulnerable populations; HIV prevention; and stigma, discrimination and human rights.

In the new programme, vulnerable populations are defined in line with the Dublin

Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia[93] (ECDC,

2004) as:

> people who use intravenous drugs, men who have sex with men, incarcerated
> people, sex workers, ethnic minorities and migrant populations who originate
> from countries with high incidence and prevalence of HIV infection. (Ministério
> da Saúde, 2011, p. 15)

The programme clearly states that, in Portugal, heterosexually acquired HIV is the

most common transmission route in new cases[94]. Given this, there appears to be

something of a paradox. Instead of addressing heterosexuals, the programme's

focus is on other groups – e.g. those, such as injecting drug users, for which the

epidemic has been managed in more sustainable and effective ways. The reasons

given relate to the continued impact that stigma and discrimination have upon

vulnerable populations who, because of this, may fail to access and utilise health

care and/or information and support. Similarly, and as pointed out earlier, much

same-sex HIV transmission may be under-reported (or reported as heterosexually

acquired) because of fear of discrimination for disclosing having been infected

through homosexual sex. The reasons for this are deeply rooted in the social and

cultural context of Portugal. However, a suitable example to illustrate such issue can

be found in the current study. When asked about the circumstances in which he may

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[93] The Dublin Declaration encouraged partnership work on the fight against HIV/AIDS in Europe and Central Asia and was signed by representatives of European and Central Asian countries on the 24th February 2004, in Dublin.

[94] Data from the INSA (2012) confirm that, in 2011 alone, 61.7% of all new diagnoses were to people who contracted HIV through heterosexual contact. This followed the same epidemiological pattern since 1983.

have been infected, Vicente changed the subject of the conversation and did not answer when probed again. In my field notes, I wrote:

> At some point during the interview, I felt that Vicente was being flirtatious and when I switched the recorder off at the end of the interview he complimented me on my looks. This is quite interesting given his clear difficulty in speaking about his own sexual experiences, or even how he was infected. He kept saying that that could have happened due to a range of possibilities, and that it didn't really matter anyway. This dismissive attitude may be simply a coping mechanism or a genuine difficulty in dealing with his own sexual preferences. I wonder how his infection was initially recorded when diagnosed – possibly heterosexual contact.

This was also supported by some of the professionals interviewed, who highlighted the difficulty expressed particularly by older men in revealing that they had engaged in sex with other men, for fear of being judged by the professional or 'outed' by them. The fear of disclosure was thus twofold: fear of disclosure of HIV status and fear of revealing their sexual orientation. Discussion will return to this issue later on in the chapter.

Returning to the programme that was launched in late 2011, the range of strategies presented to support vulnerable populations included partnerships with existing NGOs, who may be better positioned to work with some of these groups and therefore support them effectively. Whilst this approach may contribute to a reduction in HIV incidence, it is unlikely to address some of the issues highlighted by men in this study, including the need for HIV to be understood as a disease that can potentially affect anyone, regardless of their background. Men in the study feared that much of the invisibility surrounding HIV in Portugal is fuelled by lack of government action targeting the general population, not just those who are traditionally seen as being at greater risk. Respondents argued that this was why so many people remained relatively ignorant about HIV, how it is transmitted and what constitutes risk of infection. Working with and within organisations that reach out to

the so-called vulnerable populations is a valuable effort – yet it may also enhance the notion that HIV infection continues to occur in a relatively narrow epidemiological ghetto, when all the remaining indicators state otherwise. All of the above contributes to the continuing social invisibility of HIV.

This sense of invisibility is however neither constant nor homogeneous. As almost every man in the study pointed out, on the 1st of December of every year, there is hardly any other topic making the headlines. Similarly, there tends to be a session in parliament specially devoted to HIV. On the 1st of December 2011, Parliament approved the current strategic programme for 2011-2015, and a number of scholars, clinicians, experts and other professionals working in the field of HIV were interviewed and their contributions featured largely in the mass media.

Sadly, and despite lip service being paid to the inclusion of people living with HIV in prevention work, there was little presence of those living with HIV on World AIDS Day 2011. This was perhaps due to the fact that not many people currently living with HIV in Portugal want to come forward and speak out about it (given prevailing social attitudes). However, as this study has shown, there are many people who, having adapted to their diagnosis, would welcome the invitation to participate in letting other know about what it is like living with HIV nowadays. Even in moments that offer a window of opportunity for HIV to be more openly discussed, current practices in Portugal do not encourage it. Often, medical discourses prevail at the expense of the voices of people living with HIV, limiting opportunities for the latter to share their experiences and demonstrate their expertise.

Paradoxically, when presenting the new national programme, its coordinator indicated that more work needs to go into understanding the social context surrounding HIV infection and living with HIV (Freitas, 2011). The programme

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acknowledged some of the social issues associated with living with HIV, under the heading 'Stigma, Discrimination and Human Rights'. It stresses that HIV is no longer a fatal disease but a chronic illness, requiring a reformed approach to care and support. It emphasised that discrimination towards people living with HIV generates barriers to prevention, access to care and support. It explained that "episodes of discrimination have never really been quantified" (Ministério da Saúde, 2011, p. 26), and must be dealt with by a new strategy to address discrimination, particularly within health care settings. Other strategies to ensure non-discrimination included workplace policies to reduce work-based discrimination, and encouraging employers to adhere to the HIV Code of Conduct for Employers, a document produced following the guidelines set by the International Labour Organisation.

The lack of 'quantification of episodes' of discrimination is worrying. HIV-related discrimination and stigma have existed since the very beginning of the epidemic, virtually in every context affected by the epidemic. While overt discrimination may be less frequent now, it has not vanished (Dias, Matos and Gonçalves, 2006). The reported lack of data on discrimination, some 30 years since the beginning of the epidemic, may be interpreted as an indicator of disregard for the topic hitherto. However, as will be shown later in this chapter, the history of HIV in Portugal has traditionally been characterised by a certain *laissez-faire* attitude by those in charge of controlling the epidemic. This was most visible, for example, when the then Health Minister Dr Leonor Beleza said in 1988 that "in Portugal, AIDS is not a serious issue", even though the number of newly diagnosed people was already rapidly increasing at that time (Teles and Amaro, 2004).

