

**Strategies of Resisting the Stigma of HIV in Contemporary Anglo-American  
Society: A Sociological Study**

Claudio Bardella

London School of Economics

PhD Sociology

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## **Abstract**

The thesis investigates particular micrological strategies of resistance which have coalesced around the stigma of the HIV virus in the context of the AIDS crisis.

‘Western’ AIDS is a disease that has mainly affected homosexual populations; such micrological strategies have thus been mainly articulated by different factions of the subculture.

Homosexual behaviour has been systematically constrained. Homosexuality has been demonised by Christian discourse, criminalised by civil society, and medicalised by science. The thesis analyses the different systems of oppression that the homosexual body has been subjected to as a framework for the development of the analysis of current strategies of resistance to the stigma inherent in homosexual embodiment. The stigma of deviant sexuality has been magnified by the advent of the transmission of a potentially deadly virus through the enactment of (homo)sexuality.

The thesis is both empirical as well as theoretical. Qualitative analysis techniques have been employed in order to investigate how specific micrological strategies of resistance have colluded and interacted in the construction of individual identities largely forged around HIV. On a subcultural dimension both ‘spontaneous’ and ‘conscious’ resistance projects have been analysed not only on a symbolic level, but in relation to their particular role in individual processes of identity construction. ‘Spontaneous’ resistance projects represent resistance strategies that emanate from the grassroots of the affected constituency whereas ‘conscious’ resistance projects constitute culturally or structurally elaborated strategies that have either emerged from or been appropriated by specific factions of gay community

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## Chapter 1:

### Positive Homosexualities: The Role of Resistance in the Construction of Identity

The different meanings of disease, illness, and sickness reflect the sociologically and philosophically problematic Cartesian notion, which splits mind from body. The Cartesian framework results in the assignment of different varnishes to the same phenomenon. As such, human disorders are layered into three dimensions: the physical and biological, or disease; the subjective, or illness; and the social, or sickness (Turner, 1995). However, the relationship between these dimensions is more intricate than might be immediately apparent, and is dependent on social and cultural factors.<sup>1</sup> The power of the biomedical model, the principal western paradigm that deals with malady, is established through medical discourse (Turner, 1995). In order to understand how the dynamics of such a power relationship has played out in the context of Acquired Immune Deficiency Syndrome (AIDS), we will see how multi-layered processes of knowledge making have structured the epistemic contexts within which the fields of knowledge of the aetiology of HIV/AIDS, and of its treatment strategies, have been constituted.<sup>2</sup>

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<sup>1</sup> For example, the acute infectious diseases, which plagued nineteenth century individuals, have been practically eradicated in industrial societies. However, the specific socio-economic characteristics of industrialised society have been responsible for the new 'epidemic' of long-term chronic disorders that now interfere with the optimal functioning of contemporary bodies. Another instance is the cultural trend of challenge to a hitherto indisputable medical authority. This trend can be illustrated by the increasing tendency of so-called dis-eased individuals to refute their categorisation as ill people by declaring to be 'well within themselves'. Despite whatever real physiological abnormalities such individuals might present, their challenge to medical definitions of normality suggest a socially constructed dimension to medical diagnoses (Taylor and Field, 1993).

<sup>2</sup> Such processes of knowledge-making involve: the thematic organisation of certain concepts and statements; the legitimisation of some 'truth-claimers' rather than others; the assertion of certain statements as 'serious'; and the critical processes through which so-called 'serious' statements are assessed. As such, 'discursive formations' shape the possibilities for what can or cannot be conceived. 'Truth-games' are consequently dependent on the socio-historical configurations of a discursive field, which originate out of relations of power and knowledge (Rouse, 1994:93-94).

The 'epidemic of signification' and the multitude of discursive practices, which inscribe and contest the meaning of Acquired Immune Deficiency Syndrome (AIDS) and of the Human Immunodeficiency Virus (HIV), frame the experience of the HIV-diagnosed individual's health through a collection of epistemologies (Treichler, 1988). The most immediate experience of health, however, stems from the materiality of the body in its sick or healthy state. However, the deterministic impact of an HIV diagnosis alters the individual's self-perceptions; parameters of medical technology have thus been established as the main determinants in the subjectivity and self-conceptualisations of HIV-infected persons. As such, biomedicine specifies the HIV-positive body and alters its subjectivity, which becomes enmeshed with the medical schemata that has developed around the virus (Mechanic, 1974). Medical technology can be understood as an assemblage of discursive and administrative techniques through which subjects are classified, ordered, and subjected to a complex process of medical surveillance and management. In this sense HIV pathology, by intensifying the depth of the medical gaze, has fostered new modes of control. The 'positive' body represents a 'territorialized' biological entity upon whose surface and interiority these discourses (of knowledge), produced by the disciplines of the modern era, have been inscribed.<sup>3</sup> As it is upon and through the territorialized surface of the body that resistance occurs, new regimes of power-knowledge, sites of resistance and types of identity have as such emerged from the AIDS crisis (Foucault, 1973; 1980).

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<sup>3</sup> Medicine territorializes the bodies of those who 'are the subjects of care' (Fox, 1990:24).



## 1.1.- The Emergence of the Medical Model

### 1.1.1.- The Wane of the Religious Worldview and the Dawn of Individualism

The origins of the practices, discourses, and ideologies that have shaped the biomedical model can be traced back to the Enlightenment. Technology and science inspired the 'Age of Reason' where commitment to individualism substituted religious worship, and social progress and scientific method became the new route to salvation. Gradually, the systematic observation and classification of the human body coalesced into a body of knowledge, which postulated that the restoration of human health could be achieved through the attainment of the equilibrium of bodily fluids. However, even as the Enlightenment dawned, many people still resisted medical intervention; sickness was thought to be the will of God (or of the witch). If and when medical advice was procured, the treatment recommended resulted from the interpretation of the patient's multi-layered self-report. Only in the nineteenth century, when medical technology produced the microscope and enabled the medical 'gaze' to penetrate deeper into the body, did the legitimacy of the profession significantly improve. Surgeons were no longer seen as impure and polluted trades people but as experts whose 'truth-claims', substantiated by laboratories and academic training, were safeguarded by an expanded control of the regulation of the 'healing' professions (Lupton, 1994).<sup>4</sup> As such, medical knowledge came to be perceived as the superior way of objectively apprehending the materiality of disease.

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<sup>4</sup> Dissection of bodies and contact with blood had stigmatised pre-Enlightenment surgeons and physicians (Pouchelle, 1990).

### 1.1.2.- The Shift in the Political Technology of the Body

Foucault (1979) analysed the new kinds of knowledge(s) that modern practices of power articulation and social control have produced. These modern techniques, which exercise continual and subtle coercion on individual bodies, are fundamentally different from the preceding forms of power articulation. Ancient power was performed through public executions and military offensives. If spectacular displays of violence effectively crushed our ancestors, modern articulations of disciplinary forces subjugate through taming. This shift in the 'political technology' of the body constituted the essence of the change in the relationship between power and modern man.<sup>5</sup> As such, the regulatory practices of surveillance and of constraint extended through a range of social practices: scholastic tests, medical examinations, psychiatric assessments, productivity charts, social surveys are all implemented in order to monitor, elicit, and document human behaviour. Such a plenitude of disciplinary mechanisms has replaced the exercise of power based on 'relations of sovereignty' with far-reaching networks that constantly re-enact and reproduce power relations (Rouse, 1994:93-97).

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<sup>5</sup> The medical gaze, for example, was institutionalised and inscribed in social space with the new forms of hospitals that emerged in France in the eighteenth century. The principle behind the new architecture was that of the problem of the visibility of bodies. In hospitals, for reasons of hygiene and contagion, 'a surveillance which would be both global and individualising while at the same time carefully separating the individual under observation', posed specific difficulties for this system of centralised observation. However, the power of the pervading 'gaze' was epitomised in the process of re-organisation of prisons, which took place in the first half of the nineteenth century. The central figure in this process was Bentham's invention, the 'Panopticon' building. This new form of prison was characterised by a perimeter building in the form of a ring. In the centre of the building there was a tower from which an overseer could observe the movements of the inmates in their cells, which had windows facing the inside as well as the outside of the building. In the 'Panopticon' the principle of the dungeon was reversed as daylight, and the gaze of the observer, was much more apt to regulate and to know the activities of the inmates. Such an optical innovation, based on the principle of visibility, constituted a new technology of power (Foucault, 1980:147).

Medicine stands alongside education, the law and penology, psychiatry and social work, as one of the disciplines of the modern era, both a realm of expertise and a way of literally disciplining the bodies of those who are the subjects of those experts (Fox, 1990:24)

‘Discursive fields’ originate out of relations of power and knowledge; however the ‘power/knowledge nexus’ is constrained by language as ‘for Foucault we know or see what our language permits, because we can never naively apprehend or know “reality” outside of language’ (Turner, 1995:11). Semiotics, the science of signs first developed by the linguist de Saussure, recognised the multifaceted dimension of signs and how they may be organised into culturally constructed codes. These culturally mediated codes and systems frame the constitution of identity inasmuch as the establishment of meaning by language ‘is embedded in social and political settings and used for certain purposes.’ It is in the relationship between the structuralist notion of semiotics and the poststructuralist concept of discourse that we can begin to apprehend the role of language in the constitution of ‘reality’.<sup>6</sup> Discourses are *intertextual*, relying on other texts and related discourses to produce meaning, and *contextual*, grounded in specific historical, political and cultural configurations (Lupton, 1994:17-18). Discourse produces social practices as representation of phenomena is intrinsically related to how we act upon them. Each and every ‘discursive field’ delimits the possibilities of what can or cannot be said by ruling out alternative paradigms of thought and preserving particular distributions of power. As such, discourse may have an effect similar to that of ideology. As Treichler (1988:35) argued when writing about AIDS

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<sup>6</sup> Discourse is understood as ‘a pattern of words, figures of speech, concepts, values and symbols...a coherent way of describing and categorising...(which) gather(s) around an object, person, social group...providing a means of “making sense” of that object, person, and so on’ (Lupton, 1994:17-18).

Science is not the true material base generating our merely symbolic superstructure. Our social constructions of AIDS (in terms of global devastation, threat to civil rights, emblem of sex and death, the “gay plague,” the postmodern condition, whatever) are based not upon objective, scientifically determined “reality” but upon what we are told about this reality: that is, upon *prior* social constructions routinely produced within the discourses of biomedical science (Treichler, 1988:35)

In the seventeenth century ‘oppressive’ forms of power began to be substituted by ‘productive’ ones (Foucault, 1980a). Power ceased to be a unidirectional force imposed from above and became a net-like organisation suffusing all systems of social regulation. As such, power came to engender a multiplicity of relations other than domination. Enlightenment discourses did condemn the abusive character of feudal systems of punishment, but penal reform was really occasioned by an expanding capitalist system whose requirements for punishment demanded a more dependable and efficient regime (McKay, 1994). Hence, the normalisation of health parameters constituted the medical dimension of the historical process of rationalisation and standardisation, which promoted the control and surveillance of our collective and individual materialities. A proscribed normality grounds the discursive field that frames the rationalisation of society; thus the possibility of ‘innumerable healths of the body’ is denied (Nietzsche, 1974, quoted in Turner, 1995:207). It is within such a context that we see the emergence of a ‘bio-politics of populations whereby the state, through its various local and national agencies, constantly intervenes in the production and reproduction of life itself’ (Turner, 1995:210).

At the structural level medical power is constituted through ideologies and practices that maintain its plausibility structure. If we adopt a political economy perspective, the hegemony of allopathic medicine can be regarded as the result of the perceived superior validity of its 'truth-claims' amidst the power struggle of the various interest groups in their quest for power and dominance.<sup>7</sup> According to this view, the power of the medical profession is sustained by the state apparatus, which regulates the industry through a system of licensing and legal support. It has been argued that the medical profession, by individualising the root of illness rather than recognising its political and socio-economic genesis, is an accomplice of capitalistic ideology (Navarro, 1976; Waitzkin, 1984; Baer et al, 1986). As such, medicalisation depoliticises 'the social structural roots of personal suffering' by relying on an esoteric body of knowledge, which, by remaining inaccessible to the great majority of patients, dogmatizes the profession, and assures its continued dominance (Waitzkin, 1984:339).

However, if we adopt the notion of 'productive' power the medical encounter does not necessarily constitute a 'subjugating force', but represents 'a strategic relation which is diffuse and invisible' as well as 'vulnerable to resistance'. The relationship enacted in the medical encounter is thus 'closer to the idea of a form of social organisation by which social order and conformity are maintained by voluntary means' (Lupton, 1994:111).

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<sup>7</sup> The three dominant approaches in the sociology of health and illness are functionalism, the political economy perspective, and social constructionism. All schools regard medicine as a tool for the moral control of society, but functionalists regard such control as benevolent whereas the political economy perspective considers it to be malevolent. Social constructionists reconceptualise the very notion of the power that is being deployed, and emphasise the dualistic nature of the relationship between institutions and individuals socialised to accept norms of behaviour and patterns of thought. However, the 'disciplinary

Foucault's earlier writings had conceptualised the body as a passive entity utterly inscribed by discourse. However, in his later work Foucault attempted to redress his previous ontological model of the body, which had rendered it unable to articulate any resistance (Martin, 1988). As such, the passive body of the Panopticon was replaced by a reflexive self engaged in the construction of a personal ethic: 'a living, speaking, reflexive subjectivity implies the capacity to resist.' This resistance is framed 'upon this notion of something beyond and irreducible to discourse' as personal identities are not *a priori* entities but the result of 'a battlefield, in which difference and opposition are the means by which identity and the boundaries of others become discernible' (Fox, 1990:41-44). However, discourses on health require a thinking subject who is capable of agency. There is consequently a double movement implicit in this notion: the definable entity 'health' and a subjectivity positioned in relation to it. The person is dissociated from his or her health; as such the individual is able to directly influence its own health. On the other hand, as 'health' is a fundamental component of the individual, the former can radically influence the latter. This Cartesian conceptualisation of the body/mind has framed the emergence of the notion of the guilty victim of HIV. Although the homosexual, like the drug addict or the whore, is a victim of AIDS, his/her lifestyle (or his corrupted agency) is responsible for it (Fox, 1990).

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character' of the sociology of health and illness, which has been constructed as the empowering discipline in opposition to health care as the controlling one, should be acknowledged (Fox, 1993).

## 1.2.- Appropriating the Meaning of Homosexual Behaviour

### 1.2.1.- The Sin Against Nature: canon law and the penitentials

Canon law, the legal system of the Christian church, dates back to the beginning of the second century C.E. Since then, the Christian church, through its canons and the mechanisms used to enforce them, has played a key role in enunciating and defining the norms of sexual behaviour within Christian communities, particularly among members of the Catholic, Orthodox, Lutheran, and Anglican branches of Christianity. From their onset Canonical rules were markedly concerned with the moral and disciplinary problems arising from sexual attractions and desires. Christians, like pagan Romans, were expected to be monogamous; unlike their pagan contemporaries, however, married Christians were also expected to remain sexually faithful to their mates, to refrain from divorce, and to observe restraint in their sexual behaviour within marriage whilst avoiding entirely any sexual intimacy outside of it. Christian writers soon began to justify their canonical rules and other teachings about sex by arguing that these rules were grounded either in divine revelation or in human reason, or in nature or natural law. Christian justification of Canon law was a response to the criticisms put forward not only by pagan and Jewish critics, but also by unorthodox Christian critics whom mainstream Christians denounced as heretics (Payer, 1984; Salisbury, 1991). Despite having existed for almost for ten centuries, canon law only developed into a systematic intellectual discipline during the twelfth century. The appearance of the *Decretum*, authored by Gratian in about 1140, equipped canonists with their first analytical textbook, which remained the basis for the teaching of canon law in the universities and schools throughout the Middle Ages. However, the book's

influence on Christian teachings spanned a much longer swath of time. The *Decretum*, where Gratian explained that sexual pleasure was a disturbing influence in human life, a temptation that distracted Christians from the goal of salvation, and an instrument that the devil regularly used to entice souls into hell, continued in use among Roman Catholics until the beginning of the twentieth century (Bullough, 1982).

Much earlier than Gratian the most influential writer on Christian sexual ethics had been St. Augustine of Hippo, who was born in the middle of the fourth century C.E. and lived to be almost eighty-years old. St. Augustine developed an elaborate rationale for the basic tenets of Christian sexual morality whereby human sexuality, like death, was a direct consequence of Adam and Eve's original sin. In pre-fall paradise, postulated St. Augustine, sexual feelings and relations were radically different from the sexuality of post-paradise humans. In paradise sexuality had been an entirely rational and bland affair that brought none of the sinful orgasmic bliss humans began to experience after their progenitors fell from divine grace. As such, expounded St. Augustine, sex constituted both a punishment we all must bear for our ancestral parents, and a depraved temptation that if indulged in would lead us straight to hell. As such, the early Christian period was suffused by the idea that sexual activity should only be engaged in for the continuation of the species; otherwise celibacy and virginity should be *de rigueur*. To a certain extent this radical rejection of sexual pleasure was a reaction to the dominant ethos of Greco-Roman culture where the sexuality of the citizen could adopt multifarious forms, including same-sex acts (Brooke, 1989).



The anti-sex exhortations of the early Church became solidly entrenched within Christian culture through the penitentials, i.e. handbooks for confessors, which from the beginning of the sixth century began to be produced by spiritual authorities. Penitentials dealt with all possible categories of sin, and penitential officers prescribed distinct penances in accordance with what was deemed appropriate for each particular sinful situation. The penitentials put the ascetic sexual norms into writing: during Lent, Pentecost, and Advent married couples must abstain entirely from sexual relations; intercourse between married persons was grievously sinful on Wednesdays, Fridays, and Saturdays throughout the year; sexual activity during the wife's menstrual period, during pregnancy, and after pregnancy so long as the child nursed at the mother's breast was also a serious offence. Naked sex or daytime frolicking, as well as positional experimentation, were vehemently proscribed (the 'missionary' was the only sanctioned position). Non-marital sex, whether social or solitary, heterosexual or homosexual, voluntary or involuntary, was likewise abhorrent. It was only during the eleventh century that penitentials began to abandon their general approach to sin to focus on the sexual nature of most sinful acts (and especially of homosexual acts). However, if the adepts of 'contra naturam' acts were demonised even religious officials had to submit to the sexual ascetism of the time: clerics had to renounce marriage and sex as a condition of ordination.<sup>8</sup> Whereas earlier spiritual writers and some church authorities had long praised clerical celibacy and encouraged all clergymen to embrace it, celibacy had previously been required only of monks and nuns

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<sup>8</sup> The prohibition against sodomy extended to any individual who engaged in it. Medieval canonists and theologians condoned as 'natural' only marital intercourse conducted in the missionary position. Intercourse in any position where the woman was on top canonists regarded as 'unnatural' since it subverted normal power relations between the sexes. Church authorities vehemently rejected all anal or oral sexual practices, which were considered beastly and radically unnatural.

who lived in religious communities. Now a vow of celibacy was required for ordination (Brundage, 1987).

### 1.2.2.- The Medicalisation of Homosexuality

The concept of 'sodomy' arose in the Middle Ages. According to medieval theology, sodomy constituted 'the exact reversal of the lawful way of having sex' (Hekma, 1989:433). 'Sodomites' transgressed the traditional boundaries that had characterised the nature of most classical homosexual liaisons where their educational character was reflected by the exclusively 'active' role of the older man towards his pupil. Such 'transgression' became central to the modern Western conception of homosexual identity and role precisely because 'sodomy' is the very act that constitutes the symbolic centre of gay identity, and which acts as a crystallising force on male homosexual desire' (Coxon, 1996:72-74).<sup>9</sup> The medicalisation of homosexuality accompanied the wider processes of secularisation and rationalisation of society culminating in its classification as a psychiatric disorder when the World Health Organisation was established in 1948.