Taken together, these facts offer some explanation as to why men referred to HIV having a generalised sense of social invisibility. The disparity between the experiences of people living with HIV, wider social perspectives and government

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(in)action provides evidence of there being something of a crisis of identity facing HIV in Portugal today. One way of conceptualising this crisis – and the differing, conflicting, even inconsistent national responses to HIV – is to acknowledge that public perceptions and knowledge of HIV have always been complex and contested, symbolically loaded, and never neutral or straightforward. As Bastos (2002) put it:

> In the various sub-fields of HIV-related knowledge (…) there is an abundance of examples in which the established certainties are rapidly replaced by others, sometimes very different. What was once the gay cancer, came to be an infectious disease; what was once the disease of a degrading modern world and its large metropolitan areas turned out to be a disease of under-development, of those in the third world; what was associated with anal sex is now linked with pregnancy and delivery (…). What is regarded as official knowledge is constantly changing, which reflects the very nature of scientific production. Why do some ideas persist while others are revisited or rejected? (p. 209)

The tensions Bastos alluded to are focal points in the development of the social understanding of HIV, and carry serious implications for people living with HIV as well as those who work with them. As is evident from the narratives of men in the present study, some of the issues they describe derive directly from these tensions. For example, when referring to disclosure, men experience uncertainty about who they can disclose to, at what cost, and the reaction(s) they will receive. As Luciano (37) put it:

> I don't have the courage to seek a relationship with someone. I'm scared of meeting someone, falling in love, and then seeing that person turning their back at me when I tell them about HIV.

Likewise, Pascoal (37) revealed that only one of his friends knew about his HIV status, and Martim (40) had not told his GP for fear he would spread the news around in his village. Vicente (54) wore sunglasses to all our meetings, as a physician had said to him once that one could see if someone had HIV by looking in their eyes: if both eyes were pale, there was a possibility the person was HIV-

positive. He also said that that was one of his many strategies to avoid disclosure at all times. For him, disclosure was both unnecessary and banal. Whilst it is clear from these examples that the consequences of disclosure are varied and variable, there seem to be no straightforward answers as to whether or not one should disclose or when that should occur, as some men encountered severe difficulties in relationships after disclosing their status, while others strengthened their bonds with those they disclosed to.

At a political level, men identified the need for greater advocacy for the rights of people with HIV. Greater visibility socially is required to change the remaining perception from early in the epidemic that infected people are condemned to die quickly (Osório, 2003). Early on, this 'social death' (after Daniel 1993) had been *accredited* to those living with HIV. This occurred by means of the belief that anyone diagnosed with HIV infection would die in a short period of time, so any living time would be a preparation for death, a set of palliative efforts in which the person dying, the patient, would slowly be removed from their identity and lifestyle. Currently, though, people living with HIV feel more *discredited*, demanding greater visibility alongside representations of HIV that are factual and accurate. Men in this study suggested a range of actions to combat this process of discrediting, many of them deriving from their own (contradictory) experiences. Some men wanted more visibility politically while, at the same time, wanting to remain invisible personally.

In sum, there are paradoxical tensions for men who seek a clearer recognition of the needs of people living with HIV and greater visibility for HIV in general – as a way of normalising the condition and resisting social death. Similarly, there seems to be a notion that visibility is the gateway to empathy. However, this occurs alongside an unresolved desire for individuals to remain invisible with respect to their own HIV status. Such a response may occur out of fear of discrimination or direct prejudice,

but it may also be the result of not wanting to accede to a dominant HIV narrative, and the assumptions and prejudices attached to this at social and interpersonal levels.

Disrupted biographies of a disrupted illness

In chapter 5, narratives of men in the study were analysed in relation to Bury's (1982) framework for understanding chronic illness careers. This analysis focused on how men adapted to their disrupted biographies, emphasising three stages in the adaptive process. In an attempt to adapt Bury's framework to the current study, which involved some rejection of its fixed-staged approach, it was argued that the path to adaptation to the diagnosis was not a straightforward one. Instead, men often engaged in opposing processes. Upon diagnosis, for example, men initiated a process of discovery (of the illness, of its bodily influence, and so on), alongside the need for concealment (HIV status to others, or to himself). Tensions also occurred during the process of adaptation. They included the challenges of adopting an HIV career, or refusing to do so; and gaining access to a network of support or, alternatively, failing to mobilise resources to better adapt to circumstances.

HIV infection is in constant change. Its recent recognition as a chronic illness in Western countries adds complexity to the application of Bury's framework whose linear stages exist in tension with men's own experiences of their own paths as intermittent. Its apparent divorce from the social and historical contexts in which stages are negotiated and passed through is also a cause for criticism. In this final chapter, therefore, something of this context will be described. I will begin by charting something of the historical context in which HIV first appeared in Portugal.

It was argued earlier that the recent history of Portugal (its dictatorship period and the subsequent revolution) had an impact on images of masculinity and how men behave, both now and then. Similarly, it has been argued that the perceptions of risk are influenced by the level of information available – during dictatorship, for example, there was little available sexual health information as this clashed with the dictator's strict religious conduct (Freire, 2010). This allowed a number of myths and misconceptions to become widespread. It was popularly believed, for example, that menstruating women should not shower or bathe, nor should they cook, as this would spoil the quality of the food; whereas masturbation was seen as to cause mental illness, blindness or cognitive dysfunction, to give but two examples.

The dictatorship period, which lasted 41 years, emphasised the social divide between men and women. The family was the key element for the transmission of the so-called national values (family, God and the nation). These values, which had strong Catholic underpinnings, included a clear distinction between male and female tasks – some professions were even barred to women – as well as the protection of female virginity before marriage, alongside rites of sexual initiation for young men led by their father or grandfathers, as explored earlier.

The later years of the dictatorship (late 1960s to early 1970s) were characterised by a rise in emigration of young men, to France, Brazil or the USA, trying to avoid having to fight in the colonial wars that Portugal initiated with its former colonies (Barreto, 2004). The all-male exodus had a range of effects: it meant that women were required to take the lead over the occupations and jobs that men had left behind, which often meant having to take on paid work and also take the lead in family businesses, for example. In consequence, family values promoted by the dictatorship were weakened. Additionally, it allowed a number of external influences to permeate the barriers of censorship: those men that had fought in Africa were

exposed to different cultures, and so were those who emigrated to other developed countries. Gradually, this enhanced exposure to foreign cultures, different values and ways of thinking started to infiltrate Portuguese society. This had multiple consequences at various levels, and certainly affected the way men experienced their sexuality – by being able to access pornography, for example, which was banned from dictatorial Portugal. Nevertheless, as Teles and Amaro (2006) argued, the sexual revolution of the late 1960s only had its impact in Portugal some ten or more years after.

The revolution of 1974 finally put an end to the repressive political system and initiated a process of change. According to Teles and Amaro (2006), this period was characterised by new ways of thinking about and experimenting with sex. These changes were inspired by the influx of people who returned to Portugal from the countries where they had emigrated to, but more significantly by those who had returned from the former colonies. More people were having sex with more partners, and same-sex sexual activity became more visible in the metropolitan areas. The 1980s saw significant changes at political level that allowed for greater recognition of equal rights – for women, for example[95].

This was the very context in which HIV first appeared. The first case was registered in 1983 – but reports afterwards indicated that there might have been prior cases of unexplained deaths that could have been due to AIDS. In 1985, the Ministry of Health created its First Working Party to focus on HIV/AIDS, as there had been reported a total of 21 new cases in that year alone, alongside seven AIDS-related deaths. Despite this, the first official report disregarded the growing number of new cases as:

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[95] Prior to this, the male partner had been recognised as the family leader, and most decisions about the female or family members' life had to be accepted by the leader. Women were not allowed to fly on their own, for example, without the permission of their husbands. The chefe de família (family leader) role was abolished in 1978.

AIDS [was] not an issue of concern in Portugal. (...) All available sociological data is clear to reveal that masculine homosexuality is reduced amongst us in Portugal, when compared to the United States. We can therefore conclude that the epidemiological data for the Unites States that reveal an evolutionary trend cannot be reproduced to our context. (Teles and Amaro, 2006, p. 33)

Similar to many other countries, early responses to HIV were characterised by a *laissez-faire* attitude, allied to processes of 'othering', or the blaming of foreign countries or cultures for the problem. As numbers of new infections rose, the type of response did not change. As Ponte (2005) argued, the number of new cases continued to increase rapidly, yet government and the press maintained an idea that Portugal was unusually not affected by the epidemic, a safe haven where the epidemic had had little or no impact.

Things only began to change at the beginning of the 1990s. Initial responses, as discussed earlier, focused largely on risk groups. Drug use and homosexuality, which had become more visible after 1974, were branded the causes of the epidemic in highly charged moral discourses. The 1990s also saw a growth in the creation of NGOs who sought to promote the rights of those living with HIV as well as lesbians, bisexuals and gay men. However, despite the revolution of 1974 having established a clear separation between State and Church, Catholic power remained strong and highly influential in political, social and cultural arenas, which ultimately supported the overarching notions that HIV was a condition of the morally polluted (Amaral and Moita, 2004).

Despite changes in political system, and the fact that a patriarchal society had been steadily giving place to a newer, more egalitarian society, this has not always been accompanied by a change in social values. For example, recognition of women's

rights in the late 1970s allowed women to adopt a more equal social role. However, some 30 years later, there are still many women who maintain values common to the 1960s and earlier. Similarly, recent legal changes that may suggest a level of detachment from previous prejudicial discourses, as in passing a law allowing gay marriage, do not mean that Portugal is not still influenced by the Church and the values that were commonly shared during the dictatorship. While laws may reinforce the moral imperative of equality, stronger moral, religiously fuelled arguments still abound, influencing the ways in which gender, sex and sexuality are framed (Vale de Almeida, 2012).

Unlike other Western European countries, Portugal's response to the epidemic was both late and characterised by contradictory actions, reflecting the number of tensions operating at a socio-political level. Forty-one years of dictatorship, which embedded strong religious and moralistic principles, allied to the need to quickly catch up with the rest of Europe, created a series of paradoxical pressures. The need to adapt to new ways of understanding sex and sexuality, the slow dissolution of the patriarchal family, in which younger members perpetuate old repressive ideals and the various legislative attempts at regulating social norms and equality all contributed to a 'disarranged' development of HIV in Portugal. If, borrowing Bury's concept, HIV in Portugal has had a disrupted biography at the socio-political and historical levels, this in turn is reflected in individual experiences of living with HIV, as the current study demonstrates.

Beyond the structural issues affecting the response to HIV in Portugal, HIV is undergoing an identity crisis too – i.e. the current general climate surrounding HIV is one of change and paradigmatic shift. The re-categorisation of HIV from an infectious disease to a chronic illness has created a number of challenges for those living with it. At an individual level, for example, the narratives of men in the current study

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suggest the need for alternative interpretations of adaptation to chronic medically defined conditions.

Drawing upon the issues discussed in Chapter 4, it is clear that health and illness, both as abstract concepts and as practical expressions, are deeply rooted in social constructions of gender. In one of the few studies looking at chronic illness adaptation in men, Charmaz (1994) wrote:

> Serious chronic illness threatens men's taken-for-granted masculine identities and leads to identity dilemmas that can reoccur again and again. (…) What is it like to be an active, productive man one moment and a patient who faces death the next? What is it like to change one's view of oneself accordingly? Which identity dilemmas does living with continued uncertainty pose for men? How do they handle them? When do they make identity changes? When do they try to preserve a former self? (p. 270)

Charmaz identified a number of 'identity dilemmas', which she defined as a loss of valued attributes, physical functions, social roles and personal pursuits through illness. The notion of identity dilemma, which relates very closely to that of disrupted biography in Bury's framework, is useful in mapping some of the gender-specific issues that men may face when diagnosed with a chronic illness. It also ensures individuality because it is rooted in the personal identities of the self. In a way, both frameworks complement each other because Charmaz's aimed to address the apparent gender-neutrality that hitherto had dominated literature on chronic illness processes, including Bury's framework. She concluded that:

> an uneasy tension exists between valued identities and disparaged, that is, denigrated or shameful, ones. A man can gain strengthened identity through experiencing illness or can suffer a diminished one. These are not mutually exclusive categories. (p. 283)

Similar to Bury, her study is somewhat divorced from the prevailing social and historical context and does not focus on HIV. Given the context in which the current study has taken place, and embracing both Charmaz's and Bury's frameworks, one can conclude that, not only is HIV in Portugal organised in a way that makes it difficult for people affected by it to make sense of their experience at political, social and institutional levels, a number of other issues are added to the equation based on the fact that these are men living with HIV, and not women.

In the literature review presented earlier in this thesis, it was argued that men with similar social disadvantages as women tend to experience poorer health outcomes in relation to chronic illness and mortality. However, as was also mentioned, men's health tends to be overlooked and, above all, rarely interrogated bearing in mind the implications of masculinity may have on each man. For example, Courtenay (2000) highlighted that men tend to prefer to face risk and physical discomfort instead of being associated with traits perceived to be feminine, such as vulnerability, dependence and weakness. This may offer some explanation for the fact that often men delay seeking health care support or asking for help, which are seen as emasculating behaviours. Evans et al., (2011) argued that the link between masculinity and health is most evident in situations when an illness or disease is specifically identified as 'feminine'. They used the example of breast cancer to illustrate the point: although only a very small number of men are diagnosed with it, those who are have, not only delayed their diagnosis due to their threatened masculine identities but also reported feeling "shocked and foolish" for having been diagnosed with a "female cancer" (Naymark, 2006; Pituskin et al., 2007).