Since the 1970s homosexuality has been undergoing a process of normalisation. The American Psychiatric Association removed homosexuality from its *Diagnostic and Statistical Manual of Psychiatric Disorders* in 1973, and in Britain it officially stopped being regarded as mental illness in 1993 (Greenberg, 1988; David, 1997). However, that contemporary gay identity sex still echoes ancient Judeo-Christian attitudes that

conceptualised the enactment of same-sex (male) desire as an abominable sin was evident at the onset of the AIDS crisis.<sup>10</sup> The AIDS crisis has remedicalised the homosexual act in terms of unsafe sex. Anal intercourse constitutes the most likely route of HIV infection. As such, the relational aspect involved in the ‘enactment of homosexuality’ through sexual behaviour has been overlooked by HIV prevention strategies (Dowsett, 1996). Homosexuality has been reduced into moralistic and homophobic distinctions of supposedly meaningless ‘healthy’ and ‘unhealthy’ practices. This one-dimensional view of sexuality, stemming from a simple rational choice model, precludes a wider understanding of rationality that must include ‘longing and love as motives for action’ (Watney, 1990:145). ‘Safer sex absolutism’ labels any unprotected sex as ‘relapse’, and blames it on ‘depression, a sense of fatality or inevitability, lack of motivation to remain healthy, survivor’s guilt, grief and trauma’. Such claims go against the evidence of demographic studies of so-called ‘relapsed’ men, who attribute none of these reasons to their unsafe behaviour (Rotello, 1998:118).<sup>11</sup> The official discourse on gay (safer) sex creates a climate of intolerance that once more medicalises and vilifies same-sex desire. Moreover, by stigmatising those who ‘fail’ to maintain ‘new fantasy norms of how gay men are meant to behave’, such discursive practices inhibit the development of collective community values essential in the sustenance of safer sex over time (Jones and Ridley, 1997:18).

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<sup>9</sup> Data from Project SIGMA indicates that 92% of gay men in England and Wales have ever engaged in anal sex. However, gay men’s sexual behaviour is taken up in the three acts of masturbation, fellatio, and anal intercourse roughly in a 6:2:1 ratio (Coxon, 1996).

<sup>10</sup> In the beginning of the AIDS crisis a large percentage of the public perceived AIDS to be God’s punishment, and blamed homosexuals for their sinful lifestyle (Seidman, 1995).

<sup>11</sup> The reasons given by men who engage in unprotected sex include a desire to enhance pleasure, the effect of drugs or alcohol, or being ‘swept away by passion’. Younger gay men cited the following reasons:

### 1.2.3.- Homosexuality and the 'Other' Sciences

Attempts to appropriate (homo)sexual meaning were enacted first by the discourses of religion; then medical science and the law, and most recently, the social sciences. After Kinsey (1948, 1953), whose work suggested that sexuality be conceptualised as a continuum, new social models of homosexuality appeared. In particular, the discourses of the social sciences as well as the counter discourses of the new sexual movements came to regard homosexuals as a persecuted minority (Hooker, 1965; Hoffman, 1968). Despite the significant influence of sociological perspectives, as well as the labelling theory of Becker (1963), Goffman (1968), and Schur (1971), in shaping interpretative frameworks concerning (homo)sexuality, they all accepted the view of homosexuality as a 'basis of individual and social identity' (Seidman, 1996:8). Such post-war deviance theories modified the theoretical perspective that had characterised deviance as an inherent property of the individual, or of a particular act, to that of a specific historical status occasioned through social oppression. Such theories of homosexuality provided 'a distinction between homosexual behaviour, universal in its manifestations, across time and cultures, and the specific historical and social forms in which it was organised' (Weeks, 1998:133). With the emergence of the 'social constructionist' perspective in the 1970s, the argument that homosexual (and heterosexual) identity was a social and historical creation was put forth for the first time. Despite its challenge to essentialist notions of homosexuality, social-constructionism contributed to a model of lesbian and gay subcultures that analogises them to ethnic minorities. These studies looked for the

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'sense of youthful invulnerability, a belief that AIDS is the plague of an older generation, and a dread of growing old in a culture that prizes youth and beauty' (Rotello, 1998:118).

social factors that produced a homosexual identity, rather than assuming the naturalness of the condition (Seidman, 1996).

The inadequacy of the concept of homosexuality as an ethnic group was highlighted by its inability to prevent the backlash against homosexuality spawned by the AIDS crisis.

The hostility to homosexuality 'legitimised' by AIDS is evident in media constructions of the 'general public', or the 'family'. This mediated family identity, constituted through 'the active work of selecting and presenting, of structuring and shaping: not merely the transmitting of already-existing meaning, but the more active labour of *making this mean*', is more 'likely to include your dog than your homosexual brother or sister' (Hall, cited in Bersani 1996:203).<sup>12</sup> Such a heteronormative context - whose degree of homophobia has varied according to the specific cultural, social, historical, and institutional background - frames the master discourses of science and medicine through which HIV/AIDS, and homosexuality, are given meaning. As such, the subtle shift from safer sex as protected sex to safer sex as non-penetrative sex took hold. If, as Bersani (1996:222) noted, the 'rectum is a grave' it is because:

the masculine ideal... of proud subjectivity is buried... Tragically, AIDS has literalized that potential as the certainty of biological death, and has therefore reinforced the heterosexual association of anal sex with self-annihilation originally and primarily identified with the fantasmatic mystery of an insatiable, unstoppable female sexuality

### 1.3.- Micrological Strategies of Resistance: resisting appropriation

Insalubrious notions, be they of sin, crime, or disease are intrinsically linked to modern homosexual identity. The scientific encroachment onto the homosexual body has elicited, surveyed, probed, and constrained its behaviour. The advent of AIDS has only crystallised such time-honoured inclinations upon a transmissible entity (HIV). As such, the power of scientific discourse is strengthened by a (contested) virus even if the plausibility of (AIDS) science is being increasingly questioned by contemporary 'risk-society' (Beck, 1992).<sup>13</sup> Despite rhetoric to the contrary, the AIDS crisis in the western world persists in being a disease that disproportionately affects homosexual men. Hence it is the 'positive' body, now collapsed with the 'gay' one, which is elicited, surveyed, probed, and constrained. As such, science is justified in its surveillance of the diagnosed. The gay/positive body is thus simultaneously an 'inverted', 'diseased', 'sinful', *and* 'criminal' entity.<sup>14</sup> Never before has the homosexual body been cloaked with all its potential burdens. Still, it tenaciously endures; it resists 'normalisation' and refutes 'docility'. As a result, the 'gay' body is currently engrossed in a process of resistance, of transformation, of transcendence of the (loaded) self.

Stigma-neutralising strategies that have attempted to alleviate the pressure of living with a failed masculinity precluded Gay-Liberation.<sup>15</sup> In this thesis I engage in an analysis of three contemporary 'micrological strategies of resistance' articulated as challenges to the

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<sup>12</sup> The 'World AIDS Day' celebration, for example, has never featured homosexual AIDS as one of its yearly themes.

<sup>13</sup> The 'Dissident Movement' constitutes a collective of scientists who question the science and the scientific practices that have established that AIDS is caused by HIV. For a full discussion of the movement and related issues see chapter six.

<sup>14</sup> Recently HIV transmission has been criminalized in court cases in the US and in the UK.

disciplinary forces which first demonised, then criminalized, and finally medicalised the homosexual body (McWhorther, 1999). However, before analysing contemporary resistance projects I shall introduce my argument in chapter three by framing it against a socio-historical presentation of homosexuality, and the strategies of resistance that have surrounded its more ancient manifestations. In chapter four I shall describe what I have classified as a 'spontaneous' resistance project inasmuch as it first emanated from the grassroots of the affected constituency in an unplanned, unstructured way. As such, in chapter four I argue that the 'gay-circuit' phenomenon constitutes a micrological strategy that refutes the notion that the gay body must be reduced to the ailing AIDS body. In chapter five and six I shall present analyses of what I call 'conscious' resistance projects inasmuch as they constitute culturally and/or structurally elaborated strategies that have either emerged from or been appropriated by specific factions of gay culture. In chapter five I analyse the construction of what I term the 'queer' spiritual discourse, an elite-produced resistance project whose theological cultural production aims to overturn religious definitions of homosexuality as inherently sinful. In chapter six I provide an analysis as well as a description of the 'Dissident Movement', a social movement organised around the questioning of the scientific procedures that have established the truth of AIDS. In the concluding chapter I present the analysis of my empirical research where I attempt to describe how 'micrological' strategies of resistance collude and interact in the construction of identities of HIV infected individuals. The methodology of such research is presented in chapter two.

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<sup>15</sup> These strategies were: passing (adoption of a pretended heterosexual identity), minstrelisation (the cross-gendering associated with camp), and capitulation (self-hatred and shame of the damaged self)

#### 1.4. – Contemporary Homosexual Identity: gay and positive

Since the advent of AIDS homosexually-identified individuals have engaged in processes of re-evaluation and reconstruction of their pre-AIDS selves. Hence, micrological resistance projects constitute important variables in the context of identities that are not only physically but also symbolically related to HIV. However, identity is a universal social phenomenon and as such influenced by a multitude of factors. In order to analyse specific identity processes it is necessary to take into consideration the wider frame in which they are embedded. Below I briefly describe the theoretical perspectives on identity that informed the empirical, qualitative study I conducted.

##### 1.4.1.- Becoming Gay: the interactionist perspective

From the early 1950s until the mid-1970s conceptualisations of homosexuality in the Anglo-Saxon world had been grounded in the notion that such a form of sexual expression is an ‘essential’ phenomenon recognised through time and history. Through such a prism, homosexuals were seen as constitutive of an ethnic minority with their own culture and political interests. The formation of homosexual identities served as the basis for the process of community development, as well as for the legitimisation of homosexuality, which began to take place after the Stonewall riots. Inasmuch as homosexuality was understood as a unitary identity grounded in a common experience and set of values it reflected characteristics of the modernist project. However, the ‘meta-narrative’ of the homosexual experience referred only to the experience of white middle-class Anglo-Saxon homosexuality. Homosexually identified individuals who did not

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(Levine, 1998:21).



recognise their experience in such totalising versions of homoeroticism later challenged these normalising notions of homosexual identity (Seidman, 1995).

The term 'coming out' denotes the transformational process through which individuals acquire identity by actively engaging in 'historically specific communities and discourses' (Petersen, 1998:106). As the 'key' ritual of contemporary gay culture once the individual 'comes out' he or she publicly reveals the centrality of same-sex desire as a basis for self-identification (Herdt, 1992). Another reading may suggest that rather than as a process of admission of a deviant sexual orientation coming out is better understood as a process of self-labelling (Plummer, 1975). When the homosexual body declares its deviance it subjectively pledges alliance to socially constructed norms that surround homosexuality. As such, some sort of cognitive construct results from the reciprocal relationship between the homosexual body and its social context: *gay* is not sexual preference, it is identity. Some writers have objected to the application of labelling theory to gay identity on the basis that gay identity is the result of an internal condition, i.e. sexual orientation rather than the outcome of the external acts of authority. Instead of the rejection of labelling theory as an explanatory framework for homosexuality, an approach that 'can best be described as a non-deviant labelling theory', which is based on a theoretical perspective that assumes that the gay role is not really deviant, has been developed (DuBay, 1987:123). Plummer's (1975) interactionist account of the process of homosexual-identity-acquisition constitutes the departing point for such non-deviant approaches to the homosexual label.<sup>16</sup> Subsequent refinements of Plummer's model have

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<sup>16</sup> Plummer's model argues that the adoption of the homosexual role starts with the stage of 'sensitisation', when the individual makes a connection between his homosexual tendencies and the realisation that there is

discussed how the commitment to the gay role may be attenuated, and further roles adopted (Cass, 1979; Troiden, 1979). Yet, a positivist bias that points to an *internal* condition as the source of a gay identity has remained in interactionist accounts of the adoption of a gay identity (Coleman, 1982).

The specification of homosexual individuals, which Foucault claims took place in the final decades of the nineteenth century, is not undisputed. Many authors disagree with Foucault's view, and argue that 'examination of earlier history shows conception of homosexual persons, a homosexual species even... (and) that it is intellectually dishonest to treat homosexual categories as uniquely social/historical/arbitrary' (Murray, 1989:467-468). This kind of essentialist perspective assumes that interiority precedes identity, and that identity, although it allows the formation of community, pre-exists community.

Historical data does demonstrate patterned social behaviour concerning homosexuality. If early homosexual acts were devoid of specific embodiment why were there words such as 'sodomite' or 'bugger'? If there were only homosexual acts, without self-conception, why would these terms have appeared? It is also argued that social constructionists attempt to dodge the issue of ancient previous expressions of (essential) homosexuality through the concept of 'role'. Role, which as a concept is opposed to the notions of 'essence' or 'self', points towards the multiplicity of positions an individual can adopt.

As such, contemporary gay identity is deemed to result from the evolution of the

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a special category of similar people in the wider society. The second, which is termed 'signification', represents the individual's self-categorisation as a homosexual. The third stage is that of 'stabilization'; in this consolidating stage the homosexual identity becomes fixed and one's life becomes organised around it (Plummer, 1975).

homosexual role, first embodied by the seventeenth century British 'molly' (McIntosh, 1968).

#### 1.4.2.- HIV Identities: a social identity perspective

Modern identity is constituted through a 'reflexive project of the self'. As such, identity construction is an ongoing process enacted through revision and reordering of biographical narratives selected from a multitude of available alternatives (Giddens, 1991). However, encounters with 'fateful moments', those times 'where a person learns of information with fateful consequences', threaten the 'protective cocoon' that normally prevents individuals from drowning in the ontological maze of contemporary society. Such ontological crises may be met with a return to traditional sources of authority, but they can also engender processes of 'reskilling' and empowerment (Giddens, 1991). HIV diagnosis most definitely constitutes a 'fateful moment'. Although the great majority of the HIV-diagnosed deal with the break of their 'protective cocoon' through the traditional authority of medical science, a few have preferred to rely on other types of knowledge in trying to grapple with the meaning of their condition. In order to arrive at a nuanced understanding of how individuals diagnosed with HIV/AIDS come to 'reskill' their transformed identities, it is first necessary to review the development of the social processes which have shaped the organisation, representation, and containment of homosexual behaviour throughout history.

My analysis of the identity reconstruction processes of HIV-infected individuals is based on the notion that identity is more than *who* you say you are inasmuch as the possibilities

for self-definitions are delimited by *what* you can say you are. I have adopted a social identity perspective whereby socially determined categories enable, or disable, the self-evaluations through which individuals come to understand and interpret themselves (Tajfel, 1981). A fundamental assumption of my argument is that social identity is embodied. It is upon the human body that identification is articulated as our biological containers convey our similarities as much as our differences; in fact ‘social identification in isolation from embodiment is unimaginable.’ Identity is not only a self-applied label, which represents the individual in specific social situations, but also an indicator of the social category such a label refers to. Identities are thus constructed through an ‘internal-external dialectic of identification’ (Jenkins, 1996:20-21). Social identity theory examines how the organised set of self-perceptions an individual holds about him or herself is related to the socio-cultural environment. Such a perspective also takes into consideration that identity as a cognitive construct may also affect the social structures that have shaped it (Cass, 1984; Cox and Gallois, 1986).

Social identity theory demonstrates how self-categorisation implies a dialectic articulated between individual and society. Identity is always a process: a ‘becoming’ as much as a ‘having been’. As such, those who identify as belonging to a certain social group or category adopt the normative behaviours and the values associated with such groups. However, individuals always retain aspects of identity (attitudes, values, behaviours, traits) that are thought to be unique and which ultimately differentiate them from all other individuals – including those with whom they may share some sort of communal belonging. This dimension of the identity construct, the *personal identity*, always grounds

the multiple social identities an individual can simultaneously possess. The development of *personal*, or *individual*, identity is a function of primary socialisation processes that take place during infancy and childhood. For that reason, primary identities such as ‘selfhood, human-ness, gender, and under some circumstances, kinship and ethnicity’ are less easily abandoned and/or modified after they have been ascribed (Jenkins, 1996:21).

#### 1.4.3.- HIV Identities: the postmodern perspective

Other cultural and social trends have had a significant impact on the reappraisal of the concept of identity, including homosexual identity. The ‘velocity’ of life in the beginning of the twenty-first century stems from the ever more sophisticated technological developments, which have transformed our perceptions of space and time. Such a transformation has also significantly altered the ways in which human beings understand and constitute themselves. The ‘acceleration’ of life is a process that has accompanied the rise of human progress since ancient Greece. As such, the ‘political phenomenon of acceleration’ is fundamental for an understanding of history; we have evolved from ‘the velocity of the predators, of the cavalry, of railways, of ships and maritime power’ to ‘the velocity of dispatching information’ (Armitage, 1999:35). The peak of such a historical process of acceleration, which has been framed in terms of ‘information revolution’ and ‘globalisation’, has annihilated modern perceptions of time.<sup>17</sup> For the technical rationality that formed the basis of the modern age time was a cyclical, but linear phenomenon. More importantly, Judaeo-Christian notions coloured the modern understanding of time: time began with the genesis of the Earth and would end with the

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<sup>17</sup> These processes are more concretely experienced in the nations of the developed West.

heavenly salvation that would befall all human beings before their world turned to dust (Melucci, 1996:8).

Today, however, many of us exist in multiple time/space configurations; the *modern* model of time fails to grab the *contemporary* experience of it. Moreover, ‘multiple and discontinuous time reveals its nature as a cultural artefact that is entirely constructed within everyday social relationships’ (Melucci, 1996:16). What is also apparent is that the ‘salvation’ promised by outmoded conceptions of time, where the end of linear time implied the coming of the saviour, is unlikely to materialise. Not even secular versions of the salvation myth - the modern fictions of technology, science, rationality, development, and economic growth – have any lasting credibility. If all we can expect in a more or less distant future is catastrophe and ecological collapse, our experience of time reaches epic levels of fragmentation:

Linear time yields to an experience of transitions without development, to a movement between disconnected points, a sequence of fleeting moments whose meaning is entirely grounded in the present point of time (Melucci, 1996:9)

The onset of AIDS coincided somewhat with the beginning of the academic debate about ‘postmodernity’. Such debate, which analysed the social processes introduced above, was initiated with the publication of Jürgen Habermas’ (1983) *Modernity – an incomplete project* and Jean-François Lyotard’s (1984) *The Postmodern Condition: A Report on Knowledge*. Although both authors agreed that modernity implied notions of universality and unity – Lyotard’s ‘meta-narratives’ – they disagreed on the current state of the

cultural and social environment. For Habermas modernity was still unfinished, but Lyotard argued that we had entered a new period – the postmodern – and that modernity had been buried with the atrocities of the Holocaust. As such, postmodernity was characterised by different structures of knowledge where totalising narratives were substituted ‘by smaller and multiple narratives which seek no universalising stabilization and legitimation’ (Hutcheon, 1989:24). Another academic debate that took into consideration the changes in the cultural environment, but was narrower in its focus, was that of ‘Queer Theory’. ‘Queer Theory’, articulated in the eighties, challenged the assumption of a unified homosexual identity and argued that (gay) identities are multiple and unstably constituted through the intersection of several identity components. Such argument contested the ‘very telos of Western homosexual politics’ (Seidman, 1996:11).

The modern project *had* unchained individuals from traditional identities, and transformed pre-modern processes of identity construction. Rather than *inherit* self-categorisations, the modern individual had to *achieve* an identity – a process articulated in the shape of strived-for *life projects* (Bauman, 1997). Identity construction processes of *contemporary* individuals differ from their modern ancestors inasmuch as a stable identity must be forged through the institutionalised radical doubt that characterises the postmodern condition. Such ingrained environment of uncertainty has been occasioned by the plurality of available discourses, which has followed the demise of modern certainty (Giddens, 1991). As such, the self-reflexive construction of contemporary identities reflects the consciously active nature of the identity construction processes engaged in by the self. As Melucci (1996:9-12) has argued:

Establishing an equilibrium between the different vectors along which our identity is constructed becomes progressively more difficult, and there is an increased likelihood of identity crisis, as a result of the inability to maintain a coherent spatio-temporal definition of ourselves

In this fundamentally risky and unstable current social environment (late-modern; postmodern) the apparently increasing narcissistic preoccupation with the body is in fact veiling much deeper existential questions. The quest to control and shape human biological processes and forms reflects the final demise of an 'enchanted world' where flesh was subordinate to gods, not mortals. Moreover, such quest reflects the inherent risk of a contemporary existence that has led to the 'therapeutisation of life' (Melucci, 1996). If identity construction processes of contemporary individuals are self-reflexively performed, then self-categorisations are the conscious outcome of individual cognitive processes. Such processes are constituted 'by and through the characteristic plurality of discursive practices', and must result in coherent constructs 'even if such coherence must be continually open to revision.' Failure in achieving coherence results in an 'ontological insecurity' that reveals the chaotic void obscured by the imagined solidity of our daily interactions in the social world (Giddens, 1991). Although it may be argued that the religious or spiritual individual may suffer less from 'ontological insecurity' as his or her worldview may impose metaphysical meaning on what secularly is perceived as chaotic, the fact is that on the public level a 'disenchanted world' can only produce feelings of



a new type of uncertainty – not limited to one’s own luck and talents, but concerning as well the future shape of the world, the right way of living in it, and the criteria by which to judge the rights and wrongs of the way of living (Bauman, 1997:21)

Despite the fragility of ‘postmodern’ ontological security, it must be achieved for the continued existence of social life. The ‘protective cocoon’, established early in the life of the infant through its relationship with its caretakers, is a necessary (even if illusory) condition of human embodiment. The ‘protective’ bracketing of the ‘cocoon’ does allow us to carry on with our daily lives without much consideration to all the potential danger that constantly surrounds us. Yet, when one’s friends are diagnosed with a terminal disease or one’s community is decimated by a tidal wave, the frailty of such illusion is dramatically brought to the surface. The more indirect the ‘brush’ with events that disrupt the integrity of our ‘cocoon’ the more rapidly and comprehensively it can be restored, and routine life regained (Giddens, 1991). As such, an HIV diagnosis constitutes a ‘fateful moment’ inasmuch as the ‘ontological security’ of the diagnosed individual is severely challenged and his or her ‘protective cocoon’ shattered. Giddens (1991:112-113) defines *fateful moments* as:

those when individuals are called on to take decisions that are particularly consequential for their ambitions, or more generally for their future lives. Fateful moments are highly consequential for a person’s destiny...fateful moments are times when events come together in such a way that an individual stands, as it were, at a crossroads in his existence; or where a person learns of information with fateful consequences

### 1.5. Challenging Hegemonic Discourses

When GRID (Gay Related Immune Deficiency) was in June of 1981 first identified in members of gay communities in the United States, homosexually identified individuals were once again linked to notions of intrinsic sickness (Epstein, 1996). Despite the initial debate on the aetiology of the new syndrome, which was renamed Acquired Immune Deficiency Syndrome (AIDS) in July of 1982, it was postulated to be a viral disease. As such, the syndrome's appropriation by the 'germ school' of the bio-medical model soon followed (Dubos, 1959). However, and despite the institutionalisation of the biomedical scheme of AIDS, several competing knowledges and meanings continue to threaten the hegemonic discourse of biomedicine. Such sites of resistance have been articulated through authentic knowledge(s) based on personal experience, and through 'reverse' scientific discourse (Foucault, 1981). These various subjugated positions challenge hegemonic discourses, and foster the proliferation of difference by countering normalising strategies of power. The rejection of pre-ordained 'diseased' or 'sinful' identities by individuals doubly stigmatised by the labels homosexual and HIV-positive suggests that HIV/AIDS diagnosis may be used in *productive* ways that challenge the internalisation of effects of power of disciplinary society.

Such a perspective informs my analysis of how an HIV/AIDS diagnosis produces new self-understandings. Foucault (1981; 1990) was interested in the techniques of power (self-surveillance, self-confession) through which subjectivity comes to be acquired. The analytic conception of subjectivity in Foucault's genealogical work is often presumed to disallow for an account of agency dynamic enough to produce individual freedom and

self-determination.<sup>18</sup> It is argued that his idea of the subject as a result of power relations not only destabilises agency, but also fails to provide a template for its development within the power webs of modern societies (Alcoff, 1992; Norris, 1993; Heaphy, 1996). Yet, Foucault was not the first to argue against the notion that human interiority pre-exists networks of power.<sup>19</sup> However, the concession that the interiority of subjects is historically contingent, and as such can not be given any analytical priority, does not mean that subjects never exercise any power. It *does* mean that subjects must be explained with reference to power networks rather than power networks be explained with reference to subjects. Human interiority, which arises from power-effect relations, is not an illusion incapable of agency. If subjectivity is constituted by and through subjugating relations of power, and as power is not an entity but a network of events, our identities are thus dependent on certain configurations of power relations. The notion that Foucault does away with agency is misguided; our existence as subjects (a subjection which implies its conscience in the formation of self-identity) presumes varying degrees of subjection to configurations of power/knowledge which can and ought to be resisted. As such, when power networks shift identities, which are dependent on a specific set of power relations, may either undergo change or even collapse or disappear (McWorther, 1999).<sup>20</sup> We shall soon turn to the social production of such resistance projects and he

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<sup>18</sup> Genealogy is a 'history of the present specifically concerned with the complex causal antecedents of a socio-intellectual reality.' Although genealogy affirms the existence of social realities, it acknowledges their historicity, and their socially constructed nature (Gutting, 1994:12; McWorther, 1999).

<sup>19</sup> Before him both Nietzsche and Heidegger had argued the displacement of subjectivity (McWorther, 1999).

<sup>20</sup> For Foucault (1981, quoted in McWorther, 1999:78) 'power is not an institution, and not a structure; neither is it a certain strength we are endowed with; it is the same name that one attributes to a complex strategical situation in a particular society.' As such, power produces social structures, personal identities, laws, systems of thought, and so on.

identities that emerge through and across them, but not before I proceed to explain the methodology through which I empirically investigated the subject.

## **Chapter 2:**

### **Methodology of Research**

#### **2.1.- Theoretical Considerations**

##### **2.1.1.- Qualitative or Quantitative Research**

I set out to investigate issues around the main research question I had initially postulated. However, in what appears to be typical of many research projects (at least those of a doctoral nature) through the development of the research the direction of my focus significantly changed with the discovery of a fundamentally important new category. These processes will be explored in subsequent sections of this chapter. At this point suffice it to say that despite the change of focus of the research, the methodological design I had charted did not need to be altered. Yes, I was now covering an area I had not initially envisioned, but the core substance of my investigation remained unchanged: I still wanted to discover if and how HIV infected individuals restructure their lives after the ‘fateful moment’ of the diagnosis (Giddens, 1991). Yet, I had not anticipated the slant from which I would endeavour to understand the multilayered social processes that comprised the life-restructure.

Research methods constitute techniques for the collection and analysis of data, and have traditionally been dichotomised into either quantitative or qualitative project designs (Harding, 1986; Oakley, 1997, 1998). Such binary understandings of research methods associate quantitative methods with ‘hard’ values such as science, objectivity, measurement, and empiricism; qualitative methods are associated with ‘soft’ values such

as subjectivity and interpretivism (Westmarland, 2001). These two methods are generally viewed as inherently incompatible due to the presumed incommensurability of the ontological paradigms that frame them. However, regardless of which epistemological paradigm each research method is lumped under, all social science research attempts to grasp the embodied processes that underlie social phenomena. Analogously, subscription to either epistemological perspective does not translate into unadulterated objectivity even if 'real' knowledge has traditionally been measured by its objectivity, reliability, and its validity. Both quantitative and qualitative methods construct data, and as such are subject to biases.

The positivistic paradigm is employed to uncover functional relations between operationalised variables whilst the qualitative viewpoint focuses on describing and understanding the structure of multilayered social phenomena. Either approach brings distinctive qualities to the research process. Grounded Theory (GT) constitutes a research methodology which can be succinctly defined as a 'general method of comparative analysis'. To put it simply, GT represents a methodology that claims to answer the question of 'what was going on in an area' through the elaboration of either a substantive or formal theory (Rahmat, 2000:2). GT can be applied to both qualitative and quantitative data, and it is particularly effective in exploring 'uncharted territory' (Glaser and Strauss, 1974; Stern, 1995). Quantitative methods recognise the facticity of social phenomena but their analytical processes albeit precise are reductive inasmuch as many facets of the phenomenon are simplified by their operationalisation. On the other hand, qualitative methods treat phenomena as whole systems in a holistic approach which, in searching for

patterns through the incorporation of as many episodes as possible, attempts to grasp the different structural elements of the process. Hence in my endeavour to apprehend the social reality of HIV positive individuals I adopted a research method (GT) whose flexibility allowed for creativity. Without the productive insights which arose from both data immersion and the creative processes I engaged in with the data, the research would not have generated any relevant theoretical formulations about the phenomenon being investigated.

### 2.1.2.- Basic Research Design: why Grounded Theory?

A sociologist from the University of Chicago, Anselm Strauss, and another sociologist from Columbia University, in New York City, Barney Glaser, developed grounded theory in the late 1960s (Strauss and Corbin, 1990). Both schools emphasised the empirical dimension of social research. The principle objective of GT is the conceptualisation of a theory to explain how a population may resolve a main concern. GT is developed around the following fundamental criteria: generality, relevance, validity, modifiability. Whereas a number of qualitative data analysis (QDA) techniques produce conceptual descriptions of the phenomenon being studied, GT is concerned with building conceptual theories. In endeavouring to build a theory GT looks way beyond description towards the conceptualisation of latent patterns and categories (Glaser, 1978). In grounded theory 'all is data'; not only 'what is being told, how it is being told and the conditions of its being told, but also all the data surrounding what is being told' (Glaser, 2001:145). As such, in GT the role of data is not description but interpretation; the objective is to collect the

data, code it, and then analyse it. The final result ought to be abstraction of the data, not accurate description of the information collected.

It has been argued that much of the data obtained through GT techniques is of ‘a constructivist approach (that) recognizes (that) the categories, concepts and theoretical level of analysis emerge from the researcher’s interaction within the field and questions about the data’ (Charmaz, 2000:13). However, Glaser (2003) argues that the yielding of data that is biased or misinterpreted is more probable through other QDA methodologies than through GT. The focused in-depth interview is a technique often used in QDA methodologies. Although GT interviewing also includes in-depth interviewing, the principal strategy of GT interviewing is constituted by a ‘passive’ approach to listening. The ‘passive’ approach is less likely to constitute a dynamic interplay between the interpretations of interviewer and interviewee than is in-depth interviewing. As such, when the interview guide ‘forces and feeds interviewee responses then (the data) is constructed to a degree by interviewer imposed interactive bias (Glaser, 2002:3). In my research this pattern of ‘directed’ passive listening was systematically attempted. Although I did direct the interviewees to explore the content areas I was interested in, mostly respondents talked freely and were unencumbered by a schedule of questions. It was only after the emergence of the new fundamental category during theoretical sampling that some of my questioning became at times more probing.

It should not be claimed indiscriminately that constructivism applies to all kinds of data. ‘Interviewer imposed interactive bias’ *can* be limited if the passive, non-structured



interview technique of GT is observed. If GT is correctly articulated through competent comparative methods and adequate theoretical sampling then the end result will generate theoretical concepts which are as free of subjective contaminants as a humanly produced theory can be. Clearly any human endeavour may contain some sort of personal bias and/or interpretation inasmuch as it is a *human* activity; but the collection, coding, and interpretation of data can be rendered highly objective if enough cases of the phenomenon being studied are observed and care is taken to eliminate bias. Corrections can then be conceptualised into categories which are sanitized from personal projections. As such, 'validity of data' and 'reliability of method' can be ensured. In the subsequent sections I will develop such issues in greater detail as they applied to my own research process.

## 2.2.- Sampling Design

### 2.2.1.- Sampling: a complementary approach

In the initial phase of the research I determined that my population of interest was HIV-infected homosexual men who resided in London. How these men decided to identify themselves (gay, queer, post-gay) was not in itself relevant, the relevant factor was whether their sexual behaviour was primarily homosexual. The primary goal of the research was to discover if and how HIV infected individuals restructure their lives after the diagnosis, and hence to understand the different sets of conditions that affect the phenomenon of becoming an individual for whom HIV infection comes to constitute if not the *primary* vector of identity at least one of its most fundamental components. The objective of the research was not to generalise the results to the population of HIV-

infected homosexual men in London, rather than that each interview would be analysed taking into consideration the presence or absence of the categories and concepts that would arise from data immersion. The theoretical formulations developed from this research do not attempt to generalise but to specify; that is, these theoretical formulations apply under a certain set of conditions, which through specific interaction/action, produce certain outcomes/identities. If such conditions were to change, had I studied, say, the identity construction processes of HIV-infected children in the African nation of Zambia as opposed to homosexual men in London, my theoretical formulations would certainly have differed.

In the early 1980s, when the 'gay syndrome' began to emerge and the hypothesis of GRID (Gay Related Immune Disorder) was postulated, the (then) so-called AIDS 'victims' (mostly homosexuals and drug users) were not considered a population worthy enough to justify significant funds for scientific research. From the first homosexual cases in 1981 until the identification of an 'AIDS' virus in 1984 neither medical nor political institutions seemed very interested in a disease that seemed to affect only marginal segments of society. The result was that many AIDS 'victims' turned to the New Age and Holistic Health Movement for help.<sup>21</sup> Two decades into the health crisis and HIV/AIDS have been mostly appropriated by the medical system; yet I was interested to see if some remnants of the initial role of the New Age still lingered. As such, I had hypothesised that the therapeutic/medical component of the coping strategies adopted by positive gay men in order to deal with HIV/AIDS was related to their

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<sup>21</sup> This topic will be further explored in chapter six.

religious/spiritual cosmologies.<sup>22</sup> A number of questions exploring this area were included in the questionnaire. The second set of relationships I wanted to test concerned the respondents' views of a once widely-circulated theme early in the health crisis, especially before there were any significant allopathic tools, i.e. 'combination therapy'. This theme related to the work of early-crisis New Age AIDS 'healers', who entertained the idea that the new disease stemmed from a lack of self-love, and that its healing was fundamentally related to transformations of the 'inner self' (Hay, 1984, 1988). The logic was that through its disease-causing properties HIV/AIDS prompted the previously damaged self to enter into a quest for multidimensional healing that might not ever have been engaged in had the disease not manifested. HIV/AIDS constituted thus a 'blessing in disguise'. In order to explore respondents' reactions to such a theme I directly asked them in the interviews if they agreed with the statement that 'HIV is a blessing in disguise'.<sup>23</sup> Somewhere in between the beginning and the middle of the process of data collection a 'revolutionary' new category emerged; its appearance demanded that the research follow a different path. As such, one of the first changes that had to be made concerned sampling procedures.

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<sup>22</sup> More specifically, I hypothesised that those individuals who subscribed to a type of religiosity/spirituality that is described as *self-religion* would be more likely to shun orthodox therapeutic regimes, and opt for alternative ones. Self-religions are characterised by 'various synthesis of mind cure, psychotherapy, eastern religious ideas, and aspects of the human potential movement and humanist psychology, (they) combine and highlight major cultural themes: the psychological, the religious, the meaningful, and the perfectibility of man'. These movements, which are concerned with 'the exploration of the self and the search for significance ... attach great importance to positive thinking' (Heelas, 1998:69). Such type of metaphysical perspective places the self at the core of the individual's spiritual dimension, and bestows upon him or her divine quality.

<sup>23</sup> See chapter seven for a discussion of the issues of therapeutic treatment as well as HIV as a blessing in disguise.

### 2.2.1.1.- Theoretical Sampling

The initial goal of my research project was to test some theoretically hypothesised relationships as well as identify, develop, and relate concepts that the data would reveal. My initial sampling plan was ‘theoretical’ sampling, in the sense that it was a sampling procedure that takes into consideration concepts that have proven theoretical relevance to the emerging theory. Theoretical sampling is employed when the ‘process of data collection is controlled by the emerging theory, whether substantive or formal... (and the) criteria are theoretical purpose and relevance’ (Glaser and Strauss, 1974:45-48). By ‘theoretical relevance’ it is meant that concepts are significant because they are repeatedly present or absent when comparing incidents, and because they have earned the status of categories through the coding process. In the initial phase of data collection I was interested in uncovering as many potentially relevant categories as possible, and was unsure as to which of the emerging concepts would turn out to be theoretically relevant dimensions (Strauss and Corbin, 1990). Although I had anticipated that the research might uncover unknown concepts, and that constant revision and comparison would lead to the demise of a number of assumptions derived from theory and from observation, I had not envisioned my encounter with part of the HIV-diagnosed constituency of the ‘Dissident Movement’. Until one of my interviewees turned out to be a so-called ‘AIDS dissident’ I had never come across any organised *scientific* movement that challenged the scientific processes involved in establishing the aetiology of AIDS much less an individual whose identity seemed to have been organised around the reverse scientific discourse on AIDS. It was my own ‘fateful’ moment in the research process, and one that also required a fundamental restructuring of the investigation I was undertaking.

### 2.2.1.2.- Purposive Sampling

The most fundamental change I had to implement once the 'dissident' category had emerged related to the unit of analysis of the research. The analysis would now have to be implemented between HIV-infected individuals whose HIV-disease cosmology was significantly different and not, as previously planned, between infected homosexual men and infected heterosexual women. Now if I were to be able to have access to this hidden population of dissidents another sampling technique, called 'purposive' sampling, was necessary. As such, I purposefully procured persons and sites that would allow me to tap into this hidden population. The sample was thus purposive inasmuch as I actively procured the inclusion of 'dissidents' as they represented a fundamentally different, and comparatively *very* rare, process of identity reconstruction.

### 2.2.1.3.- Link-Tracing Sampling

Link-tracing or chain-referral sampling, also known as 'snowball' sampling, are techniques utilised in order to access 'hard-to-reach', or 'hidden' populations (Biernacki and Wald, 1981; Hendriks et al, 1992; Spreen, 1992; Coxon, 1996). 'Hidden' populations are characterised by their generally 'covert' behaviour and 'elusive' sampling characteristics (Bell et al, 2003). These populations are often constituted by disenfranchised and disadvantaged social groups, such as young unemployed males, drug users, people with AIDS and other stigmatising conditions such as rare deformative diseases and anorexia, criminals, prostitutes, homeless people, and as my research has uncovered, dissidents. The logic of using such sampling procedures in my research is

supported by the fact that not only are homosexual men difficult to reach (as the proportion of 'out' gay men is small in comparison to those 'hidden' populations of men who have sex with men and who may not be highly gay-identified), but the fact that *positive* homosexual men constitute an even more indistinct population. The amalgamation of homosexuality and HIV infection when added to the highly stigmatised anti-establishment posture towards HIV diagnosis embodied by AIDS dissenters yields an almost invisible population.

'Snowball' sampling constitutes a technique for locating research subjects whereby the names of new potential research subjects are referred to the researcher by each respondent. 'Snowball' sampling constitutes an element of the wider link-tracing methodologies that use the social networks of identified respondents in order to expand the researcher's possible contacts. The method is also used in order to obtain more data on a particular research question. However, particular combinations of number of links and/or distinct referral chains allows the researcher to decide whether the generation of more substantial data about a particular sample or the possibility of inferences about a wider hidden population is the focus of the research. The assumption which underlies these models is that a 'link' exists between the initial sample and others in the same target population (Thomson, 1997; Berg, 1998; Vogt, 1999). To successfully embark on this sampling procedure the researcher must consider the possibility of hostility and/or 'fatigue' amongst marginalised groups, and how one is meant to tackle it (Moore, 1996). Another advantage of employing link-tracing methodology in this piece of exploratory

research is that it imbued the researcher with characteristics of being an 'insider', and allowed for entry into settings that may otherwise have been 'off limit'.

Despite the recent trend towards increased sophistication in methods of error estimation and sampling frame, there are several problems involved in using snowball sampling.

Issues concerning the representativeness of the sample constitute one of the main shortcomings of chain-referral methods because of the non-random nature of respondent identification. This was not an issue I was concerned with since the subjects of my exploratory research constituted subsets of a 'population whose membership is not readily distinguished or enumerated based on existing knowledge and/or sampling capabilities' (Wiebe, 1990:5). As such, the impossibility of an *a priori* definition of my sample precluded the consideration of probabilistic sampling. In this situation, sampling, much like coding, emerges through the process of data collection. Grounded theory studies are concerned with representativeness of concepts, not generalisability to population. However, inasmuch as qualitative research is concerned with the validity, the reliability, and the applicability of its results it also contains a strand of objectivity (Boyatzis, 1998). What should also be clear is that even quantitative methods can never produce a purely objective study; humans, unlike computers, can never process all information without some degree of subjectivity. In any event, the nature of my research question, where subjective processes are fundamentally implicated in the reconstruction of the self, constituted an explanatory situation where qualitative design represented the appropriate choice. My goal was to have access to the hidden populations of dissidents as well as of HIV-infected gay men in order to explore the experiences of the marginal

groups I was studying. As such, snowball sampling was used in conjunction with the techniques of theoretical and purposive sampling. The goal of this complementary sampling strategy was thus to include as many instances of the units of sampling and achieve as much density and saturation as practically as possible.

### 2.2.2.- Sampling Issues

#### 2.2.2.1.- Size of sample

In order to identify potential categories involved in the process of identity reconstruction after an HIV diagnosis I initially conducted sixty-seven interviews: fifty-four homosexual men and thirteen heterosexual women. Although a few more interviews with women would have increased the density of female interviews, I was satisfied with the level of saturation I had achieved in the female category. The subset of HIV-positive (non-dissident) men started producing new categories, and as the relationship between their categories seemed to be well established and validated, I stopped sampling them. As far as the dissident subset I interviewed as many as I could possibly find within the time and accessibility constraints I had to identify this hard(er) to reach population.