Comparatively, the current study can offer an explanation for the difficulties in adaptation of those men who do not identified as gay: their masculine identities as heterosexual men mean that they are likely to experience embarrassment and

shame for being diagnosed with a condition that is traditionally associated with more marginalised forms of masculinity (Connell, 1995).

Similarly, a number of men suggested that processes of identity adaptation following diagnosis with a life-long disease tend to benefit from previous experiences of adaptation to a disrupted identity. This was particularly relevant for men who self-identified as gay. There were many references to a similar path that they had to follow when adjusting to a new identity with regards to their sexuality ('coming out') and their HIV diagnosis (disclosure). Some men even said that HIV-positive people should all 'come-out' as that would allow others to realise just how many people are living with HIV, not just those belonging to socially marginal groups. Yet again, the idea of visibility re-appears in men's narratives, this time mirroring the call for visibility, tolerance and respect towards sexual minorities. In particular, those men who were more avid supporters of this call for visibility tended to be either involved in activism linked to LGBT rights, or could be regarded as 'expert patients'. They were also the men who were referred to by professionals as being key contacts, in case they needed to advise someone who had been recently diagnosed, and thus gain some understanding from someone already living with HIV.

In sum, those who struggled more in adapting to HIV are similarly those who found it harder to embrace their condition and feel comfortable with the diagnosis, disclosure process and so on. This compounding effect may mean that heterosexual men who live with HIV in Portugal represent a marginalised group in that their needs seem to be overlooked by government action. As pointed out earlier, their masculine identities are also greatly affected by the diagnosis, and the support networks that were created within the informal sector may target, and therefore privilege MSM and gay men, who are then more motivated to learn about their condition, offer support to others and generally feel better adapted to their diagnosis.

However, and despite the difficulties faced by some heterosexual men in adapting to a life with HIV, a number of men in this study (including some heterosexual men) had adapted to living with it in a positive and meaningful way. Often, however it is the structural aspects of their lives, those at a more macro level, and therefore harder to control directly, that subject them to a disrupted sense of biography. In particular, as some men revealed, it is possible to live with HIV and barely remember or mention it, not because of fear or repression, but because that aspect of identity – being a person living with HIV – has been so well accommodated into the person's lifestyle. However, when seeking to establish relationships with others, these same men are often reminded that processes of adaptation are not solely individual, and that it may not be enough for them to adapt individually when the overarching context of their lives forces them to look beyond the self. The various tensions that characterise HIV at a social level therefore impact directly on the ways people living with HIV adjust and (re)adapt to their conditions. The emphasis that the literature and programmes also place on those who 'suffer' from a chronic illness, as opposed to those who are well adjusted, also may prescribe a sick role which it is difficult to adjust to.

Some men resorted to a level of abjection when faced with these contradictions and struggles. This was more common if the person displayed visible symptoms of living with HIV. Despite this being uncommon, there is a sense of uncertainty as to whether or not others can 'see' that they are living with HIV. And processes of abjection also took place beyond the individual. As this study has shown, practices of sero-sorting and non-disclosure are ways of avoiding the potential consequences of explicitly dealing with diagnosis. The 'waiting area syndrome'[96], that many men referred to, also highlighted how some men may choose to remain invisible even when present

[96] This was commonly reported amongst the men in the study. When encountering a familiar face at the HIV clinic waiting room, some people often avoid speaking or making any kind of contact, so as to remain invisible and not identifiable as being HIV-positive.

within a clinical space. Their experiences may reflect a form of self-stigma, or simply a defence mechanism. In any case, these practices highlight a tension within the person's identity that adds complexity to understanding chronic illness at a macro level too.

Transcending stigma

Popular perceptions of HIV in Portugal are rich in pre-conceptions, prejudice and ignorance, and create a favourable ground on which stigma and discrimination can flourish. As was argued in chapter 2, stigma and discrimination influence one another across a range of situations and settings. Despite stigma and discrimination being intimately related concepts, there is more than a simple conceptual difference between both terms and what they mean in practice. Stigma, as described by Goffman (1963), refers to any attribute or characteristic that, because it confers a degree of difference, can become discrediting for that person. Discrimination, which is the practical face of stigma, refers to the negative actions and behaviours by which discredit is shown towards that person or group. In other words, while stigma refers to the motives by which someone is caused to discredit and reject another person or group, discrimination refers to actions that an individual or group takes to explicitly or implicitly demonstrate their aversion to those individuals or groups.

Despite this, both terms tend to be used interchangeably, particularly in HIV research. This is, in itself, a reflection of how they have become a complex integral aspect of living with HIV (Parker and Aggleton, 2003; Scambler, 2009). Unfortunately, the origin or the motive behind a particular use of either term or both is not always clear, also because, as seen in chapter 2, the concept of stigma can encapsulate a range of meanings and applications, including self, enacted or felt

stigma[97]. It is crucial therefore to recognise that some theoretical notions of stigma and discrimination may not match emic experiences of stigma and discrimination, which tend to be more heterogeneous and multi-dimensional.

Additionally, writing about chronic illnesses in general in western countries, Millen and Walker (2001, p. 93) have argued that the importance attributed to notions of stigma and discrimination in the literature as "a brake on full social integration of people with chronic illness seemed to pale away and even appear an outdated concept". Scambler has added that "while Goffman's contribution retains its insight, subtlety and theoretical acuity, it is time to move on, or rather *beyond*" (2009, p. 442). Barroso and Powell-Cope (2000)'s meta-analysis of qualitative research on living with HIV across different contexts showed that there are a number of similar issues relating to stigma of people living with HIV. In their analysis, as in the current study, narratives of fear, rejection and shame were commonly reported as the visible effects of discrimination. As such, notions of stigma are often linked to one (or all) of the above.

Moving beyond existing conceptualisations of stigma and discrimination, as Scambler suggested, involves acknowledging that people living with HIV often have more nuanced and sophisticated experiences than existing notions of stigma and discrimination allow for. A reinterpretation of HIV-related stigma and discrimination should also acknowledge that some people living with HIV may not necessarily

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[97] Self-stigma (also known as internalised stigma) is a form of stigma by which people may accept society's stigmatising notions towards their particular stigmatised identity factor, and suffer diminished self-esteem and self-efficacy as a result. This is widely encountered in mental illness research (see Gallo, 1994, for example). Enacted stigma is the type of stigma that occurs towards someone whose stigmatising identity factor or condition are obvious and therefore they are more exposed to discriminatory practice from others. One example would be how people identify lipodystrophy as a visible sign of someone living with HIV and hence discriminate against that person based on that. Felt stigma is the perceived social rejection of a stigmatised condition which is shared by the sufferer. This is partly linked with the idea of self-stigma, in that most people who suffer felt stigma may actually feel diminished in their own self-worth. However, felt stigma is more connected with the perception of others towards themselves and their condition.

engage in pre-established conceptualisations of shame and fear that are abundant in the stigma literature; nor do their perceived notions of stigma allude to those pre-established by previous research. This certainly was the case for men in the current study.