#### 2.2.2.2.- Discovery of a New Category: changing the Unit of Analysis

As I explained in earlier sections the discovery of the category of ‘AIDS Dissent’ constituted a turning point in the research process. It was at this point of my ‘field work’ that I really understood the dynamism of the interviewing process. The data were not a



feebly static collection of concepts, but a much richer fabric of different, sometimes disparate, experiences of embodying an HIV diagnosis.

Before the emergence of the new category of AIDS dissidence the sample of the research project had been divided into two subsets: heterosexual HIV-infected women and HIV-positive homosexual men. The logic was that these two subsets would be compared in terms of how their identities were constructed. Once I came upon the new category the sampling design was modified. Now one subset was comprised of HIV-infected homosexual men whose cosmology of HIV/AIDS corresponded to the conventional, allopathic model (orthodox), and the other subset was composed of HIV-infected individuals whose cosmology of HIV/AIDS corresponded to that articulated by all or some of the elements of the Dissident Movement (dissident). Of the eleven individuals who constituted the dissidents only one was a (heterosexual) female, the remaining ten individuals were all male homosexuals. As such, the main criterion for comparison became the HIV/AIDS cosmology inasmuch such disparaging cosmologies coalesced around very distinct identity (re)construction processes.

### 2.2.2.3.- Biases

Another issue that needs to be considered when implementing a qualitative research project is the fundamental question of the validity of the sample, and the consequent quality of the data (Van Meter, 1990). As qualitative samples – in the case of my research a combination of theoretical, purposive, and link-tracing techniques – are not randomly drawn they are likely to be somewhat biased and as such not allow for generalisations.

Link-tracing techniques, for example, depend not only on the subjective choice of respondents but also over-emphasise cohesiveness in social networks as they tend to include interrelated individuals (Griffiths et al, 1993). The problem with interrelated networks is that 'isolates' will be overlooked (Van Meter, 1990).

The generation of a large sample may partially address the issue of bias in link-tracing techniques. My sampling strategy attempted to create a large sample of the two subsets. Yet, I only really succeeded in reaching a larger (comparatively) number of 'orthodox' individuals whereas the identification of 'dissidents' produced much poorer results (not only because they are hard(er) to reach but because their number is very small). Despite such problems, the complementary methodology of the research enabled me to not only identify, but also study the lifestyles of two distinctively marginalised groups with as little bias as was possible for a research project of this scope and nature.

#### 2.2.2.4.- Additional Dissident Interviews

Increasing the number of dissident interviews from the original nine to eleven was not an easy task. Managing to find the nine initial dissidents had proved to be a difficult enterprise; a hard-to-reach population indeed. However, as in the nine initial dissident interviews only one was female, and since the objective was now to compare between dissidents and non-dissidents in order to increase the homogeneity within the two sub-samples, and increase validity of comparison, I asked a particularly important member of the movement to refer me to another possible male respondent. By then I had gained the trust of the Dissident Movement's most prominent articulators and of some of its

members; as such, I was able to generate a couple of additional interviews through the access not only to the movement's 'gate keeper' but through my own 'knowledge of insiders' (Groger at al, 1999). Snowball sampling was thus invaluable and showed its efficacy in obtaining respondents when they are few in number, and when the research context requires an element of trust. However, it should be noted that the small sample of dissident individuals may not approach the theoretical rigour of theoretical saturation dictated by a GT approach where sampling is exhausted only when no additional data is being found. In an ideal scenario I might have been able to locate further dissident respondents in order to exhaust the saturation of my data; in the context of this research project saturation ended where plain impossibility started.

### 2.2.3.- Data Collection

#### 2.2.3.1.- Ethical Issues

Prior to the interviewee's participation the research project was fully explained. Respondents were assured that the interviews would not only be completely confidential, but that if results were ever published names and biographical details would be modified to guarantee anonymity. Respondents were also told that it was their prerogative not to answer any question if they so desired, and that they could terminate the interview at any time. None of the participants refused or felt they should not answer any particular question. Once the participant was fully aware of the issues, and indicated that he or she was willing to participate, the interview commenced.

### 2.2.3.2.-Questionnaires

#### 2.2.3.2.1.- Questionnaire Themes Based on Literature Review

The nature of the research questions signified that the process of data collection would touch upon some highly sensitive areas. As such, the data would best be obtained through personal interviews. The method envisaged for data collection was thus semi-structured interviews. The objective of building a questionnaire at the beginning of the research process was to ensure that the interview would be centred on topics which might play a fundamental role in the development of identity, and on issues surrounding HIV/AIDS. To avoid the potential 'construction' of data the questionnaire served simply as a general guide to the outline and the structure of the interview topics, not as a schedule of questions. Hence, I developed a series of open-ended and close ended questions covering the content areas, which I had devised from the literature review. Such content areas provided me with a *beginning focus* to start collecting data. Although the 'passive' approach to interviewing was maintained, interviewees had to be coached towards responding the topics as laid out in the interview guide. However, the initial topics were provisional ones, many of which were later revised or abandoned whilst new ones emerged (Strauss and Corbin, 1990).

The main focus of the research was the interaction between HIV/AIDS and identity. Therefore, the composition of the interview guide covered the following five areas: identity, sexuality, diagnosis, health, and religion. The final part of the questionnaire was where the respondent engaged in self-evaluative thinking; the objective here was to bring all the previous elements together and wrap up the interview in terms of the meaning of

the experience of disease. The scope of the interview was allowed to widen if particular relevant areas emerged in individual interviews.

#### 2.2.3.2.2.- Constructing Questions According to Standard Questionnaire Design

##### Procedures

Standard questionnaire design procedures were followed (Johnson, 1975; Judd et al, 1991; Kvale, 1996; Silverman, 1997). Issues such as the role of the wording of questions, as well as the sequencing of questions from the simplest to the most complex or probing, were taken into consideration so that the data collected would not be influenced by the manner in which questions were asked.

#### 2.2.3.2.3.- Copy of Questionnaire

A copy of the questionnaire is provided in Appendix A.

#### 2.2.3.3.- Interviews

##### 2.2.3.3.1.- Pilot Interviews

Initially I endeavoured to follow the order of the interview topics as I had laid them out in the questionnaire. However, the first few pilot interviews revealed that the interview situation was best utilised if I allow respondents to talk as freely as possible even if, or most fundamentally, and perhaps *especially* if, they deviated from the devised topics. Despite the respondents' freedom and my passive approach, I was the one guiding the interview. As such, I ensured that in each interview the content areas were always

covered. Ultimately the direction of the exchange was always guided by me; yet, each interview proved to be a different experience with its own rhythm and cadence.

Pilot interviews were conducted on individuals who had been located through advertisements in the HIV press, more specifically in the magazine 'Positive Times'. These advertisements yielded a poor response; only three interviewees were located in this manner. These three interviewees were asked to refer me to a couple of individuals whom they knew to have also received an HIV diagnosis. Another three interviewees were found in this way. The six initial interviews produced a large amount of data, and some new concepts emerged from studying and comparing the material I had collected. Further advertisements produced no response.

#### 2.2.3.3.2.- The Evolution of the Interview Process: from Structured to Semi-Structured interviews

Despite the plethora of approaches towards qualitative interviewing, the methodology can be basically classified into three distinct techniques: structured, unstructured, and open-ended (Fontana and Frey, 2000). Interviews can be simply described as 'a conversation between two or more people where one or more of the participants takes the responsibility for reporting the substance of what is said' (Powney and Watts, 1984:2). With the objective of reducing interviewer bias in an encounter that constitutes an interactive and dialectic social relation, general norms on how to tackle the process have been established (Goode and Hatt, 1952; Kalekin-Fishman, 2002, Fielding, 2002). In order to increase reliability and validity in qualitative interviews the researcher is

supposed to maintain emotional distance towards the interviewee. The researcher should not reveal any feelings or whatever other standpoints he or she might hold related to the research; and no knowledge should be shared (Goode and Hatt, 1952; Westmarland, 2000). However, such tenets have been questioned not only by feminist approaches to sociology (Oakley, 1981), but also by specific theoretical orientations (Spradley, 1979; Silverman, 1985). In sum, interview techniques have been adapted by interpretivist sociologists and feminist researchers to be more participant-friendly (Dubois, 1983). Such innovations have been integrated into mainstream sociological research textbooks (Burgess, 1984). Still, no consensual definition of interviewing exists (Kalekin-Fishman, 2002).

The principal outcome of conducting the pilot interviews was the realisation that the data collection process I had designed was not as efficient as it could be. The questionnaire, or interview guide, I had formulated constituted a semi-structured interview of mostly open-ended questions. The pilot interviews were supposed to have followed a sequential order of exploration from areas of a general nature towards more focused and sensitive topics of inquiry. That was the plan, but the reality was indeed quite different. To follow the questionnaire proved to be wrong: not only was the physical presence of the questionnaire a hindrance to the relaxation of both the interviewee and I, but also in formulating questions in such a prescribed way the 'distance' between the respondent and the researcher was magnified. The first two pilot interviews felt rigid and artificial. It was clear at that point that I would never elicit the necessary trust relationship that was required in the interview context unless I completely changed not only the way but the

manner in which I was asking my questions. Hence, after the first two pilot interviews I decided to adopt a much more unstructured approach to the interviews. For the future dozens of ‘conversational face-to-face interactions’, where through in-depth probing I would try to improve knowledge about HIV-centred identities, I adopted an ‘unstructured-in-depth’ approach. My role as interviewer was to guide the direction of the respondents’ utterances, to allow for an enlargement of the scope of the interview when particular relevant areas were revealed, and to probe revealing categories that were emerging from the data (Wengraf, 2001). Below I describe the process in further detail.

#### 2.2.3.3.3.- The New Category: how it emerged

Almost half-way through the data collection process I came upon an individual whose HIV/AIDS cosmology was of a very different nature from the ones I had so far encountered. Some conceptual categories were emerging from the data, but nothing as radical as that had surfaced. Here was an HIV-infected individual whose belief system ran drastically counter to the conventional medical wisdom on AIDS, and the biosocial processes that are deemed to cause it. He had been referred by a previous interviewee, an ex-lover. This individual identified himself as an AIDS dissident, and organised his identity very much around the existence of a scientific critique of the science surrounding AIDS. At this point, after analysing our long interview, I realised that if there was a *community* of such people then they certainly constituted a very significant group. Numerically they might be relatively small but in terms of enriching the understanding of



identity construction and HIV diagnosis they could be very significant indeed.<sup>24</sup> These HIV-infected individuals constructed their post-diagnosis identities in what appeared to be a radically recalcitrant, maybe revolutionary, context. Not only did this discovery change my sampling design but it also fundamentally changed the prism through which my data would be analysed.

#### 2.2.3.3.4.- 'Doing' the Interview

The nature of my research required that a considerable amount of trust developed between my respondents and I if I really wanted to obtain revealing and sincere responses from them. This was true with both sampling subsets but especially with the dissidents; the great majority of the latter were obtained through an initial contact with the movement's most prestigious 'gatekeeper' in Britain. With positive women, a 'fatigued' group, I was not as lucky (Moore, 1996). Perhaps the fact that the researcher is himself a gay man, and the fact that positive women may feel neglected in a health crisis that in the West has been appropriated by gay men, in this case constituted not an advantage but a hindrance.

After ethical issues had been explained and confidentiality assured the interview commenced. The method of empirical data collection was audio-recorded 'lightly-structured in-depth' interviews (Wengraf, 2002). In the unstructured format the researcher had chosen for the interviews some kind of rapport-establishment was procured before the actual 'interview' started (even if my tape recorder was turned on as

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<sup>24</sup> This dissident community is a loosely organised network of individuals mainly connected through publications that spans the principal swath of the Anglo-Saxon world (United States, United Kingdom, and

soon as it could be done without offending the interviewee). As such, 'interviewer' questions, rather than 'theoretical' ones, would be asked and an informal, relaxed atmosphere hopefully created. As such, and quite often, especially if the context of the interview was the respondent's home, the dialogical interaction flowed in a very organic manner without any distinction from the initial 'chatting' and the 'interview' *per se*. Usually respondents talked at length about their situation, their views on their situation, and all the social processes their situation had engendered

In preparing for an interview the researcher took into consideration issues of 'presentation' (which clothes I wore). Another important consideration was the importance of trying to attune to the respondent's general cultural factors (ethnicity, age, social class, for example). An interview with a middle-aged orthodox solicitor requires a different set of sociolinguistic postures than does an interview with a thirty-something unemployed orthodox man who deals drugs. Also fundamental was to know which 'language' to use depending on to which sampling subset did a respondent belong: interviewing 'dissidents' required a complete set of new knowledge(s) inasmuch as their conception of HIV/AIDS was based on the tenets of the Dissident Movement (Spradley, 1979). These procedures were followed in order to assure that the rapport the researcher developed with the respondents was substantial.

The interviewing process took almost two years from mid-1997 to 1999. A typical interview lasted about ninety minutes; some lasted longer some were shorter. The longest interview lasted approximately three hours, and the quickest about one hour. After the

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Australia).

interview was finished and I had departed from the interview context I made comments into a small tape recorder (a dictaphone); these comments constituted my field notes. A significant percentage of the interviews were conducted in interviewees' homes, many were conducted within the premises of the institutions of the HIV- service industry, a small number in bars and pubs, and one was conducted in a hospice. If interviews were conducted in public places without privacy the researcher made sure that there were no other individuals within the hearing range of the interview. The geographical scope of my sample extended from the centre of London to its outer edges.

The interviews explored emotive and deeply personal topics; not surprisingly some of the respondents became occasionally distressed and tearful. Many interviews constituted open, frank, even emotionally saturated interactions. A number of sociological theorists disagree with the (increasingly challenged notion) that for research to be objective the researcher can not in anyway be involved in the subject of his/her research interview. I, as the researcher, agree to disagree. My respondents were aware of the fact that I am a gay man, and as such have also been affected by the HIV/AIDS crisis even if not in a life-threatening way. Had I maintained an artificially distant posture my interviews would not have been more objective, they would have elicited poorer data. Proximity and equality towards the interviewees, especially in research projects that deal with deeply personal matters, can only yield richer, more significant data (Oakley, 1981; Finch, 1984; Greed, 1990).

#### 2.2.3.4.- Method of Transcription

##### 2.2.3.4.1.- Issues of Transcription

The most important factor to take into consideration regarding the transcription of the data is which CAQDAS (computer assisted qualitative data analysis software) is going to be used in the analysis. Such a decision should be taken in the early stages of methodology design so that consistent transcription that is in accordance with the specific requirements of the software is performed. In order to maximise the management of my research data, I employed the computer package QSR NUDIST (Non-numerical Unstructured Data Indexing Searching and Theorizing). NUDIST enables one to make connections between codes, develop categories, formulate and test propositions concerning the data, and engage in interactive enquiry through processes of system closure. I decided on NUDIST because the objective of data analysis through NUDIST was to develop categories and to organise the large amount of data that had been collected. I wanted to have as much flexibility as possible in my capability for coding and retrieving, as I needed the freedom to reorganise conceptual categories. As such, NUDIST4 functioned as a tool in helping the management of the data as well as the creation and exploration of provisional categories in the earlier stages of theory building and data analysis (<http://www.qsr.com.au>).

Coding was an essential part in the process of analysing and thinking about the data as it provided the 'link between data and conceptualisation' (Bryman and Burgess, 1994:5). Concepts 'are the basic unit of analysis in the grounded theory method'; thus, coding was the first step I undertook in order to understand the data that began to emerge (Strauss

and Corbin, 1990:63). Although I had an initial scheme of concepts and categories derived from the literature and observation, which was informed by some theoretical insight into the field of identity as well as in terms of HIV as a social and bio-physical problem, new categories began to emerge as soon as I went into the field. Categories are classifications of concepts that are derived from comparing concepts to one another; when they appear to pertain to a similar phenomenon concepts are grounded together under the more abstract notion of category. The conceptual framework was often rethought and modified after encountering a new piece of information or after an interviewee described a new account of how he or she developed coping strategies in order to deal with HIV/AIDS. In choosing the program, I took into consideration that my data were going to be collected through individual, in-depth interviews; that it would be collected from one source only (the interviewees); and that it wouldn't be strictly organised but 'free-form' (i.e. unstructured interviews and field notes).

NUDIST was, however, not the only CAQDAS I used in order to analyse the data. Several authors have discussed a multitude of methods to analyse respondents' talk about their experiences (Spradley, 1979; Taylor and Bodgan, 1984; Mahrer, 1998). 'Thematic Analysis' constitutes one such method; one that focuses on the exploration and analysis of the identifiable themes and patterns that emerge from the interviews (Taylor and Bodgan, 1984; Benner, 1985; Leininger, 1985; Boyatzis, 1988). The emergence of the new sampling unit occasioned the rethinking of the analysis process. The strategy hence became to focus on the richness of the content of identity restructure processes that could be yielded from conducting thematic analysis on five dissident and five orthodox

interviews. The goal of honing in on ten interviews was to explain ‘how different ideas or components fit together in a meaningful way when linked together’ (Leininger, 1985: 60). As such, it was decided that the CAQDAS better suited to the task was HAMLET (<http://www.soton.ac.uk/~apb/hamlet95.pdf>), which is available for no cost on the Internet. The pragmatic process of thematic analysis starts with data collection, followed by the identification of patterns and then the identification and ascription of all data to the patterns that have been recognised. Transcription guidelines differ from NUDIST to HAMLET particularly in what concerns the conventions through which chunks of data can be made codeable.<sup>25</sup> As a result, I had to go back to original word processed transcripts to adjust the coding conventions to the requirements of HAMLET and prepare the ten interviews for thematic analysis. Once the modifications had been made the next step was to combine the patterns into themes and sub-themes so that a clear and comprehensive panorama of the respondents’ experience could be drawn. The ‘drawing of the panorama’ constituted the theory-building stage of the research and will be described in chapter seven.

#### 2.2.3.4.2.- Process of Transcription

Transcription constituted a long, arduous process. I personally transcribed all the interviews through listening and re-listening to each recorded tape. On average an interview occupied two double-sided sets of one-hour cassette tapes. Each thirty minute

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<sup>25</sup> For example, in QSR NUDIST the ‘text unit’, i.e., the codable ‘chunk’ is defined by the hard return. As such, line breaks of the ‘save as text’ option result in text units that correspond to the lines of the text; for variable codable segments hard returns can be inserted, as the researcher sees fit, in order to reflect contextual breaks. In HAMLET codable chunks can be words (fixed context units, collocation within a span), characters (variable contexts) or sentences (as normally punctuated). For this research project the

side took anything from ninety to one-hundred-and-twenty minutes to transcribe. The speed of the transcription depended on the speed of the respondent's speech, its clarity, the quality of the recording, the amount of words included in the respondent's utterances, and the interference of background noise in the recording. At the end of the data collection process I had seven-hundred pages of single-spaced transcript.

#### 2.2.3.4.3.- Description of Transcripts

In this section my objective is to home in on the ten transcripts that were used for thematic analysis, and provide a lexical description of each file. The tables below indicate the size of the files, their word counts, their type/token ratios, as well as the distinction between interviewer and interviewee's word counts for each file. Type/token ratios indicate the complexity of an interview by dividing the number of unique words identified in the transcript by the number of its total words (Popping, 2000). The word counts of both interviewer and interviewee specify the total number of words uttered by each. The specification of separate files for words uttered solely by interviewees reduces potential biases that might be present if the interviewers' words were also included when text analysis is performed.

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codable chunks in QSR NUDIST were line brakes, and in HAMLET sentences as normally punctuated (which in practice meant respondents' uninterrupted utterances).

### Orthodox Transcripts

	Size of File	Word count	Type/Token Ratio	Interviewees word count	Interviewer word count
Interview 1	109 kb	10184	0.176	9437	747
Interview 2	129 kb	13518	0.115	12731	787
Interview 3	100 kb	9392	0.147	8596	796
Interview 4	81 kb	9315	0.139	8448	867
Interview 5	71kb	6645	0.160	6291	354
Averages	98kb	9811	0.147	9101	711

### Dissident Transcripts

	Size of File	Word Count	Type/Token Ratio	Interviewees word count	Interviewer word count
Interview 1	88 kb	8604	0.176	7931	673
Interview 2	88 kb	10368	0.142	9737	631
Interview 3	84 kb	9433	0.159	8789	644
Interview 4	74 kb	7701	0.173	7116	565
Interview 5	94 kb	9747	0.116	8842	905
Averages	86kb	9171	0.153	8483	684



#### 2.2.3.4.4.- Example of Full Transcription

See Appendix B.