However, as was explained in chapter 6, specific stigmatising experiences were not always easy to identify, and respondents oscillated between a definition that encompassed both a perception of stigma and the enactment of it. To some extent, this may be due to the recruitment procedure that was adopted. By contacting men who were accessing care and support through a NGO or a clinic, it may be possible that they were also less likely to highlight issues of malpractice or discriminatory action within those settings, had they experienced this before, or recently. Perhaps due to similar reasons, those who could identify stigma often recalled traumatic or upsetting experiences that had occurred sometime in the past, and described these as something that was not always fully materialised. This 'invisible' stigma could have similarly harsh effects on those experiencing it – and the uncertainty it generated contributed to isolation and anxiety, and encouraged non-disclosure. The various narratives that alluded to this form of stigma (which can be characterised as a form of 'felt stigma') demonstrate that overtly enacted stigmatisation may be less common these days compared to the beginning of the epidemic. In any case, men's narratives revealed a marked unevenness in the experience of stigma that must be acknowledged. Similarly, polarised experiences of living with HIV, alongside the crisis of identity affecting the interpretation of HIV by society, make it difficult for men to predict the reactions from other members of society in relation to being HIV positive. This may contribute to a feeling of "repressed fear" that some men alluded to.

As noted earlier, the Portuguese government's response to the epidemic has been neither consistent nor effective in addressing HIV-related stigma. One example of

this can be seen in the campaign of 1994 which aimed at reducing discrimination and stigma. A person curled up in a corner of a dark room appears in one image, and another person sat on the ledge of a window in another picture. These images, as Teles and Amaro (2006) explained, aimed to encourage a sense of solidarity and understanding towards people living with HIV. However, they may have instead suggested that death (suicide) and despair were the main characteristics of being HIV-positive, which undercuts the aim of the campaign.

It is not possible to understand HIV-related stigma and discrimination without appreciating the historical, cultural and societal contexts within which stigma is enacted. In other words, the experiences of stigma that were reported by men in the study were deeply affected by and may reflect some of the broader social tensions within Portugal referred to earlier. For example, certain accounts revealed prejudiced attitudes towards those who inject drugs, or expressed a moralistic stance towards issues of sex, reproduction and sexuality – as witnessed in the quote from Valdemar (chapter 6, page 173) in which he described a nurse's negative attitude towards his and his wife's choice of conceiving a child. These issues were mentioned not only by men, but also by professionals, as is revealed in Silvia's words when explaining how difficult it was to talk about gay sex, given her conservative upbringing (chapter 6, page 185). Prejudice permeates professional practices and personal attitudes and behaviours, and thus perpetuate issues of stigma and discrimination across society.

In many respects, Portugal bloomed late on questions of sex and sexuality, influenced by a long period of dictatorship and the power of the Catholic Church to define what is normal. This means that issues pertaining to sex and sexuality, as well as drug use, tend to belong to a more individualised and almost 'secretive' arena. As Portugal modernises, there is more open public discussion of sexual intimacy but this, as Aboim (2010) explained, this also allows for new forms of sexual regulation.

These changes are evident in the latest survey of Portuguese sexualities (Ferreira and Cabral, 2010) which revealed, for example, that younger people have a considerably wider network of people with whom they are comfortable discussing details of their sex lives. These networks are usually made up of friends rather than family members – the latter group being considered more conservative towards issues of multiple partners, infidelity and so on.

In contrast, the majority of man taking part in that survey reported not having someone, a confidant, to talk about their sexual life. This reinforces 'silencing' – i.e. the unspoken narratives that seem to characterise some of the experiences of the men in this study. For example, when Martim (40), who was infected through sex with another man, was admitted to hospital and was diagnosed on the same occasion, his parents were also informed of his status at the time. He explained:

> my mother was like, 'but you don't do drugs, you're not into that … you're not a junkie'. And I said nothing. Later I overheard my father saying that it must have been because I had unprotected sex with a prostitute. In a way, it would have been a bigger disappointment for them if I was taking drugs without them knowing about it.

Assumptions and silences, words left unspoken, practices of hiding and omission characterise the attitudes and behaviours of many men in the study. They are also picked up by professionals, who often feel they are not equipped to dealing with the full complexities of men's lives, and prefer to ignore and focus instead on the clinical management of each case. It should be expected then, for such a socially charged illness as HIV, to be strongly influenced by these predetermined aspects. Putting it another way, existing social determinants have the power to feed into, and sometimes exacerbate, the stigma associated with HIV. At the same time, however, previous experiences of stigma (e.g. homophobia, racism) may lessen the impact of subsequent stigmatisation on grounds of HIV. As was explained earlier in this

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chapter, those men considered expert patients also tended to be actively engaged in supporting other people living with HIV or worked alongside NGOs. They showed themselves as being better adapted to dealing with the various issues that living with HIV may present. Similarly, adapting to being gay, or coping with racial prejudice, may better equip a person for living with HIV in a less stigmatised manner. This is an important and major insight. Despite the adversity they had faced, the majority of men in the present study seemed reasonably well-adjusted and had not adopted the sick role – highlighting how part of the adjustment to living with HIV may encompass positive and meaningful experiences which help individuals cope with the discrediting traditionally associated with HIV.

Chapter summary

The previous four chapters have offered an analysis of the experiences of men living with HIV in Portugal, from a variety of perspectives. Grounded in men's narratives, this analysis focused, initially, on how gender norms work their way through the lived experiences of men in the study. It then highlighted men's trajectories with regards to adapting to life with HIV, from the point of view of the patient career (when focusing on frameworks to understanding living with a chronic illness) and the more holistic approach (focusing on the overarching issues that affect men with HIV, including stigma and discrimination).

The current chapter, which aimed to position the previous chapters against current discussions surrounding the experiences of living with HIV, leads to a number of conclusions that may have relevance beyond the specific context in which work took place. Of special importance, the current study focuses on the experiences of men living with HIV in a developed country. Current studies focusing on these issues tend

to be focused not only on specific (vulnerable or most-at risk) populations, but take place within the developing world. The findings of this study may therefore shed some light on the experiences of living with HIV in the Western world, as well as offering some insight into the particular narratives of uncommonly reported experiences, such as those from heterosexual men.

More specifically, by locating its findings within the socio-political context of Portugal, this study offers not only a unique insight into the biography of HIV, but also evidence of how more macro determinants impact directly in the ways in which men adjusted to living with HIV. HIV in Portugal has had a disrupted biography at the socio-political and historical levels; this in turn is reflected in individual experiences of living with HIV.

As the history of the epidemic unfolded, changes at socio-political levels in turn result in other changes at more individual levels. Experiences of stigma, for example, shifted from being overtly enacted in the past, to more subdued and less visible in the present. The various tensions that characterise HIV at a social level therefore unswervingly influence the ways people living with HIV adjust and (re)adapt to their conditions.

Finally, living with HIV is not a linear process. Indeed, as the study showed, there are a number of different trajectories that men followed with regards to different aspects of their lives. Often, these trajectories were embedded in a range of opposing tensions: the need to 'come out' against the wish to remain anonymous; the want to be accepted against the fear of rejection. Ultimately, this highlights the need for further empirical enquiry into the variability of experiences that exist in living with HIV.

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APPENDICES

Appendix 1

Consent Forms (Men and Professionals interviewed)

Universidade de Londres – Instituto de Educação

Viver com HIV: homens e masculinidades em Portugal

O estudo que lhe proponho participar faz parte do curso de Doutoramento em Socio-Antropologia Médica que frequento na Universidade de Londres, em Inglaterra.

Este estudo tem como objectivo explorar as experiências e as perspectivas dos indivíduos do sexo masculino infectados com o VIH em Portugal, no que respeita à sua saúde sexual e necessidades socias, em contextos clínicos (hospital) e sociais (organizações de apoio), examinando as implicações que estes possuem nos seus padrões de **saúde** e **bem-estar**.

Este estudo envolve entrevistas individuais a adultos do sexo masculino com o diagnóstico de infecção por VIH e profissionais de saúde e outros profissionais envolvidos no cuidado a esses indivíduos.
As entrevistas serão gravadas por suporte audio, e depois transcritas pelo investigador.
Tanto as notas como a transcrição das entrevistas serão apenas lidas pelo investigador. Para além disso, serão utilizados pseudónimos para identificar todos os participantes.

Toda a informação recolhida será codificada para que não seja possível a identificação de quem participou no estudo, ou das instituições envolvidas, de modo a garantir o anonimato e confidencialidade dos dados.
Não existe nenhuma implicação física ou psicológica em participar, ou seja, não será necessário colher sangue, por exemplo, ou preencher testes psicológicos.

Este estudo irá proporcionar-lhe uma oportunidade para reflectir sobre os seus conhecimentos e situação pessoal ou profissional a respeito da infecção por VIH.

É importante saber ainda que a sua participação neste estudo é completamente voluntária e que pode recusar-se ou interromper a sua participação a qualquer momento, sem penalizações ou perda dos benefícios que tem direito. Caso decida abandonar o estudo, o investigador deve ser informado, sem necessidade de justificação, e a sua participação será imediatamente interrompida.

Se ainda tiver perguntas em relação ao estudo, pode discuti-las com o investigador a qualquer altura.

Muito obrigado pela atenção dispensada!

DECLARAÇÃO DE CONSENTIMENTO E ASSINATURA

Li as informações acima e entendi o propósito deste estudo assim como os benefícios e riscos potenciais da participação no mesmo. Tive a oportunidade de fazer perguntas e todas foram respondidas. Eu, por intermédio deste, dou livremente o meu consentimento para participar neste estudo.
Entendo que poderei ser convidado para uma entrevista (ou várias) que serão gravadas, e que não receberei compensação monetária pela minha participação neste estudo.

Eu recebi uma cópia assinada deste formulário de consentimento.

_____   ____/ ____/ ____
(Assinatura do Participante)   dia   mês   ano

_____   ____/ ____/ ____
(Assinatura do Investigador)   dia   mês   ano

Appendix 2

Interview Guides
(ENG/POR)

Interview Guide I – Men living with HIV

- Prior to the interview, all participants will be informed of the nature and objectives of the study and verbal and written consent will be sought.
- Immediately before the interview starts, the researcher will stress that the interview will be recorded and that everything that will be said is confidential and will be anonymised.
- The researcher will also inform the interviewees that they can stop at any moment they wish, and are free not to answer any question they wish.

General information

- Age
- Years since diagnosis of HIV infection
- Years attending hospital/organisation
- Route of transmission
- Years on ARVs

HIV/AIDS issues

1. Where did you find out you had HIV?
2. Can you tell me about some of your feelings and reactions when you were first informed you had HIV?
3. What immediate support did you receive? Who/Where from?
4. Did you inform people at the time about the change in your HIV status? Have you told people subsequently? Who? How was their reaction and how did you feel by doing it?
5. Where would you normally go if you would like to receive support (treatment, social support or counselling) regarding HIV?
6. Do you know anyone with HIV? If so, how and where did you meet them? Do you meet other people living with HIV regularly?
7. Do you think it helps meeting other people living with HIV? How so?
8. What is your opinion on the way HIV is presented by the media?
9. How is HIV perceived by Portuguese society generally? Have there been changes over time? Are things getting better?

Reproductive and sexual health and rights

10. How has HIV affected your relationships with people generally?
11. Are you currently involved in a relationship? What kind of relationship is it?
12. (Based on Q9) Can you tell me about your experiences of informing your partner(s) of your status?
13. Do you plan on having children? If not, why?
14. How have you found that HIV affects your relationships in general?
15. What can you tell me about the options there are regarding people with HIV and reproduction? Have you thought about accessing these services?
16. There are some studies that have shown that people with HIV have problems relating to their sex life, some related to side effects of the medication, and others because they don't want to tell people of their status or when they tell, they are rejected by others. What is your opinion on this?

17. Have you ever experienced any of the problems mentioned on the previous question?

Experiences of health care

18. Do you consider having good medical and social support to any health problems you may get?
19. Do you feel you have you ever been discriminated against based on your HIV status or your sexual orientation?
20. How often do you visit a hospital for your routine HIV checkups? Other checkups?
21. In your opinion what is the impact of the support people receive here (hospital/NGO) on people living with HIV?
22. Have you ever been hospitalised as a consequence of HIV infection? How was that experience?
23. Can you tell me about your views on how HIV is seen inside the hospital? Do you think people with HIV are treated differently than other patients?
24. How happy are you with your current medical and health care support? What are the good things about it? What is less good?
25. Are there any services that you cannot get from this hospital and would like to?
26. Do you feel you can communicate your ideas and thoughts to your doctor, nurse, etc. fully?
27. Have you ever suffered discrimination from anyone involved in your health care?
28. Have you ever had any issues regarding receiving the treatment you needed, for example side effects, difficulties in taking medication, drug resistance or lack of information?