### 2.3.- Description of Sample

#### 2.3.1.- Recruitment Methods

##### 2.3.1.1.- Recruiting: where and how to get a hold of the hard-to-reach samples

The subjects of the research project epitomise the notion of ‘hard to reach’ populations. Their stigma is multifaceted and compounded: they are homosexual; they are infected with the HIV virus; and some of them, to top it off, have adopted a marginalised ideological position. During the pilot phase of the research advertisements recruiting participants were placed in ‘Positive Times’, but only three respondents were located in this way. Further advertisements in ‘Positive Times’ produced nil results, as did a number of notices posted in the HIV clinics of Ealing, St. Mary’s and St. Barth’s hospitals in London. Consequently, in order to recruit HIV-positive individuals, who subscribe to the biomedical model I mainly relied on the institutions of the AIDS service industry.

The AIDS service industry can be defined as ‘the private-sector non-profit organisations devoted exclusively to AIDS work.’ Although the idea of an ‘industry’ runs the risk of over-generalising and over-simplifying particular differences, these institutions do assume similar policy directives and reproduce material conditions ‘that construct AIDS

as a particular kind of problem and legitimate only a limited set of solutions and administrative structures' (Patton, 1990:13-14). As these institutions are elemental in reproducing the biomedical model of HIV/AIDS they were used in order to locate HIV-positive individuals likely to have embraced the biomedical model of HIV/AIDS. I worked closely with two major statutory institutions of the local HIV/AIDS service industry: the 'Globe Centre' in East London and 'Body Positive' in West London. Both institutions provide legal advice as well as social, moral and emotional support and free access to alternative and complementary therapies to HIV-infected men and women. In order to access the orthodox subset 'gate keeper' figures of the 'Globe Centre' in East London and of 'Body Positive' in West London were fundamental. The researcher established a trusting relationship with one key figure in each institution, each the main 'gate keeper' of their constituency and through their assistance was able to locate a significant amount of respondents.

Individuals who are regular attendees of AIDS service institutions are likely to represent a specific constituency of highly-gay-identified HIV-infected men. As such they constitute the 'tip of the iceberg' of a much bigger infected population 'lurching' underneath. My sample was thus biased inasmuch as the great majority of 'orthodox' respondents were found in this way. Advertising in the HIV press as well as link-tracing techniques were implemented in order to increase the representativeness of the sample. However, recruitment through advertising yielded very low response levels and although the link-tracing technique produced comparatively better results, most of the respondents found in this manner were recruited through interviews which originated in the

institutions of the AIDS service industry. Nevertheless, the link-tracing technique did lead the research to the dissident subset as the referees were specifically asked to refer other HIV-infected individuals whom they knew from contexts other than the service industry (such as sexual partners, friends, or colleagues).

The journal 'Continuum' constitutes the main forum of the 'Dissident Movement' in the U.K. The publication appears four times a year and has approximately four-hundred-and-fifty subscribers in the UK. 'Continuum' serves as a focal point for dissidents to articulate their unconventional ideas. 'Continuum' also organises the so-called 'occasional meetings' that serve as a focal point for dissidents to meet and derive some support from each other. Similarly to the institutions of the AIDS service industry; 'Continuum' is fundamental in the production and maintenance of 'dissident' identities. Accessing the dissident subset was only possible through the relationship I established with one of the journal's most respected figures. After the mutually trusting connection had been established with this individual I was granted easy access into the group's meetings; I was allowed access to all their information and publications; and was introduced or referred to a number of dissident-identified individuals. Except for the interviewee who introduced me to the dissident category, all other dissident individuals in my sample were recruited via 'Continuum'. The recruitment was implemented through personal communications with the staff of 'Continuum' as well as through the occasional meetings I was allowed to attend. The magazine provided me with free advertising space to recruit interviewees, but these advertisements, which ran in three subsequent volumes, produced no response. As such, although the representativeness of my sample would

have definitely benefited from a larger sample I was unable to locate any more respondents.

**2.3.2.- General Demographics of Interviews**

**2.3.2.1.- Demographics of NUDIST Interviews**

This section provides some basic demographics about the whole sample in terms of gender, ethnicity, educational level, employment, welfare benefits, and religious affiliation.<sup>26</sup>

Gender	No. of Individuals
Male	54
Female	13

Ethnicity	No. of Individuals
White	58
Other	9

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<sup>26</sup> Many respondents refused to claim welfare benefits even if they would have been entitled to them. The role of welfare benefits and orthodox and dissident identity will be discussed in chapter six.

<b>Employment</b>	<b>No. of Individuals</b>
<b>Full-time</b>	<b>18</b>
<b>Part-time</b>	<b>16</b>
<b>Unemployed</b>	<b>33</b>

<b>Educational Level</b>	<b>No. of Individuals</b>
<b>No O-levels</b>	<b>10</b>
<b>O-levels</b>	<b>8</b>
<b>A-levels</b>	<b>15</b>
<b>Graduate</b>	<b>27</b>
<b>Post-graduate</b>	<b>7</b>

<b>Welfare Recipients</b>	<b>No. of Individuals</b>
<b>Recipients</b>	<b>18</b>
<b>Non-recipients</b>	<b>16</b>
<b>Unemployed</b>	<b>33</b>

Religious Affiliation	No. of Individuals
Atheists	26
Self-religion	29
Catholic	8
Other	4

**2.3.2.2.- The NUDIST sample and HIV: symptoms, time of diagnosis, and therapeutic strategy**

The sample is also characterised in terms of HIV symptomatology and therapeutic strategies. In terms of symptoms of HIV disease the respondents were classified according to their own accounts of what symptoms or diseases associated with HIV they had experienced.<sup>27</sup>

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<sup>27</sup> Asymptomatics were defined as those who presented no symptoms of HIV disease. Mildly symptomatic respondents were classified as those who presented the relatively minor ailments usually associated with HIV disease. Severely symptomatic respondents comprised those who had been diagnosed with opportunistic infections (OI) and as such had also been diagnosed with full-blown AIDS. The category of asymptomatic could be over reported as some of the respondents who claimed mild symptoms, or A.R.C. (AIDS-related-complex), could have underplayed their condition in the same way that a number of respondents who had been diagnosed with an OI told me that they preferred to refer to themselves as 'positive' rather than as having an AIDS diagnosis. For a fuller discussion on issues of what defines an AIDS diagnosis, refer to chapter six.

Symptomatology	No. of Individuals
Asymptomatic	11
Mild Symptoms	13
AIDS	43

Symptomatology was further classified in relation to HIV-identity.

Symptomatology	Orthodox	Dissident
Asymptomatic	6	6
Mild Symptoms	11	3
AIDS	39	2

The sample was also characterised in terms of how long they had been diagnosed.

Time Since Diagnosis	No. of Individuals
1-3	20
4-6	15
7-9	11
10-12	10
> 12	11

Another characterisation of the sample was constructed in terms of respondents' consumption of orthodox therapeutic strategies (OT) and/or complementary and alternative (CAM) therapeutic strategies for HIV/AIDS.

Therapeutic Strategy	OT User	CAM user
Current user (CU)	42	38
Used but stopped (US)	7	5
Never used (NU)	18	24

### 2.3.2.3.- Demographics of Thematic Analysis Interviews

From sixty-seven interviews I homed in on ten. The selection process of these interviews was based on their richness of content (not representativeness) inasmuch as if taken on a whole they contained all the categories which were deemed relevant in the construction of identity after an HIV diagnosis. Three other factors were taken into consideration. Firstly, as there was only one female dissident in the dissident subset, female interviews were not considered for thematic analysis so that comparison criteria would not be influenced by gender. Secondly, I decided on orthodox interviews from the later stage of the interview process as they contained data on orthodox perception of the Dissident Movement. Thirdly, all orthodox thematic analysis interviews are of individuals who present (mild or strong) symptoms, whereas in the dissident subset one of the interviews is of an individual who claims to be asymptomatic. My logic was to analyse interviews of individuals who have experienced some level of disease, not just a diagnosis of infection, as the process of identity reconstruction in such cases is more likely to have been fully



undertaken. In the dissident subset I included an asymptomatic individual since only five of the respondents had developed symptoms, one of which was the female interviewee.

Orthodox Interviews of Thematic Analysis

In t.	Age	Ethnic ity	Educati on	Employment	Benef its	Religi on	Sympto ms	Time Diagno sis	O T us er	CA M user
1	50	White	Postgra d	No	Yes	Atheis t	AIDS	4	C U	NU
2	41	White	Gradua te	No	Yes	Atheis t	AIDS	3	C U	NU
3	36	White	A levels	No	Yes	Self	AIDS	4	C U	NU
4	41	White	Gradua te	Full	No	Self	AIDS	6	C U	NU
5	40	White	Gradua te	No	Yes	Self	Mild	10	N U	CU

Dissident Interviews of Thematic Analysis

In t.	Age	Ethnic ity	Educati on	Employment	Benefits	Religi on	Sympto ms	Time Diagno sis	O T us er	CA M user
1	45	White	Graduate	Full	Yes	Atheist	AIDS	7	N U	US
2	30	White	A levels	No	Yes	Self	Mild	10	US	CU
3	58	White	Graduate	No	No	Self	No	7	N U	CU
4	62	White	Graduate	Part	No	Self	Mild	3	US	CU
5	31	White	A levels	Part	Yes	Atheist	AIDS	5	US	CU

2.4.- Future Research: integrating paradigms

‘Reality’ as we know it has existed for billions of years whereas ‘social reality’ only appeared with the emergence of human life many billions of years later. Quantitative and qualitative research, recent additions to the many dimensions that compose the

contemporary 'reality' of (social) life, are humanly constructed analytical tools concerned with understanding the 'social reality' of which they (both humans and social science) are part. Whether research is conducted from a positivistic or constructivist perspective it is bound to be influenced by the values of its perpetrators. As long as social research continues to be implemented by social beings, the human factor and its corresponding biases will remain present. However, the collateral consequences of the human factor in social research can be ameliorated through the increasing range of competent technical subterfuges that the social sciences, in their positivistic search for the achievement of objectivity in its purest form, continue to develop. As such, even if research is 'not a clear cut sequence of procedures following a neat pattern, but a messy interaction between the conceptual and empirical world, deduction and induction occurring at the same time' (Bechhofer, 1974:73), it can and ought to be sanitized.

The official discourse of the patriarchal society characteristic of modernity, which under the grasp of 'masculine' utopias founded on the myth of the unbounded potential of science, framed the birth and development of social science in the nineteenth century. As such, the positivistic stance of social research was occasioned by the socio-historical background of the era in which it emerged. Social science was biased at birth. As the modern gave way to the post-modern (or late-modern) new values began to surface, and new techniques for interpreting reality appeared. 'Deconstructive' analysis, for example, a post-modern technique primarily employed in literary analysis demonstrated how Pythagorean-originated dichotomies have permeated the construction of (male) knowledge of nature as the (female) object of knowledge (Lloyd, 1984). It has been

argued that the positivistic approach is thus incompatible with the emerging post-modern paradigm (Graham, 1983; Mies, 1983). However, history shows us that the lessons of the past should never be ignored even as one constantly adapts to the ever-changing, ever-moving present. Changing times require the integration of new and traditional forms of knowledge and knowledge production. The potential complementarity of the traditionally antagonistic paradigms of positivism and constructionism should be recognised, and their amalgamation promoted. As such, a new ontology that accommodates both traditions, what some are already calling 'Constructivist Realism', will be able to successfully take social research into the new century (Cupchik; 2001).

## **Chapter 3:**

# **The Homosexual Body through History: Representation, Containment and Resistance**

I caught myself foolishly imagining that gays might some day constitute a community rather than a diagnosis

(Edmund White, 1988)

## **3.1.- Ancient Homosexual Histories**

### **3.1.1.- Pre-Historic Homosexuality**

LaBarre (1984) has suggested that homosexuality can be traced all the way back to the Palaeolithic Age (500.000 – 10.000 BC).<sup>28</sup> According to this view, our Old Stone Age ancestors believed that semen carried the life force. The brain, which produced the élan vital, dispatched it to the testes via the spinal cord. The qualities of virility, courage, and prowess were thought to be contained in semen. As such, cannibalism, headhunting, and ritual pederasty were the practices that allowed the acquisition of masculinity. Such theory may be supported by the well-known Palaeolithic ritual practice of extracting the brain from the head. However, most anthropological research regards cannibalism, and headhunting, as practices devoid of any symbolism: the goal was simply to eat (Greenberg, 1988).

### 3.1.2.- Classical Homosexuality

In the ancient world homosexual behaviour was a widely diffused practice, which was enacted according to strictly defined norms. Homosexuality was mainly organised around two principal axes: the 'transgenerational', which was characterised by the older partner assuming the masculine (active) role; and the 'transgenderal', whereby one of the partners assumed the gender associated with the opposite sex. The former was most famously rampant in classical Greece, but it can still be found today in indigenous populations of Brazil and New Guinea. The latter was quintessentially exemplified by the 'berdache'. The 'berdache', the native-American male or (less frequently female) individual who laid claim to the gender of the opposite sex, entered into sexual relations with members of his (or hers) own biological sex. 'Transgenderal' homosexuality, which is often associated with shamanism, has also been documented between Central and South American Indians, in parts of the East Indies, Africa, Siberia, Vietnam, Burma, India, Korea, the Nepal Himalayas, and among the Maori in New Zealand. Also in the ancient civilisations of Central and South America was homosexual behaviour widespread. Archaeological evidence has shown that institutionalised homosexual roles existed in the societies of the Incas, the Mayans, and of the Aztecs (Greenberg, 1988).<sup>29</sup>

Despite the regularity of homosexuality in classical Greece, there were no words to denote homosexual (or heterosexual) individuals (Greenberg, 1988). The great Greek

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<sup>28</sup> Several Stone Age depictions of sexual relations between males have been found (Greenberg, 1988).

<sup>29</sup> The missionary Father Pierre de Gand reported that sodomy, involving children as young as six, was universal among the Aztecs (Greenberg, 1988:163-165).

philosopher Plato, who was born in Athens around 427 BC, together with his disciple Aristotle (384-322 BC), 'laid the foundations of most branches of speculative and natural philosophy' (Davies, 1997:110). Plato wrote a series of 'dialogues' in which he critically analysed philosophical ideas, and discussed the issue of homosexuality. In *Lysis*, *Phaedrus*, and *Symposium*, Plato discussed homosexual love as a force both educative and aesthetic. In *Symposium* the general ambisexuality of classical Greeks was explained. In classical Greece homosexual love was represented as an elevated kind of love. Its customary social pattern involved a teenager boy, or a younger man (known in Greek as the *eromenos*, or 'beloved'), who was pursued by an older man (an *erastes*, or 'lover'). The homosexual relationship of the ancient Greeks was comparable to the heterosexual norm in which the man assumes the dominant role. The younger male would yield only after a period of courtship. Women were completely excluded from public life, and spent most of their lives within the confines of the 'female' parts of the household. As such, boys and young men constituted the only possibility for objectification in classical Athens. Despite their sexual nature, the main point of such homosexual liaisons was their educative function. Not unlike the pederasts of the Stone Age, the *erastes* impregnated the *eromenos* with the masculine virtues of courage and honour. As soon as the *eromenos* reached maturity the relationship ought to become platonic (Jowett, 1991). However, homosexual liaisons between adults did take place even if they were less common, and were not severely stigmatised (Greenberg, 1988). Only after Athens became a republic was there a shift in the attitudes concerning such relationships. Plato's friend Socrates, 'the best *erastes* (lover) of all', was executed on charges of corrupting Athenian youth. A

disillusioned Plato left Athens, and only returned in 387 BC when he founded the *Academy* (Jowett, 1991).

Despite the educational function of homosexual relationships in classical Greece, the archetypal homosexual liaison of antiquity was that of class-structured master-slave relations, and prostitution. Greece herself was a slave-owning society where social status determined sexual activity. Such unequal relations were neither defined by the kind of sexual practices exchanged nor by the age or gender of the partners. Feelings and mutuality did not have to be taken into account: 'satisfaction was mainly associated with the phallic pleasure of the active male who imposed himself and his organ on its passive recipients.' Sexual power stemmed from a superior economic position, and men of superior status 'often took it for granted that they could penetrate their inferiors at will; and inferiors included women, boys, servants, and foreigners' (Davies, 1997:126).

Whatever its conceptualisation, the fact is that homosexuality was widely and permissively practiced amongst our classical ancestors. As the writer Diodorus Siculus wrote in the first century BC:

(Celtic) men are much keener on their own sex; they lie around on animal skins and enjoy themselves, with a lover on each side...this isn't looked down on, or regarded as in any way disgraceful: on the contrary, if one of them is rejected by another to whom he has offered himself, he takes offence (Diodorus Siculus, *Bibliothèque Historique*, bk.5, quoted in Herm, 1977:58)



### 3.1.3.- Homosexuality and the Beginning of Christianity

Ancient Mediterranean life was fundamentally transformed by the development of large cities, which became important administrative and religious hubs. Increased urbanisation disturbed the plausibility of polytheistic religions centred around agricultural and fertility themes. As such, the religious worldview of Antiquity began to shift as the pagan polytheism of moral and amoral deities was juxtaposed to the emerging dualistic notions of good and evil. In addition, imperial expansion fostered a religious syncretism whose trans-national and monotheistic character undermined the basis that had supported the magic associated with cultic homosexuality. Political life also changed as a result of increased urbanisation, which demanded an amplification of the governmental apparatus. Such developments limited the scope for popular participation in public affairs, and provoked a feeling of alienation among the lower classes. Plato, who had earlier praised homosexual love, in his later 'dialogues' changed his mind. His new opinion reflected the changes in the material conditions and symbolic systems of classical society. Plato's ideal pursuits were Truth, Good, and Beauty; he was critical of lustful behaviour and surrender to animalistic passion. Although lust was not exclusive to the relationships of the *erastes-eromenos*, Plato considered them more likely to succumb to it. In his last work, *Laws*, Plato concluded that sex should be procreative and limited to spouses. However, and although Plato came to refer to homosexuality as contrary to nature, he never considered it abnormal (Greenberg, 1988).<sup>30</sup>

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<sup>30</sup> *Para Phusin* was the term employed by Plato to denote the 'unnatural' character of homosexuality, but Boswell (1980) has noted that *phusis* had other meanings. Such a radical change in Plato's thinking is perplexing since until his final work he had conceptualised sexual desire as almost exclusively homosexual.

It is within such a context of rapid social change that Christianity evolved from its roots within the Judaism of Roman-occupied Palestine into a distinct religion. Early Christian writings and canon law were unquestionably disapproving of the 'paidiophthoros', or the *erastes* of Athens. In the Old Testament God's law certainly condemned them to death. However, although in the New Testament they are 'denounced as transgressors of the natural order', interpretations of several New Testament passages thought to refer to homosexuality remain open to question (Bailey, 1955:215).<sup>31</sup> In any event, by the latter part of the first millennium Rome was the new Empire, and the Middle Ages had mostly superseded classical Antiquity. Despite the entitlement of the Crown, in the emerging era the Church exercised *de facto* jurisdiction over individuals who engaged in homosexual behaviour. Church functionaries of the Middle Ages may have been 'aware of the complexity of sexual behaviour and the difficulty of assessing the morality of sexual acts'. Still, the verdict was ultimately untouched: homosexual acts constituted 'peccata contra naturam'. Their enactment was a mortal sin (Bailey, 1955:154).

Roman law, specifically the codifications of Theodosius and of Justinian, has profoundly influenced ecclesiastical canon law, and European systems of civil and criminal jurisprudence. As a result of C. Scantinus Capitolinus' conviction by the Senate in 226

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Boswell (1980) suggests that what Plato meant was not 'unnatural' in the sense of contravention of some moral law, but in the sense of 'unrelated to birth' or 'non-procreative'.

<sup>31</sup> For example, in the first Epistle to Timothy the term *arsenokotai* is usually understood to refer to male homosexuality (Bailey, 1955; Scroogs, 1983). However, as Greek literature constantly referred to homosexuality, and since never once before had such a term been employed to denote it, it has been argued that the term might not at all refer to homosexuality (Boswell, 1980).

BC, 'Lex Scantinia' was passed.<sup>32</sup> 'Lex Scantinia' penalised homosexual acts, but scarce evidence exists of actual punishment of such acts during the time of the Republic. The next undisputed evidence of legal measures against homosexuality refers to the much later period of Emperor Severus Alexander, in the beginning of the third century AD, when male homosexual prostitution flourished in the Italian peninsula. Once Christianity had become the religion of the Roman Empire, four edicts against homosexuality were instituted. The edicts of 538 and 544 claimed scriptural evidence to conclude that homosexual acts endangered the state inasmuch as the wrath of God - in the form of earthquake, famine, and pestilence - may be provoked. Yet, the 'sinners' themselves were not condemned, and the Emperor Justinian urged them to salvation through penitence. Although Justinian has been characterised as the most venomous of a series of Christian Emperors engaged in a crusade against homosexuality, he was in reality the only one who preoccupied himself with the salvation (as well as the punishment) of the offenders. Justinian, however, was pivotal in shaping western Christian attitudes towards homosexuality. In appealing to the fate of Sodom and Gomorra in his codification of the law, Justinian inaugurated the deployment of the 'reinterpreted' tale for legal measures against homosexuality (Bailey, 1955).<sup>33</sup>

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<sup>32</sup> Capitolinus was convicted of homosexual behaviour. However, it is unclear how 'Lex Scantinia came to pass (Bailey, 1955:64).