Interview Guide II – Health professionals

General information

- Age
- Years working in HIV
- Years working at that hospital/organisation
- Profession
- Gender

HIV/AIDS issues

1. How did you come to work in this field?
2. What is it like working in this field (HIV Medicine)? What is good? What is less good?
3. What are the biggest challenges surrounding your work and HIV in general? And what is rewarding about it?
4. In your opinion, how have things changed over the years regarding HIV?
5. Do you feel your initial training was comprehensive enough in the area of HIV? And do you feel you have received enough continuing professional development in this field?
6. Are there any changes you would suggest regarding the training doctors/nurses receive on HIV?

Reproductive and sexual rights

7. do you talk to patients/clients about sex and sexuality? What kinds of things do you talk about?
8. Do your patients/clients come to you for advice about sex?
9. How do you think HIV affects their sexual life and their relationships?
10. What are your patients/clients' main concerns regarding reproduction?
11. Do you think your patients/clients have difficulty in accessing contraception or other services related to reproduction?
12. Are they sufficiently informed about their options?
13. How would you describe the current governmental support for people living with HIV, specifically in terms of their sexual and reproductive health?
14. Do you think there is stigma associated with people living with HIV within this hospital/NGO? Explain.

Experiences of health care

15. How happy are you with the medical and health care support you are able to provide to your patients/clients?
16. Do you feel you can communicate well with them? On what issues? On what issues is communication more difficult?

17. Have you ever suffered negative responses or discrimination from anyone because you work in the area of HIV?
18. Do you feel the health team is well equipped to provide all the support necessary: social, clinical and psychological support? If not, what would you like to see implemented?

PORTUGUESE VERSION

Guião de entrevista

* Antes da entrevista propriamente dita, os objectivos e o tipo de estudo serão apresentados a todos os participantes, e o consentimento informado será obtido verbalemte e por escrito. Todos os participantes serão ainda informados de que a entrevista será gravada em suporte audio, mas que toda a informação providenciada será tratada de forma anónima e confidencial. Todos os participantes serãao ainda informados de que podem desistir a qualquer momento ou optar por não responder a uma ou mais questões, sem que necessitem apresentar justificação para tal.

GUIÃO 1 – Homens

Informação Geral

- Idade
- Número de anos a visitar o hospital
- Número de anos ARVs
- Número de anos desde diagnóstico VIH/via de transmissão

Questões relativas ao VIH/SIDA

1. Em que circunstâncias é que descobriu/foi informado do seu diagnóstico de infecção por VIH?
2. Que tipo de apoio (social, psicológico ou médico) recebeu nessa altura?
3. Após o seu diagnóstico, informou alguém acerca desse facto? Qual foi a reacção que obteve?
4. A onde se dirige normalmente para receber apoio social, psicológico ou médico?
5. Qual é a sua opinião acerca do modo como o VIH é retratado nos meios de comunicação social?
6. Como é que a infecção por VIH é vista pela sociedade Portuguesa? Sente que têm havido mudanças ao longo do tempo?
7. Já alguma vez se sentiu discriminado devido a ser seropositivo para o VIH?

Questões relativas a saúde e direitos sexuais e reprodutivos

8. Como é que o seu diagnóstico afectou o estabelecimento de relações?
9. Alguma vez teve que informar o/a seu/sua perceiro/a acerca do seu diagnóstico? Que reacções obteve? Como se sentiu?
10. Quais são as opções disponíveis para pessoas seropositivas para o VIH no que respeita a reprodução? Já utilizou/pensa utilizar alguns desses serviços?
11. Alguns estudos mostram que pessoas seropositivas para o VIH apresentam problemas relacionados com a vida sexual, nomeadamente efeitos secundários da medicação ou outros problemas relacionados com o receio de informar os parceiros acerca do diagnóstico. Qual é a sua opinião acerca destes factos?

Questões relativas a cuidados de saúde

12. Considera que os cuidados de saúde que recebem são apropriados?
13. Já alguma vez foi hospitalizado como consequência da infecção por VIH?
14. Qual a sua opinião em relação ao modo como as pessoas com VIH são vistos dentro do hospital?
15. Acha que existem alguns serviços que gostaria de receber do hospital mas não recebe de momento?
16. Considera que existe uma boa comunicação entre si e os membros da sua equipa de cuidados de saúde?
17. Já alguma vez se sentiu discriminado dentro do hospital? Explique.
18. Caso tenha algum problema relacionado com os seus cuidados de saúde, onde ou a quem se dirige em primeiro lugar?

GUIÃO 2 – Profissionais de saúde

Informação Geral

- Idade
- Número de anos a trabalhar com pessoas VIH+
- Número de anos a exercer funções no hospital
- Categoria profissional
- Sexo

Questões relacionadas com VIH/SIDA

1. Explique como começou a trabalhar nesta área?
2. Quais os aspectos mais e menos positivos em trabalhar nesta área?
3. Qual a sua opinião acerca da forma como o VIH tem evoluido em termos científicos e sociais?
4. Considera que recebeu formação suficiente nesta área durante a licenciatura/bacharelato? E durante a carreira profissional?
5. Que mudanças gostaria de ver implementadas a nível da formação de médicos/enfermeiros relativamente ao cuidado de pessoas com VIH?

Questões relativas a saúde e direitos sexuais e reprodutivos

6. Fala com os seus clientes acerca de sexo e sexualidade?
7. Acha que o diagnóstico positivo de infecção por VIH afecta a vida sexual e reprodutiva dos seus clientes?
8. Quais as questões mais frequentes que os seus clientes lhe colocam relativamente a reprodução?
9. Considera que os seus clientes estão bem informados acerca das suas opções a nível reprodutivo?
10. Como descreve o apoio governamental que existe relativamente às opções reprodutivas disponíveis a pessoas com VIH?

Questões relativas aos cuidados de saúde

11. Sente-se satisfeita/o com o apoio e os cuidados que presta aos seus clientes?
12. Sente que comunica eficazmente com os seus clientes? Que áreas são mais dificeis de abordar?
13. Acha que existe discriminação em relação aos seus clientes, dentro do hospital? E em relação a si e aos seus colegas?
14. Considera que a equipa de saúde onde trabalha proporciona os cuidados necessários aos seus clientes? Caso negativo, que mudanças faria?