<sup>33</sup> The earthquakes and floods that devastated the eastern cities of Edessa, Anazarba, and Pompeiopolis in the East, as well as of Corinth and Dyrrachium in Europe in 525, are likely to have influenced the Emperor in his evocation of Sodoma in the edict 538. The plague that swept over Constantinople in 543 was certainly a factor in the edict of 544 (Bailey, 1955). The 'reinterpretation' of the story of Sodom and Gomorra is dealt with in chapter five.

### 3.1.4.- Homosexuality in the Middle Ages

The concept of 'sodomy' arose in the Middle Ages. According to medieval theology, sodomy constituted 'the exact reversal of the lawful way of having sex.' Despite the multitude of meanings applied to the concept, ranging from the specific act of anal penetration to any waste of semen, its core significance implied the impossibility of procreation (Hekma, 1989:433). The 'sodomite', who was not necessarily an exclusive homosexual, obtained sexual pleasure from the 'catamite', whom received gifts as valuable as positions in public office in exchange for his favours (Murray, 1989:469). Sodomites abounded during the Middle Ages. By the tenth and eleventh centuries, 'what might be called a gay subculture...a body of gay literature of the proportion and types... (which) had not been seen in Europe since the first century AD and would not be encountered again until the nineteenth', had been established.<sup>34</sup> This medieval subculture did not reproduce classical models of homosexuality; it presented new forms of homosexual liaisons.<sup>35</sup> Its members, who developed a distinct argot, referred to themselves as 'Ganymede'. The medieval term, by alluding to Greek mythology, and by invoking notions of cultural and personal superiority, is deemed to have attenuated the negative connotations associated with the 'sodomite' label (Boswell, 1980:243:251).<sup>36</sup>

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<sup>34</sup> The application of the sociological concept of 'subculture' to medieval urban homosexual life is problematic. It has been argued that not only the argot of urban medieval homosexuals was not exclusively restricted to them, but also that if there was a subculture it was one based on the marginality of its members (gamblers, prostitutes, drunkards, and sodomites) and not on their sexual preference (Greenberg 1988; Johansson, 1984).

<sup>35</sup> Most of the homophile poetry of the twelfth century expressed an innovation in homoerotic desire: that of religious functionaries (Boswell, 1980).

<sup>36</sup> According to Boswell (1980:251), Ganymede 'was the beautiful son of the king of Troy who was carried off by Jove to be a cupbearer in heaven'; the term is thought to represent the medieval counterpart of the contemporary *gay*.

In the twelfth and thirteenth century a renewed hostility towards homosexuality took place. Homosexuality began to be associated with religious dissident, heresy, and Islam. Although the Church was cautious in its response to the increasing animosity towards homosexual behaviour, by the year 1300 the relatively tolerant climate of the previous two hundred years had been shattered. Repression of homosexuality during this period is thought to have resulted from ecclesiastical efforts to establish sacerdotal celibacy, and from an augmenting morality suspicious of the luxury and excessive life-styles of the upper castes of medieval society. By the end of the thirteenth century the homophile literature of the previous three centuries, and the 'subculture' which had fostered it, had completely disappeared. The formidable dread of homosexuality is evident in the secular and canonical laws, in the literature, and in the philosophy of the late Middle Ages. More importantly, opposition to homosexuality ceased to be a critique of a larger social element and became a condemnation of *individual* sinners (Greenberg, 1988). After the death of Todros Abulafia, the last Jewish homophile poet, in 1287

the voice of Europe's homosexual minority was stilled, not to be heard again for centuries, and not until the present century with the variety and profusion of the eleventh and twelfth (Boswell, 1980:266)

Yet, homosexuality did not disappear altogether; there is evidence of urban social networks that continued to facilitate homosexual transactions (Hekma, 1989).

3.2.- Modern Homosexuality

### 3.2.1.- Homosexuality in Early Modern Europe

The study of the history of classical antiquity framed the understandings of homoeroticism of the early modern period. During the fifteenth and the sixteenth centuries classical explanations of Eros were redefined; (sexual) love in the context of heterosocial liaisons came to be understood as platonic love (Hekma, 1989). In the eighteenth century, however, Europe was shaken by the greatest cultural movement of the early modern period.<sup>37</sup> As the Enlightenment rose, and impacted all areas of European life and culture, conceptualisations of homosexual behaviour were also rethought in terms of the movement's liberal ideas.<sup>38</sup> The 'philosophes' pondered over 'Socratic love', or the 'crime of nature'.<sup>39</sup> Its causes were deemed to be the shortage and inaccessibility of women, and the widespread corruption of morals. The enlightened thinkers were unanimous in their opposition to the Judeo-Christian views on sodomy, and disapproved of the barbarian death that might await its perpetrators.<sup>40</sup> Yet, their unanimity also extended to the condemnation of homosexuality; 'prevention' was proposed as the best

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<sup>37</sup> It is undeniable that Montesquieu (1689-1755), Voltaire (1694-1778), and Rousseau (1712-1778) - the 'trinity' of French writers known as the 'philosophes' - constituted the formative influence of the movement. However, the enlightenment extended well beyond France. There was the enlightenment of the German-speaking world; there were the Scottish philosophers, notably David Hume (1711-76) and Adam Smith (1723-90); and the Italians Vico (1668-1744), Galiani (1728-87), and Beccaria (1738-94). Moreover, many other names could be added to this list, and the geographical scope broadened to encompass Russia, the Habsburg Empire, Scandinavia and the Iberian peninsula (Munck, 2000).

<sup>38</sup> These liberal ideas were concerned with the development of a 'science of man'. The 'science of man' constitutes what we now call 'psychology, religion and ethics, parts of jurisprudence, sociology, political science, political economy, history and economics, together with the theoretical and philosophical basis for each of these areas (Munck, 2000:14).

<sup>39</sup> 'Socratic love' and the 'crime of nature' were the terms employed by Voltaire and Montesquieu, respectively, to denote homosexual behaviour.

<sup>40</sup> Although several hundred executions of sodomites have been uncovered in Venice, Paris, London, and the Spanish cities after the colonisation of America, they do not justify the claims of 'gay genocide' invoked by some historians (Hekma, 1989).

strategy against it.<sup>41</sup> The relatively unknown Dutch Enlightenment philosopher A. Perrenot, for example, suggested a ‘closely watched civil household’ in order to halt homoerotic behaviour. By the eighteenth century the conceptualisation of sodomy, and the self-conceptualisations of the sodomites, had undergone a fundamental change (Hekma, 1989:433).

By the turn of the nineteenth century three philosophical approaches towards homosexuality co-existed: the moral theology of sodomy, the enlightened vision, and the cultural history of male Eros. Materially, homosexuality manifested itself in the self-aware sodomite subcultures of the great cities of Western Europe. These had existed since the 1700s when the economic climate of Mercantilism first spawned the appearance of the ‘coffeehouse culture’ in England. By the beginning of the 1800s, the coffeehouse had become an English institution catering for the specialised tastes of different clienteles. The ‘molly-house’ – an offshoot of coffeehouse culture – catered for those Elizabethan males interested not only in buggery but also in effeminate behaviour.<sup>42</sup> Molly-houses fostered the emergence of a ‘new social role based on the fusion of gender transformation and homosexuality’, and changed medieval and Renaissance conceptions of homosexuality not yet directly linked to effeminacy.<sup>43</sup> The beginning of the shift from

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<sup>41</sup> D.A.F. Marquis de Sade (1740-1814), the libertine Enlightenment writer, was the most important exception to enlightened philosophical thinking on homosexuality. In 1772 he was sentenced to death for sodomising his male servant, and for (mistakenly) poisoning prostitutes with a supposed aphrodisiac. He was set free, however, soon after the French Revolution in 1790. His work, *Philosophy in the Boudoir* published in 1795, was one of the most fervent apologies not only for sodomy, but also for any other form of stigmatised sexual behaviour. For Sade there was no rational basis for the argument that any kind of sexual practice was against nature (Hekma, 1989).

<sup>42</sup> Not all ‘Mollys’ adopted feminine behaviour (Murray, 1989).

<sup>43</sup> Effeminacy had been previously associated with homosexuality in the context of the vices of the aristocracy (Greenberg, 1988).

the medieval conception of sodomy as a sinful act to that of homosexuality as the property of a distinct kind of human being can be traced to the coalescence of the new gender-bending identities of the English molly-houses (Greenberg, 1988). Yet, medieval notions of ‘purposive sex’ lingered in the redefinitions of homosexuality of the nineteenth century, and shaped its subsequent conceptualisation as derangement or sickness (Weeks, 1990).

3.2.2.- The Criminalisation of Homosexuality in England and Wales

During the nineteenth century the *laissez-faire* doctrines of Adam Smith and other classical economists were widely disseminated. These economic theories advocated as little government interference with the economic system as possible, and defended the freedom of all individuals to enter into any contractual agreements they desired. A corollary of *laissez-faire* ideology was that individual freedom could not only apply to the commercial sphere but should naturally extend to the personal level. Sodomites, a diverse group collapsed under the ‘portmanteau’ label, were quick to realise the potentialities of *laissez-faire* doctrines (Weeks, 1990).<sup>44</sup> The French Penal Code of 1791 had pioneered the recognition of the logical extension of the economic doctrine to bodily matters. As such, the Napoleonic Code paved the ground for the decriminalisation of homosexual acts between consenting adults, which first took place in France in the beginning of the nineteenth century. After France, decriminalisation first followed in the

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<sup>44</sup> In England the precise meaning of the term ‘buggery’ was up for grabs. The term sodomite applied to ‘buggers’ as well to other individuals who engaged in non-procreative sexual practices ‘from homosexual acts to birth control’. In 1817 a man had been sentenced to death for ‘buggery’ although he had only engaged in oral sex with a younger man. The criminal reforms of the 1820s, which marked the transition from the amateurish system of law enforcement of the eighteenth century to the professional police force in the nineteenth century, tightened the law on sodomy. In 1826 Sir Robert Peel abolished the death penalty



enlightened state of Bavaria, and in its colonies (Hekma, 1989). Still, for much of the rest of Europe and the world it would still take more than a century for homosexuality between consenting adults to become (largely) legal. Yet, despite continued prejudice and legal repression, homosexual subcultures did flourish throughout the nineteenth century, if not globally, at least in Europe (Greenberg, 1988).

In England and Wales, where Enlightenment was slower to dawn, the death penalty for buggery was only officially abolished in 1861; in Scotland, death for homosexuals caught in the act would continue to be sentenced until 1889.<sup>45</sup> If after 1836 the death penalty for sodomites was never put into practice, until then its execution had depended on the historical moment, the social class of the sodomite, and on the degree of public outrage caused by each specific case. In 1885 the Criminal Law Amendment Act, which had been initiated as a House of Commons bill to raise the age of female consent, was successfully amended by the radical MP Henry Labouchère. Section 11 of the amendment (simply) criminalized all homosexual acts, with the exception of buggery, whether publicly or privately committed. Buggery was to be penalised with a penal sentence between ten years and life. The ‘Labouchère Amendment’, soon dubbed the ‘Blackmailer’s Charter’, and the ‘Vagrancy Act’ of 1898, permitted a large-scale prosecution of homosexual men.<sup>46</sup> Yet, in its oppression of homosexuality the Acts of 1885 and 1898 had an

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for over one hundred crimes, but excluded sodomy. After 1826 it was no longer necessary to prove penetration and emission of seed for conviction under sodomy charges (Weeks, 1990:13-14).

<sup>45</sup> The spread of dissent in the seventeenth century, coupled with the revivalist movements of the eighteenth century, ensured that there was no single church in England. As such, there was no single agent against whom to rebel; a fact that has made an English enlightenment difficult to identify (Munck, 2000).

<sup>46</sup> The 1898 Act condemned also those who solicited or importuned for immoral purposes (Weeks, 1990).

unexpected effect: the 'creation of a community of knowledge, if not of life and feeling, among male homosexuals' (Weeks, 1990:22).

Both the 'Labouchère Amendment' and the 'Vagrancy Act' reveal the traditional linkage between homosexuality and prostitution, which was thought to result from male lust and upper class decadence. In the early 1880s the general disgust towards homosexuality had been stirred by a series of scandals involving homosexuality and prostitution.<sup>47</sup> The alleged cover-up of the Cleveland Street scandal of 1889-1890, which involved aristocrats, a homosexual brothel, and even perhaps the son of the Prince of Wales himself, seemed to give credence to such widespread feelings. However, only during the trial of Oscar Wilde in 1895 did the popular loathing of homosexuals really manifest. Such developments must be set against a European context of renewed hostility towards homosexuality, which had swept over the Continent (especially in the German Empire), after 1870. Although rooted in traditional religious belief, such antagonism significantly fashioned (secular) modern attitudes towards homosexuals (Weeks, 1990; David, 1997).

3.2.3.- The Decriminalisation of Homosexuality in the Post-War Period

It was not until the 1950s that the first effort to reappraise the legal situation of homosexuality in Britain was undertaken. Four centuries had passed since the 1533 Act of Henry VIII had criminalised all acts of sodomy. The process started with the examination of the 'problem' of homosexuality by the Moral Welfare Council of the

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<sup>47</sup> Such as that of the 1884 trial, and acquittal, of a brothel-keeper, Mrs Jeffries. Jeffries was supposed to have been acquitted due to her upper-class connections. In addition, noted *The Sentinel*, during her trial the courtroom was filled with young men wearing 'patent shoes' (an assumed signifier of effeminacy) (Weeks, 1990:17).

Church of England in 1952. The result was the 1954 publication of *The Problem of Homosexuality: An Interim Report*, which equated the sinfulness of homosexuality to that of adultery and fornication. Nevertheless the Council, and the Howard League for Penal Reform, pressed the Home Secretary to establish a Royal Commission to investigate the ancient laws regulating homosexual acts (Jivani, 1997). These efforts led to the Royal Commission publishing a report in 1957; the 'Report of the Wolfenden Committee' concluded that the role of criminal law was not to impose particular types of behaviour. As such, it was recommended that homosexual behaviour between men over twenty-one be decriminalised. Although the 'Wolfenden Report' did not legitimise homosexuality, it framed homosexual behaviour as an 'unfortunate condition' which, for the sake of social decency, should be accepted (Weeks, 1990). The Report had no practical consequences, but led to the foundation of The Homosexual Law Reform Society in 1958.<sup>48</sup>

The declaration of war in 1939 brought together homosexual men from all corners of the Isles, and the blackout that ensued provided opportunities for indulgence in 'areas that had previously been taboo'.<sup>49</sup> The impact of war on sexual behaviour had been such that once the allies had defeated Hitler, the Archbishop of Canterbury called for a repudiation of 'wartime morality' and a return to the values of a Christian life (Jivani, 1997). Since the beginning of the Great War American and British servicemen were identified as the sources of homosexual *contagion*. Homosexuality was thought to be an *infectious*

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<sup>48</sup> The Society, a middle-class single-issue pressure group typical of the 1960s, had the support of the establishment. A letter, signed by a number of public figures, which called for the reform of the law appeared in *The Times* in March of 1958. In addition, and perhaps oddly, fifteen distinguished married women constituted the founding members of the Homosexual Law Reform Society (Weeks, 1990).

<sup>49</sup> As evidenced by the seventy percent rise in the incidence of venereal disease amongst the general population between 1939 and 1942 (Jivani, 1997).

condition, which was 'passed on' by infected adult men to uninfected boys or men. With the end of the war the model of the nuclear family was institutionalised in Britain, and in other capitalist nations. The decreasing importance of religion in social life, which had been spurred by the rationalisation and secularisation processes of modernity, occasioned the substitution of the divinely attributed disapproval of homosexual behaviour for an apparatus of control and homophobia.<sup>50</sup> The emergence of such a system of control was intrinsically related to the growth of competitive capitalism, which, in turn, had partly emerged as a consequence of ascetic Protestantism.<sup>51</sup> Capitalism had sharpened the sexual division of labour, shifted the relationship of women and men towards production and consumption, strengthened gender stereotypes, and created the differentiated spheres of public and private life. As such, the family was redefined as a mobile conjugal unit without the traditional extended kinship ties of its patriarchal predecessor. Within the Calvinist ethos of work and postponed rewards non-procreational *heterosexual* sex came to be understood as wasteful; *homosexual* sex as a fundamental threat to the established order (Greenberg, 1988). In such a social context, the homosexual could only belong as an aberration.

In the fifteen years following the outbreak of the Second World War there was a five-fold increase in the number of indictable homosexual offences. However, it was only under the shadow of American McCarthyism in the 1940s and 1950s that homosexuals really came to the fore as political scapegoats. In 1938, 956 British men had been prosecuted

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<sup>50</sup> Homophobia may be defined as the socialised state of prejudice, hatred and fear towards the content, as well as the contenders, of same-sex desire (Rich, 1983).

<sup>51</sup> The connection between Puritanism and modern Capitalism was postulated by Weber (1930).

for homosexual offences, but in 1952, after American pressure, this number had gone up to 3,757 (Jivani, 1997). The media, enjoying its recently acquired freedom to discuss the subject of homosexuality, magnified the demonisation of homosexuals by portraying them as traitors, corrupters, or 'carriers of contagion' (Weeks, 1990). However, the emerging cultural and social climate of the 1960s contradicted the official position on homosexuality. Its 'new hedonism' glorified sexual pleasure and sexual freedom. As such, male homosexual activities in England and Wales were finally, albeit only formally, decriminalised by the Sexual Offences Act of 1967. Still, the material consequences of the law for homosexual individuals were minimal. The 1967 Act only decriminalised homosexual acts performed in 'private', and for adults over the age of twenty-one. Moreover, the Act applied neither to the merchant navy nor the armed forces, and defined 'public' as anywhere where a third person was likely to be present. The inability of the Sexual Offences Act 1967 to achieve any substantial reform was partly a consequence of the incapacity of The Homosexual Law Reform Society to argue whether homosexuality was a legitimate manifestation of human interaction.

Despite such limitations, the work of The Homosexual Law Reform Society did act as a stimulus to homosexual self-organisation. It fostered the emergence of a new type of social organisation, the homosexual-support-group, which encouraged the crystallisation of positive homosexual identities. For most of the 1940s and 1950s, and even throughout the 1960s, the policing of public spaces had discouraged associational life in Britain. Yet, a homosexual subculture had evolved even if it had been organised by the most despised element of homosexual culture: the effeminate, flamboyant men known as 'queens'.

There is limited evidence that within the subculture a masculinised identity was also taking shape. However, in the 50s and 60s the 'queen' dominated 'the social space which was the lifeline for many homosexually inclined men in post-war Britain.' As such, in cafes, baths, and clubs the origin of a 'community', which would coalesce into a communal phenomenon in the 1970s, was beginning to come together.<sup>52</sup> Despite the increasing acceptance of medical and psychological explanations of homosexuality, as well as of the first signs of a future 'community', the situation remained relatively repressive well into the late-1960s. The British medical Association (BMA), which had appended its memorandum on homosexuality with evidence of the role of Jesus in the cure of homosexuality, and who represented the 'family' doctors of Britain, considered the homosexual an 'enemy of the state'. As such, homosexual individuals, and bodies, were linked to 'an alien ideology' that undermined the basis of democracy (Higgins, 1996:24-35). The most devastating effect of such characterisations was the self-hatred and self-doubt that ultimately permeated homosexual consciousness (Weeks, 1990).

As we have seen, it took an entire decade until the recommendations of the Wolfenden Report had any legal impact in Great Britain. In the rest of Europe the situation was similar. In (a previously enlightened) France, under the legislation of the marshals Petain and de Gaulle for example, the 1960s and the 1970s were marked by hundreds of arrests. In Western Germany, Paragraph 175 of the criminal code wrecked havoc on the lives of homosexuals; homosexual survivors of Nazi extermination camps had to endure prison

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<sup>52</sup> This is the time when a new type of gay club, the convivial coffee bars featuring the Italian coffee 'steaming Gaggia', began to appear. This is also the time when the first tentative steps towards the establishment of a specialised press were undertaken: the magazines *Timm*, *Spartacus*, and *Jeremy*

sentences as long as six years. Still, despite the generally adverse conditions of homosexual life in the post-war period, homosexual identity, which in the 1950s had been synonymous with criminal identity, and in the 1970s would still be equated to social corruption, would soon begin to feel the transformative potential of the gay liberation movement.

3.2.4.- The Medicalisation of Homosexuality

The competitive markets of the Western economies of the nineteenth century required the development of particular human attributes. The disciplinary mechanisms embedded in the systems of power relations of competitive capitalism rewarded ‘competitiveness, foresight, discipline, and instrumental rationality’, and devalued ‘emotional expressiveness, dependence and nurturance - traits that would have been dysfunctional in the competition.’ Self-restraint, a personal articulation of the capitalist ethos of efficient capital usage, was evident in the preoccupation with sexual restraint. Ancient Greek medical conceptions were borrowed by nineteenth century medical writings. The classical notion of semen as the ‘material substratum’ of male virtues was used to prescribe as little sexual activity as possible. The goal of such sexual restraint was to conserve the *élan vital*, which ought to be expended in more productive activities. Even *within* marriage it was recommended that couples had sex no more than once a month, and even then solely for procreative purposes. Surely, medical manuals do not reflect the real sexual habits of the general population. However, evidence suggests that although

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appeared throughout the 1960s in London. Outside of London, it was the ‘little corners’ of the better hotels that would discreetly serve as public spaces for homosexuals (Jivani, 1997).

men of the middle-classes may not have conformed to such puritanical ideals they *thought* they ought to and felt guilty when did not (Greenberg, 1988).

The weakening of strict gender divisions, and the accompanying increase in gender stereotypes, foregrounded medical speculation that homosexuality may be a case of gender deviance. As notions of family organisation, gender roles, and sexual relations underwent major transformations hostility towards homosexuality burgeoned. At the same time that the 1870 Education Act widened the scope for female employment in England, medical professionals started to argue that unless biological differences between men and women were respected women's reproductive capacities would be impaired (Greenberg, 1988). Medical speculation on the fertility potential of women had little to do with science. It was part of a concerted effort to resist the 'feminisation of culture', which threatened male supremacist ideologies and identities. Not surprisingly, the increasing potential for female participation in the capitalist system provoked the 'second crisis in masculinity' of modern history (Kimmel, 1987; Badinter, 1955). The outcome of such a crisis was 'an outpouring of new natural science and social science work seeking to demonstrate women's ontological inferiority and close relationship to the animals and lower races' (Petersen, 1998:20).<sup>53</sup> Such a loathing of the feminine frames the general despise towards homosexuality, and the gender-bending practices of some homosexuals only confirmed the imagined threat of the 'feminine' (Greenberg, 1988; Weeks, 1990; Young, 1995). However, the most significant process to have affected the conceptualisation of homosexuality was the medicalisation of society.



Prior to the dominance of germ theory in the 1880s, European medical practice had been based on classical (Greek) medical traditions.<sup>54</sup> The classical paradigm of health and illness viewed disease as the result of natural causes. With the encroachment of Christianity, however, illness began to be increasingly seen as either divine punishment or divine lesson. As such, medicine assumed an explicit moral function. Medieval Europeans believed that the healing of the *body* could be achieved through the cure of the *soul*. Rituals of penance were prescribed as medical therapy. Although secular physicians participated in the treatment of illness, their role was parallel to that of the priest. The linkage between ‘sinner/confessor’ and ‘patient/physician’ is attested by the popularity of pilgrimage culture, a prevalent feature of medieval life, where the healing powers of religious relics constituted the main focus of many pilgrims. Eventually, the Christian ethic of asceticism, whose core derived from the seven deadly sins set out by Gregory the Great in the sixth century, appropriated the ‘religio-medical management of the body’ that had been inherited from medieval monastic practice.<sup>55</sup> Such appropriation sets the context within which the disciplinary practices of modernity began to coalesce. If modernity would later be characterised by institutions, disciplines, and practices that regulated both the social and the personal, it is because ascetic Protestantism succeeded

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<sup>53</sup> The ‘first’ crisis in masculinity occurred in France and England in the seventeenth and eighteenth centuries, and the ‘second’ in Europe and the United States at the turn of the twentieth century. The ‘third’ crisis is the current one (Kimmel, 1987; Badinter, 1995).

<sup>54</sup> The humoral theory of disease was used in European medicine until the middle of the nineteenth century. This theoretical school, based on Hippocratic medicine, conceived the world in terms of four basic elements (fire, earth, air, and water), four qualities (heat, cold, dry, and dampness), four humours (blood, phlegm, yellow bile, black bile), and four personality types (sanguine, phlegmatic, choleric, and melancholic). Illness was considered the result of an imbalance in humoral activity. As such, the restoration of health was achieved through a rebalancing of humoral activity through dieting, exercise, bleeding and rest (Turner, 1995).

in its quest for mastery over the human flesh. The rationalisation of western society ultimately secularised the human body, voiding it of its traditional role as mediator between man and the natural order. Such a process *formally* separated medicine and morality. Yet, despite medical categories eventually triumphing as distinctive forms of discourse, the ambiguity between medicine and religion continued to linger in modern medical practice (Turner, 1995).

The Enlightenment emphasis on rationality and science bore on the shifting conceptions of sexuality, but the ascendancy of the medical profession in continental Europe since the beginning of the nineteenth century played a much greater role. The prominence of the medical profession was not a result of its actual success in curing disease, but derived from its plans towards a social policy of public health, and from its undisputed expertise of the human body. The massive projects of urban reconstruction that took place in European cities in the middle of the nineteenth century promoted the increasingly influential science. Urban life had always involved health regulation, but now the emphasis was placed on prevention and, consequently, social measures. The first example of public health regulatory action was the regulation of prostitution, which began under the Napoleonic regime (Hekma, 1989). The concurrent growth and professionalisation of the urban police force, as well as the encroachment of the criminal justice system by forensic psychiatrists, contributed to the medicalisation of sexuality. These new scientific forces encroached on ‘bodies and their pleasures’ in an attempt to discover their hidden truths. That which was found to be irregular was thus conceptualised as unnatural, i.e.

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<sup>55</sup> The ‘seven deadly sins’ are: vainglory, anger, envy, dejection, gluttony, fornication, and covetousness (Turner, 1995).

sick or deviant (Foucault, 1981; 1986). Before the 1850s, for example, the involvement of the medical profession in the penalisation of sodomy had been limited to the diagnosis of anal penetration; after that, doctors concerned themselves not only with the mental constitution of (any) criminals but with their responsibility as well (Hekma, 1989).

After the revolution of 1848 the 'social question' became central in political discourse, and the distinction between public and private wilted (Hekma, 1989). As the various aspects of social life were structurally differentiated and institutionalised, precise notions of different categories of disorder emerged (Turner, 1995). A process of bureaucratic management of entire populations of sinners, criminals, as well as of diseased and deviant individuals, took place. One of the principal consequences of such a new configuration of power relations - 'bio-power' - was the containment, classification, and the secularisation of disorder (Foucault, 1973). The asylum, the clinic, and the hospital became the medical perpetrators of the much broader process of regulation and control engendered by the modern state. As such, medicalisation, and the late nineteenth century discourses on the loss of empire and degeneration of the nation, framed the construction of a new type of disordered embodiment: the homosexual (Bleys, 1996).<sup>56</sup> Sodomy was thus personified, and came to represent the essential 'inversion', the fundamental 'other', of the principal nodes of thought and knowledge of modern Western culture (Sedgwick, 1990).

3.2.5.- Science and the Homosexual

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<sup>56</sup> The term homosexual was first coined by the Viennese writer Karoly Maria Benkert in 1867, and used for the first time in English in 1869 (Young, 1995).

Religious confession 'was first copied and then replaced by psychoanalytical investigations'. Through this process of secularisation the human body was forced to give up its mysteries, and became open to the anatomical gaze (Turner, 1995:33). As such, a new field of knowledge, a *scientia sexualis*, emerged and transformed sexuality into a 'natural' phenomenon to be studied by the scientific gaze. Early in the nineteenth century, the phrenological school of psychology had developed an aetiology of homosexuality that located its origin in the pathological excessiveness of the brain's capacity for 'adhesiveness'. The notion of 'adhesiveness' corresponded to the faculty of the human brain that was deemed responsible for friendship (Greenberg, 1988). Although physiological explanations of homosexuality can be traced to classical Antiquity, the *systematic* questioning of the role of heredity in the aetiology of homosexuality reflected the institutionalisation of the medical paradigm. Interest in issues of perverted sexuality was marked by a series of publications that appeared in the 1880s. These works, which defined the new condition of 'sexual inversion', reconceptualised non-procreative sex into 'perversions' and 'deviations', and distinguished 'innate' from 'acquired' homosexuality.<sup>57</sup> In 1886, to cite one of the most influential 'inversion' theorists, the professor of Psychiatry in Vienna, Richard von Krafft-Ebbing, published his *Psychopathia Sexualis*. A massive compilation of unusual sexual behaviour and interests, the volume argued that 'antipathic sexual feeling' (i.e. congenital homosexuality) constituted a 'latent' form of perverse sexuality. It 'developed under the influence of masturbation,

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<sup>57</sup> The writings of the German lawyer and writer Karl Heinrich Ulrichs, which appeared in the 1860s, preceded the 1880s trend by twenty years. According to Ulrichs, the 'third sex' resulted from an anomalous development of the originally undifferentiated human embryo, which produced either the 'Uring' (female mind in a male body) or the 'Dioning' (male mind in a female body). It is important to note that what was inherited, however, was not homosexuality. Most anomalously developed embryos came from heterosexual parents; degeneracy was the inheritance. Ulrich's writings, which constituted the first modern attempt to

abstinence and otherwise', and resulted from both acquired and congenital factors (Krafft-Ebing, 1886, quoted in Weeks, 1990:26). Krafft-Ebing's 'psycopathology', which was grounded on rationalist and biologist notions, finally translated into social practice the ideas of the Enlightenment.

The publication of *Sexual Inversion* by Havelock Ellis in 1897 first articulated the voice of homosexual-liberation movement in Britain. Ellis, whose ultimate concern was the respectability of homosexuals, argued that homosexuality was congenital but not pathological. The final version of *Sexual Inversion*, with its elaborations on the distinctions between the inherent homosexuality of 'inverts' and the acquired homosexuality of 'perverts', created a lot of confusion.<sup>58</sup> However, by asserting the normality, or even the moral excellence of 'inverts', *Sexual Inversion* challenged stereotypes of homosexual behaviour that denigrated effeminacy (Weeks, 1990). In an effort to promulgate the scientific approach to the study of sexuality initiated by Ellis, the British Society for the Study of Sex Psychology (BSSP) was founded in 1914. One of its members, Edward Carpenter, who published extensively on homosexual issues, emphasised the spiritual side of homosexuality.<sup>59</sup> Carpenter's most influential work, *The Intermediate Sex* (1914), made use of anthropological evidence to show that homosexuality was not only accepted in many 'primitive' cultures, but also regarded as characteristic of highly evolved shamanic beings. Unlike Ellis, Carpenter was a

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support claims that homosexuality was congenital, were later instrumental in the development of the first homosexual-liberation movement formed in Germany by Magnus Hirschfeld (Greenberg, 1988).

<sup>58</sup> Havelock Ellis, who was not homosexual, was nevertheless sensitised to the spectrum of sexual differences by his own form of sexual variation: 'urolognia'. As such, Ellis was sexually excited by the sight of women urinating (Weeks, 1990).

<sup>59</sup> His work includes *The Intermediate Sex* (1908) and *Intermediate Types Among Primitive Folk* (1914).

homosexual, and the only member of the homosexual-liberation movement to distinguish sex from procreation (Greenberg, 1988). The ideas of writers such as Ellis and Carpenter disseminated the most progressive continental views on sexual matters.<sup>60</sup> The goal of such writers was the reformation of public opinion of homosexuality, which had been significantly shaped by Darwinian theories of evolution that saw it as a symptom of degeneration.<sup>61</sup>

In the early part of the twentieth century Havelock Ellis and Sigmund Freud debated about the origins of homosexuality. Although Ellis recognised that his tripartite division of sexual preferences was hardly scientific, he stuck to it (Ellis, 1897). In *Three Essays on the Theory of Sexuality* (1905) Freud had defined three types of homosexuality: 'absolute'; 'amphigenic' (or bisexual); and 'contingent'. 'Contingent' homosexuals were those whose personal circumstances of constrained heterosexual contact could lead them into (possibly fixed) enjoyment of homosexual acts. Freud was suspicious of a distinction between 'acquired' and 'innate' homosexuality. Freud's model of sexual development, of the 'polymorphously perverse' infant who derived sensual pleasure from all parts of its body, made homosexuality an element of everyone's psychological history. Freud's psychoanalytic explanations removed a *physiological* basis for the manifestation of homosexuality. As such, Freud equalised the non-pathological status of both homo and heterosexuality inasmuch as the two were deemed be a product of family interaction.

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<sup>60</sup> The prominent Continental voices were Karl Ulrichs and Magnus Hirschfeld (Weeks, 1990).

<sup>61</sup> American Darwinistic theories on homosexuality were inspired by the work of the Italian-Jewish physician Cesare Lombroso. In 1876 Lombroso proposed that criminals were biological atavisms unable to adapt to the modern world. The American physicians James Kiernan and Frank Lydston applied such ideas to homosexuality by recalling that the human race had evolved from primitive organisms, which were once

However, Freud's preoccupation with sexuality as the determinant of every facet of human behaviour meant that sexual orientation was not one of many aspects of human identity, but the key that unlocked its real, if uninherited, essence. Freud's psychoanalytic model of sexual development implied that homosexuality fell short of the normal standards of psychosexual development. As such, the normative judgement of psychoanalytic theory *did* stigmatise homosexuality by equating sexual deviance to intrinsic pathology (Greenberg, 1988).

Another psychological to have a significant influence on modern perceptions of homosexuality was behaviourism.<sup>62</sup> Behaviourism rejected the psychological constructs of Freudian theory, and postulated instead that behaviour was positively related to pleasure. Also known as 'Learning Theory', Behaviourism asserted that sexual choice was not instinctual (and homosexuality not pathological), but that it resulted from regular encouragement. Behavioural therapy was consistently applied on patients who either wanted or were forced to change their sexual orientation. Following the recommendations of the Wolfenden Report that medical 'treatment' ought to be made available to homosexuals, a series of different behaviourist approaches were developed to 'cure' homosexuality. Such 'treatments' were widely used in the late 1950s and in the 1960s. They consisted of aversion therapy, which included the use of emetics and electro-

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hermaphroditic or bisexual. In the United States Lombrosianism and degeneracy theory led to compulsory sterilisation for sex offenders, including homosexuals (Greenberg, 1988).

<sup>62</sup>J.B. Waters was one of the most influential proponents of behaviourism. Between 1913 and 1919 Waters adopted the position that consciousness was useless as an object of study. For him, thinking was a by-product of 'real' behaviour, such as physiological functions. Today, however, such a perspective has few (if any) advocates. Inasmuch as the only data psychologists can work with are observations and measurements of behaviours, they are all behaviourists. However, the psychological definition of behaviour is much broader and encompasses semantic aspects of language and communication as well as patient's self-reports of feelings and emotions. As such, psychologists take account of mental processes (Wright, 1970).

convulsive shock treatment; lobotomies; and even castration (Greenberg, 1988). The words of a Peter Price, who underwent aversion therapy in 1963 to assuage his family's homophobia, capture the climate of shame and dishonour that such treatment entailed:

And for seventy-two hours I was injected, I drank, I was sick. I went to the toilet in bed. I had no basin, no toilet facilities nothing. I just had to sit on my own vomit and excrement...What was going through my mind was not the fear of being gay; it was the fear of not coming out of this psychiatric wing alive (Jivani, 1997:123-124)

In the 1940s Alfred C. Kinsey, famous for his two studies on human sexual behaviour, showed that one-third to one-half of all American men had at least one orgasmic homosexual contact in the course of their lifetime (Kinsey, 1948; 1953).<sup>63</sup> His research, which was based on the sexual lives of 18,000 American white men and women, suggested that the distinction between homosexuals and heterosexuals was impossible. Kinsey argued that physiological, psychological, or behavioural traits were incapable of explaining homosexuality. Its high incidence indicated that it was a type of behaviour, not an identity. Despite Kinsey's critique, notions of constitutional factors of the supposedly unique bodily entity of the homosexual continued to shape the 'scientific' theories that aim to contain it. In the 1940s medical science explained the genesis of homosexuality through the specialised domain of endocrinology.<sup>64</sup> The theory of

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<sup>63</sup> Kinsey also found no distinction between 'true' (passive) and 'acquired' (active) homosexuality (1948:425-427).

<sup>64</sup> In 1905 biochemical agents thought to control a variety of bodily functions were identified as 'hormones'. In the 1920s and the 1930s endocrinologists identified, and synthesised, specifically female and male hormones. These 'sex' hormones were conceptualised as gender's chemical agents. As such, it was hypothesised that heterosexuality resulted from hormonal balance, and that homosexuality was, by default, a question of hormonal imbalance (Kenen, 1996).



homosexuality as a hormonal imbalance appeared as a 'theodicy' for the 'anomie' of the institution of heterosexuality, which was occasioned by the intersexuality phenomenon (Petersen, 1998).<sup>65</sup> By the 1990s homosexuality was first (briefly) blamed on a shrunken hypothalamus, and then on a 'sissy' gene (Le Vay, 1991, 1993; Hamer et al, 1993).<sup>66</sup> As we have seen, constructions of the masculine depend on time and context. As such, the usual convergence of biologist and essentialist notions that have produced the idealised European and heterosexual masculine ideal of Modernity has been challenged by the post-modern society of mass consumption. Not only does the figure of the 'new man' (Nixon, 1996) emerge as the re-worked flagship of masculinities, but the usual correspondence of masculinity with heterosexual object choice has been subdued in societies where tolerance for variant sexual self-identifications has increased (Petersen, 1998).

### 3.2.6.- The Gay Liberation Movement

The defiant and proud style of 'Gay Lib' marked the 'turning point in the evolution of a homosexual consciousness'. Gay Liberation constituted a 'new type of movement which stressed openness, defiance, pride, identity - and, above all, self-activity'. The tactics and goals of the movement were deeply affected by the radical utopia of the revolutionary year of 1968, as well as the by 'Black Power' and the New Left movements (Weeks,

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<sup>65</sup> Ambiguities in physical sex led scientists to develop the theories of gender. Sex change technologies, which also developed in the 1950s, were fundamental in the enforcement of the gender binary through the material production of sex (Petersen, 1998).

<sup>66</sup> The first to claim a neurological basis for homosexuality were the Dutch researchers Swaab and Hofman in 1990. However, it was only when the distinguished neuroanatomist Simon Le Vay (1991) claimed that the brains of a small number of homosexual men who had died of AIDS were significantly different in size that the theory received worldwide attention. The methodological reliability of Le Vay's study was immediately contested both from within and without science (Weeks, 1996).

1990:185-186). Its symbolic marker was the Stonewall Riot, which erupted in Sheridan Square in New York's Greenwich Village on Friday June 27, 1968. It has been argued that the death of the singer Judy Garland, an 'archetypal gay icon', whose funeral was held during the riots, marked the beginning of a new kind of gay subjectivity (Jivani, 1997).<sup>67</sup> Whether Garland really did play any role in the liberation of homosexuality is questionable. However, that the weekend long conflict was pivotal in the future development of homosexual identity across the western world is an undisputed fact.

The immediate aftermath of the momentous weekend was the establishment of the New York Gay Liberation Front. Soon after that gay liberation groups sprung up everywhere, including Britain and Europe (Greenberg, 1988). Although the Stonewall riots were a specifically American phenomenon, encouraged by the wave of civil rights protests that had shaken the country during the 1960s, its echoes were soon felt in Britain's own gay brigade. The London Gay Liberation Front was established in the early autumn of 1970 at the London School of Economics; in November the first ever British gay rights march took place in the streets of London (David, 1997). The revolutionary changes advocated by GLF were articulated around the notions of 'coming out' and asserting 'gay pride'; the idea of a concerted, communal effort against oppression; and the identification and elimination of the causes of oppression rooted in the new concept of sexism.<sup>68</sup> The London GLF adopted the 'personal is political' motto of feminism, which inspired its

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<sup>67</sup> Garland is deemed an 'archetypal gay icon' as she 'represented bravery through adversity, but that bravery was characterised by a passive stoicism' (Jivani, 1997:160-161).  
<sup>68</sup> Initially the concept of sexism (prejudice against women), which had been adopted by British feminism after its development in the American women's movement, had little to do with the gay movement. Only later, in more radicalised feminist texts did the subject of female, and male, homosexuality appear (Weeks, 1990).

tactics. GLF's political action ranged from the 'zapping' of hostile organisations to the staged celebrations of 'gay pride' in public spaces. 'Gay pride' was asserted and celebrated in the small scale 'gay days' as well as in the massive celebrations of 'gay pride week'. The first 'gay pride' march, with 2,000 women and men marching down Oxford Street, was held in July of 1972 (Weeks, 1990).