Appendix 3

Participant Vignettes

Participant Alias, Age, sexual orientation	Biographical Profile
Gaspar, 44, heterosexual	Gaspar has always lived and worked in urban Portugal, despite his parents being originally from a rural area and having moved to the city looking for a better life. Employed as a manual labourer during the course of the research process, Gaspar is a single parent. The mother of his child passed away. He did not have a partner at the time. Contacted through a local NGO, where Gaspar seeks social support on a regular basis.
Valdemar, 40, heterosexual	Valdemar was born in the colonial Angola, and moved to urban Portugal as a child. He started experimenting with drugs in his adolescence when his parents were divorcing. He, too, is divorced and has two children. He lives in a large urban area and works in a family company. He was recruited through a NGO, in which he accesses social support.
Salvador, 36, heterosexual	Salvador lives in a large urban area, was unemployed and did not have children or a partner. He received psychological and social support through the NGO and has lived with HIV for 16 years.
Paco, 42, homosexual	Paco was seeking support from the NGO as he had become unemployed and was going through severe financial difficulty. He had always lived and worked in a large urban area, and was single. He has been living with HIV for 18 years.
Patricio, 29, homosexual	Patricio was recently diagnosed at the time of the data collection. He had a high-profile job in an urban centre. He was recruited through snowballing, as he did not receive any support. He was single and starting a relationship at the time. Born in a suburb of a large city, he moved to the city later as an adult. He said he had a very protected childhood.
Gabriel, 52, homosexual	Gabriel was a (early) retired professor. Despite always feeling attracted to the same sex, he got married and had three children. He later divorced. Upon being diagnosed and initiating ARVs, Gabriel suffered severe side effects, and hence was seeking support from an NGO. He was in a relationship.
Agostinho, 43, homosexual	Agostinho was university-educated and was brought up by his grandparents in a small village, as his parents often lived in separate locations due to his father's job as a businessman. He feels he was heterosexual until the age of 31. Had a 9 year non-consummated relationship with a woman. Had his sexual debut with his second girlfriend at the age of 30. Currently single.
Leonardo, 31, homosexual	Leonardo was born in the southern countryside of Portugal and moved to a large urban centre in order to undertake university studies. He considered himself to be bisexual until recently. He married his first serious girlfriend and had three children. The marriage lasted 5 years. Leonardo worked in education, and had done some volunteering work with some NGOs.
Pedro, 50, homosexual	Pedro was born in the colonial Africa, which he felt was an important aspect of his personality. He felt the African upbringing he received allowed him to be more open minded and more tolerant. He moved to Portugal aged 17, and considered himself to

	be bisexual, having had his sexual debut aged 9. He came out to his family as gay aged 21 and worked in various LGBT and HIV NGOs supporting people with HIV and gay men.
Vicente, 54, bisexual	Vicente was brought up in a small village in countryside Portugal. His parents were employed in manual jobs and experienced some financial difficulties whilst growing up. Said he received a very conservative upbringing, with very little demonstration of emotions. When he moved to the big city, he trained as a police-officer. He then retired and was working freelance as a television and film extra, as well as involved in local politics. He did not identify with any sexual identity but said he had had sex with both men and women throughout his life. He was single.
Luciano, 37, homosexual	Luciano was born and bred in urban Portugal. Educated and working in a high profile job, he had lived and worked in the USA, which he felt was beneficial for him in understanding his sexuality better. He had only had 3 relationships, the last of which with the man who allegedly infected Luciano. He had never accessed support from a NGO, nor felt he would want to.
Filipe, 54, homosexual	Filipe was born in Africa and received a very privileged yet conservative education. Upon moving to Portugal, his family established itself in a wealthy suburb. Filipe retired after being diagnosed HIV positive. He was single and the only support he required and received was from his private physician.
Pascoal, 37, heterosexual	Pascoal was born in countryside Portugal and was still living there. He considered himself to be very religious and was keen on passing on those values to his children. He was married and worked as a health professional.
Martim, 40, homosexual	Martim was born in Africa and moved to Portugal in the mid-1970s. Initially he lived with his uncle and aunt. He did not enjoy school but managed to get his A-levels. After that he started working in various temporary jobs. He had his sexual debut with a girl when he was 16, and ten years later with a man. He was single and was still living in the same rural area where he moved to after arriving from Africa.
Samuel, 48, homosexual	Samuel was born in Africa and returnd to Portugal in his teenage years. He lived in many different countries throughout his life. He was single. And worked as an activist for people living with HIV, also running his own support group.
Serafim, 53, heterosexual	Serafim was born in India, as his father was working there in the army. He then moved to Portugal where he was educated in the military academy and later went to Oxford University to study. He married at 21 and had children. He worked in the army all his life and was infected through a blood transfusion whilst on operation in Africa.
Cristiano, 38, heterosexual	Cristiano was born in Africa and moved to Portugal aged 3. Having moved from city to city, his family then established itself in a deprived suburb. He had a troubled adolescence, and eventually started using and selling drugs. He lived in the UK for a while. He had some employment difficulties and received some support from a few NGOs. Had a relationship with a 'special friend'.
Leopoldo, 35, homosexual	Leopoldo was born and bred in a small city in northern Portugal, and had always lived there. He worked as an artist. He was single. He had never accessed support from an NGO, but occasionally did some volunteering with a local one.

Rodrigo, 35, heterosexual	Rodrigo was born in urban Portugal and worked as an office clerk since leaving school. He never married but had a few serious girlfriends. He did not received any support from NGOs as he felt he did not need to.
Mateus, 39, homosexual	Mateus was born and bred in a large urban centre. He worked as an architect and as an LGBT activist in his spare time. He did not have a relationship at the time of the study.
Alice, social worker	Alice had been working in the field of HIV for 8 years, as part of a NGO which offers support to people living with HIV only.
Alfredo, nurse	Alfredo was a registered nurse who specialised in medical and surgical nursing care. He had worked in a infectious diseases ward for 10 years.
Romeu, support worker	Romeu worked as a support worker for a NGO 5 years. Most of his work took the form of offering home-based support for people living with HIV in a large suburban area.
Maria, psychologist	Maria had been a psychologist for 10 years and had worked in the field of HIV for 2 years. She was also involved in supporting incarcerated people living with HIV.
Roberto, physician	Roberto is a specialist infectious diseases consultant, and has been working in the field of HIV medicine for 12 years, mostly in a large university hospital.
Guilherme, physician	Guilherme is an consultant infectologist who has worked in the filed of HIV medicine for over 20 years.
Silvia, nurse	Silvia is a general nurse who cares for people living with HIV. She has been working in the field for 13 years.
Marcia, nurse	Marcia currently works in A&E but has worked in infectious diseases in the past. She continues to care for people living with HIV when in A&E, and has a special interest in the field, having done postgraduate studies in the area.
Manuel, social worker	Manuel is a mental health specialist social worker who also provides support for people living with HIV in a large urban centre in Portugal. He has worked in the field for over 20 years.
Paula, nurse	Paula is a specialist nurse, and a nurse in charge of an HIV ward in a large hospital. Most of her work entails caring for people living with HIV, both from a clinical perspective, but also engaging with social services for those who require further support.

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