The relative success of the gay movement must be framed against both the economic prosperity of the post-war era, and the relative hedonism of the 1960s. However, as 'the last major product of late 1960s euphoria', gay liberation had exhausted itself by the early 1970s. In 1971 the New York Gay Liberation Front had been substituted by the much more moderate Gay Activist Alliance. In London, although by 1972 the activities of the GLF continued in fragmented form, by 1973 its office had closed. In other capitalist countries, such as Canada and Australia, the pattern would soon be repeated. The utopian ethos of the 1960s, when confronted with the harsh economic climate of the mid-1970s, and with the growth of the 'strong state', seemed unexpectedly naïve. In addition, Gay Lib's expectation that there was a 'mass force of revolutionary homosexuals willing and able to follow its lead' proved to be an illusion.<sup>69</sup> However, the influence that gay liberation would have in the development of homosexual communities 'are still being realised'. Moreover, gay liberation made homosexuality not only a political issue in the widest sense, but fundamentally changed the view that gay-identified individuals could construct of themselves (Weeks, 1990:185-206)

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<sup>69</sup> The reasons for such difficulty will be elaborated in my discussion of gay community in chapter four.

### 3.3.- Homosexuality and AIDS

In its weekly bulletin *Morbidity and Mortality Weekly Report* 30 of June 5, 1981 the American federal epidemiology agency 'Centres for Disease Control' (CDC) first alerted the world about an impending epidemic.<sup>70</sup> The report acknowledged that the five 'active homosexuals', who had contracted the very rare form of pneumonia *Pneumocystis carinii* (PCP), did not know each other and were not aware of sexual partners with similar illnesses.<sup>71</sup> However, the CDC ventured that it was likely that such outbreak was related to 'some aspect of a homosexual lifestyle' (250-2). A few weeks later, *Morbidity and Mortality Weekly Report* 30 reported a rare form of cancer of the blood vessels known as *Kaposi's sarcoma* (KS).<sup>72</sup> Twenty-six young homosexual men in California and New York had recently been diagnosed with it (July 3, 1981:305-8). Despite the fact that even as early as 1982 8% of the 159 reported cases had occurred amongst exclusive heterosexuals, the complex of PCP/KS soon became popularly known as the 'gay cancer', or as 'Gay Related Immune Deficiency' (GRID) (Grmek, 1990; Garfield, 1995; Epstein, 1996). It was only as more symptoms and invading organisms were identified that the complex acquired the status of *syndrome*. GRID was eventually substituted by the more neutral 'Acquired Immune Deficiency Syndrome' (AIDS) in July of 1982. In 1983 the newly defined syndrome, which had by now been indelibly associated with

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<sup>70</sup> It was the gay newspaper *New York Native* (18/05/1981); in an article by physician Lawrence Mass entitled 'Disease Rumors Largely Unfounded', which first published a report on the mysterious illness.

<sup>71</sup> *Pneumocystis carinii* is a protozoan that parasitizes numerous animals, and which is also often found in the human body. However, this ubiquitous protozoan only causes disease in individuals who show a compromised immune system. Until AIDS such individuals were normally newborns or adults under immune suppressive drugs (Grmek, 1990).

<sup>72</sup> 90% of Kaposi sarcoma's sufferers are elderly men of well-defined ethnicity: Jews (or eastern European descent; dark-skinned men from the northern Mediterranean; and certain black African tribes, mostly the Bantu). Unlike the highly malignant form of KS of these homosexuals, in these populations KS is a relatively benign, chronic disorder (Grmek, 1990).

stereotypical generalisations of homosexual identity and lifestyle, had become a global 'epidemic' present in thirty-three countries. In July 9, 1982 *Morbidity and Mortality Weekly Report* 31 reported thirty-four cases of AIDS amongst heterosexual Haitians living in the United States, only one of whom with a history of injection drug use. A week later *Morbidity and Mortality Weekly Report* 31 documented the first cases of PCP amongst haemophiliacs. From the series of postulated etiological hypotheses surrounding the emerging health crisis, the viral one seemed to provide the best explanation for the appearance of AIDS in these distinct populations (Mass, 1982). However, it was acknowledged that 'a number of superficially similar epidemics, each with its own primary aetiology', could be taking place simultaneously (Epstein, 1996:57).<sup>73</sup>

In the years prior to the epidemic, the explosion of venereal diseases among urban homosexual communities that had followed the 'sexual-liberation-as-personal-ethic' motto of the gay liberation movement was well documented. Such medical literature concluded that homosexuality *per se* was a risk factor in infectious disease, and warned clinicians of 'the homosexual hazard'. Despite such a notion of inherent susceptibility to disease, the intrinsic health of the homosexual body had indeed improved (at least through the scientific eyes of the medical gaze). That the emerging syndrome of immune suppression even caught the attention of the Centres for Disease Control only attests to the fact that the bodies in which it was first detected had recently been defined as healthy. Despite the plethora of sexual diseases embedded in the concept of the 'homosexual hazard', (homo)sexuality had indeed achieved a status never previously ascribed to it.

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<sup>73</sup> The other etiological hypothesis was the 'immune or antigen overload' theory, which attributed the syndrome to the excesses of the 'gay life-style' (Epstein, 1996:48).

Had AIDS been identified in pre-Stonewall homosexuals, it would have probably been assigned to the innate inferiority of homosexuality. Still, it is easy to see how the conceptualisation of GRID as a 'gay disease' reflected not the fortuitous initial discovery of the syndrome among gay men, but vestiges of the medicalisation of the homosexual body. Otherwise how can we explain the legitimisation of a social category of individuals as 'plausible victims of a medical syndrome' (Patton, 1990:28)?

The medicalisation of homosexuality framed the mediatised linkage of the emerging 'gay disease' to the sexual voracity of its victims. Homosexually-identified individuals were *all* reduced to sexual compulsives, who had 'multiple and frequent sexual encounters with different partners, as many as ten sexual encounters each night up to four times a week' (New York Times, 3 July 1981, A-20 quoted in Epstein, 1996:46). It is interesting to note the effect of ideology on the normalising science of epidemiology. In attempting to identify and contain a mysterious illness, this branch of science focused 'upon the most sensational markers of homosexual difference'. As such, the numerous reported cases of monogamous or sexually moderate homosexuals who were also succumbing to the new syndrome were duly ignored (Epstein, 1996). Such a configuration of power/knowledge created the perception of AIDS as the result of the inherent deviance of homosexuality, and legitimised the notion of the 'innocent victim' of AIDS. In any case, whether AIDS is 'a nexus where multiple meanings, stories and discourses intersect and overlap, reinforce and subvert one another', or a narrative for the articulation of the homophobia of the heterosexual mainstream, or both, the fact remains that blatant public neglect characterised the beginning of the epidemic (Treichler, 1988:42-55). Consequently,

efforts to provide services for those suffering from the devastating syndrome, as well as to deal with issues of public policy, had to first be devised by organisations from within gay 'communities'. Thus, the linkage between AIDS and homosexuality was solidified both within and beyond the affected communities (Epstein, 1996).

### 3.3.1.- The Health Crisis Today

'Second Wave of AIDS Feared by Officials in San Francisco' was the title of a front-page article, which appeared in the New York Times on December 11, 1993. As early as 1989 there had been signs that increasing numbers of American gay men were engaging in unprotected sex.<sup>74</sup> The statistics contradicted the widely held belief that safe sex education had permanently altered gay men's sexual behaviour, and had curbed the spread of the epidemic among gay communities. In the 1980s several studies had revealed that gay men across the western world were behaving 'properly', and had substantially altered their sexual behaviour (the San Francisco Men's Health Study [Winkelstein et al., 1988]; the Macquarrie University study in Australia [Kippax et al., 1993]; Project Sigma in England and Wales [Davies et al., 1993]). However, in 1997 the American magazine for HIV positive gay men - *POZ* - published an article by AIDS activist Stephen Gendin who, inspired by a trend he had noticed in gay personal columns in the Internet, defended the right of positive men to have unprotected anal sex with each other - what came to be known as 'barebacking' (Positive Times, 02/1998).

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<sup>74</sup> In November of 1989 the CDC's *Morbidity and Mortality Weekly Report* revealed that gonorrhoea cases among gay men attending STD clinics in King County, Washington had considerably risen (Rotello, 1998).

In Britain, between 1990 and 1997, the number of HIV infections classified under the exposure category 'sex between men' remained between 1,350 and 1,650. Yet, 1996 saw the highest rate of infection since the beginning of the epidemic: 1,706 cases of homosexually acquired infections (Public Health Laboratory Service - HIV/AIDS & STD Surveillance in the United Kingdom). Up until the first half of 1999 35,011 people in the UK were estimated to carry the HIV virus; 16,430 of those have developed AIDS. Homosexual men account for 68% of the AIDS cases and for 58% of HIV infections (Public Health laboratory Service AIDS Centre– AIDS/HIV Quarterly surveillance tables no.44). Of these, around one third remain untested and, consequently, unaware of their HIV status. The 1998 HEA report 'Life on the Scene' revealed that despite the high level of awareness of highly gay-identified men concerning safer sex campaigns, 36% of them routinely engaged in unsafe sex (Pink Paper, 9/01/98). Attempts to 're-gay' HIV prevention, an effort initiated in 1992 by AIDS activists, have indeed resulted in more efficient allocation of resources targeted specifically at gay men. However, re-gaying has had no impact on the observed increase in infection rates. Whereas the rate of heterosexual transmission of HIV continues to grow most HIV infection in Britain occurs between gay men. As such, cases of HIV among gay-identified individuals will continue to dwarf the total number of heterosexual cases. It is estimated that by 2003 the number



of gay men who know they are positive will increase by almost a third. In London, the projected increase in HIV infections is even gloomier: some areas of the capital are expected to have up to 54% more people diagnosed with HIV by 2003 (Pink Paper, 18/05/2001).

## Chapter 4:

### AIDS Pilgrimages: Dance, Sex, and Drugs as Resistance

Homosexuality did not constitute a society, just a malady, although unlike many other maladies it was a shameful one – a venereal disease

(Edmund White, 1988)

#### 4.1.- Gay Tribes: a community?

Homosexual acts have been documented since the early civilisations, but homosexual identities and subcultures only began to crystallise under the impact of urbanisation in the late seventeenth century (D’Emilio, 1983; Weeks, 1990).<sup>75</sup> The role of urbanisation in the formation of modern homosexual subcultures is undisputed, but Greenberg (1988) has argued that social networks of male homosexuality preceded the configuration of proper subcultures. However, the notion that differing social structures shape or disable the response to the homoerotic feelings potentially present in human beings across history is uncontested. The cultural meanings attached to (homo)sexual ‘scripts’, which are articulated through a dense network of social activities and institutions, constitute an interdependent set of relationships (Simon and Gagnon, 1973). We can confidently analogise the statement that ‘each culture gives shape to a unique *Gestalt* of health’ to the realm of sexuality (Illich, 1976:128). The ‘spontaneous’ resistance project I will be analysing in the present chapter, which emerged from the grassroots of the American gay subculture, was only feasible because organised gay communities had coalesced in the

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<sup>75</sup>‘Essentialists’, who view sexual identity as the cognitive representation of underlying biological differences, dispute this social constructionist perspective (Stein, 1992).

1970s. As such, I should introduce the subject of the 'circuit' by framing it against my understanding of how such a community should be understood.

The 'homosexual role', which establishes clear boundaries between acceptable and impermissible behaviour and thus contains the 'deviance' of those labelled as homosexuals, frames the developmental process of modern homosexual identities (McIntosh, 1968). In Britain such role began to emerge as early as the 1600s, but it was not until the end of the nineteenth century that it took its modern form (Weeks, 1990). Yet, the accelerating secularisation process that accompanied capitalism did not prevent the 'inverts' or 'urnings' of the 1860s from being conceptualised within an ideology heavily influenced by the taboos of the Judeo-Christian tradition (Halperin, 1990; Katz, 1990; Weeks, 1990). The homosexual condition was identified, and the term homosexual coined, as doctors became the new 'licensed magicians' of secularised society (Illich, 1976). This was also the time when the concept of *heterosexuality* appeared as notions of the productive and procreative body were de-emphasised in favour of the consuming and sensuous one (Katz, 1990). The 'crisis of masculinity', which occurred in Europe and in the United States at the turn of the nineteenth century, sets the context within which both homosexuality *and* heterosexuality emerged as two opposite forms of eroticism (Badinter, 1995; Katz, 1995).

Almost half of the twentieth century was dominated by the psychoanalytic construct of homosexuality. It was not until the publication of Kinsey's (1948) *Sexual Behaviour in the Human Male* that same-sex desire was represented as other than an aberration.

Concurrently with Kinsey new social models of homosexuality appeared. These approaches regarded homosexuals as an oppressed and persecuted minority rather than as congenital freaks (Hooker, 1965; Hoffman, 1968). Sociologists, prompted by the increasing public awareness of homosexuality, began to study the subject (Seidman, 1996). Post-war deviance theories modified the theoretical perspective, which had characterised deviance as an inherent property of the individual, or of a particular act, to that of a specific historical status occasioned through social oppression. In addition to the sexual script perspective of Simon and Gagnon (1973), these transformed theories were of particular relevance to alternative constructions of knowledges of (homo)sexuality. As we have seen, in London the establishment of the Gay Liberation front (GLF) at the London School of Economics in 1970 marked the British inauguration of the gay liberation movement. Yet, it was not until the first wave of gay affirmative politics (1968-1973) had passed that the notion of homosexuality as natural, which had been held by the homophile movement of the 1950s, was abandoned.<sup>76</sup> The era of 'social constructionism' thus dawned both in academia and in political activism. Foucault's (1981) 'constructed' homosexual challenged previous essentialist notions of sexual orientation, and inspired a model of homosexuality as an ethnic minority (Epstein, 1987; Seidman, 1996). As such, gay and lesbian individuals entered 'into a period of community building, personal empowerment, and local struggles' (Seidman, 1996:8).

Briefly, and according to a social-constructionist perspective, gender-neutral but deviant sexual acts once inherently stigmatising evolved into specific social identities, which later

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<sup>76</sup> McIntosh (1968) and Altman (1971) defended a (social constructionist) view of homosexuality that differed from the (mostly essentialist) approach of the era.

coalesced into a complex cultural group. Subjective aspects of human activity had been disregarded by the behaviourist paradigm that had dominated the social sciences until the 1950s. As such, ideas about culture only shifted after its definitions abandoned notions concerning patterns of behaviour, actions, and customs and took into consideration aspects of human activity such as consciousness, intention and meaning of behaviour (Irvine, 1996). Culture came to be theorised as the conjunction of symbolic, non-biological aspects of human society: the 'webs of significance' (Geertz, 1973). That our last century witnessed the development of complex urban aggregations with an established array of social institutions catering to 'metropolitan lesbian and gay identities' is unquestionable (Sinfield, 1998).<sup>77</sup> The institutional apparatus of such collectivities comprises gay and lesbian media; legal, lobbying and political groups; an internationalised calendar of dance events; churches; travel agencies; health organisations; newspapers and magazines; holiday resorts; and even a gay and lesbian version of the Olympic Games: the 'Gay Games'. But despite the relative institutional wealth, can we really attribute cultural status to these human aggregations?

If oppression provides 'the conditions within which the oppressed can begin to develop their own consciousness and identity', then the labelling of homosexuals as deviants encouraged the generation of a distinct social world (Weeks, 1990:33). However, the medicalisation of homosexuality was a reaction to the emanating groupings of individuals who were beginning to self-identify *through* sexual behaviour, not a fundamental component in their genesis ((Faderman, 1981; Chauncey, 1982; Irvine, 1996). There is

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<sup>77</sup> Sinfield (1998) concept of 'metropolitan' gay and lesbian identity refers to post-Stonewall identification processes of some homosexual individuals who inhabit post-colonial global centres of capital. In some non-

much discord in how to categorise such highly elaborated collectivities: a community (Murray, 1979; D'Emilio, 1983), an ethnicity (Epstein, 1987), a national identity (Duggan, 1992; Newton, 1993), a life-style (Bellah et al, 1985), or a culture (Altman, 1982; Bronski, 1984; Weeks, 1990; Herdt, 1992)? Some sort of 'consensus that lesbians and gay men constitute a community with a distinct culture' appears to exist (Irvine, 1996:224). However, others have questioned whether a movement that has only been organised as a public way of life for a quarter of a century, and whose members' subjectivities constitute interlocking sites of 'gay' as well as a multitude of other deeply established cultural and ethnic affiliations, 'can or should claim a cultural power anything like that of a true ethnic, racial or linguistic people with centuries (or millennia) of history' (Browning, 1993:6). Perhaps, however, to judge the validity of claims to cultural status by means of tradition may be a misguided enterprise. Contemporary life transforms itself too rapidly and demands new configurations of relating and belonging; the narrative of sexuality grounds 'all our disparate belongings'. The concept of citizenship has been magnified by the inclusion of sexuality. As such, our attention is called to

new concerns, hitherto marginalised in public discourse: with the body, its possibilities, needs and pleasures; with new sexualised identities; and with the forces that inhibit their free, consensual development in a democratic polity committed to full and equal citizenship (Weeks, 1998:37-38)

The 'sad and lonely (individual) homosexual' of the Wolfenden Report, whose protection was procured by such groups as the Homosexual Law Reform Society, characterised the

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western cities, these 'metropolitan' identities co-exist with traditional, local sex-gender systems (1998).

absence of any conceptualisation of a homosexual community in Britain until the late 1960s. Despite the individualistic rhetoric of the Wolfenden Report and of the Homosexual Law Reform Society, some form of community had begun to be articulated within the commercial sector much before the arrival of the Gay Liberation Front (GLF) in the early 1970s. Although the gay liberation movement continued to exist throughout the decade, after the middle of 1972 its activities were no longer conducted within the auspices of the GLF. Four reasons can be cited for the failure of the GLF as a viable vehicle of reform: first, GLF's sexism, which led the women in the London GLF to abandon the organisation and set up one of their own; second, the rift between the activists and the feminists; third, the disparity between the realities of 1972 and the organisation's idealistic aims; fourth, the clash between the utopian socialism of the GLF and the non-politicised gays and lesbians of the commercial scene (Weeks, 1990). Contemporary tensions were thus sown as communal identity was first articulated

The passing of Section 28 of the Local Government Act 1988 represented the greatest menace to the articulation of homosexuality since the Labouchère amendment of 1885. By imposing heterosexuality as the only lawful and acceptable form of social relationship, Section 28 dramatically inflated the symbolic expression of 'gay community' by undermining its geo-social boundaries. As such, Section 28 provoked the socio-political coalition of all the homosexual factions residing in the Isles (Cohen, 1985). Paradoxically, such artificial amalgamation bred the current crisis over the idea of an all-embracing 'gay community'. The tactical rhetoric of communal homogeneity of the anti-Section 28 campaign allowed for the inclusion of all camps of homosexual life

into the political arena, and dissolved the traditional boundaries between the commercial scene and its political and cultural counterparts. However, the radical activists, who had monopolised the control of gay identity rhetoric since the time of the GLF, could savour the evanescent condensation of their utopia only for a fleeting moment. The instrumental myth of the homogeneity of the homosexual population might have been a political necessity of the early 1970s, but almost two decades later its moment had long passed (Woods, 1995). The identity crisis of 'gay' demonstrated that as much as it may be possible to recognise behavioural signifiers of gay culture, meaning systems within specific lesbian and gay communities are constructed along the differential axes of race, gender and class: an intersubjective system of symbols that may only be imperfectly shared.

In her 1991 address to the 'National Federation of Community Organisations' Jo Smith declared 'that there is no such thing as a Lesbian and Gay Community' (Smith, 1991:1). Burston (1998:4) recently reiterated that 'gay men living in Britain have too little in common with one another to ever be called a community.' Yet, lesbian and gay lives are articulated through 'a series of communal identities based on various elements (such as gender, sexual preference, geographic location, musical taste or class) which coincide in varying degrees under the nebulous label of homosexuality' (Woods, 1995:9). However, it would seem that the increasing vinculum between homosexuality and specific types of consumption has overpowered all other self-identifying options.<sup>78</sup> Such a hegemonic model of homosexuality reflects the globalisation of capitalism through an

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<sup>78</sup> This concept of consumption includes not only goods, but also all of life's activities. As such, it is instilled with ethical and aesthetic significance (Chaney, 1996).



internationalised iconography of masculinity, which is instantly recognisable in urban landscapes as distinct as those of London or Rio de Janeiro.<sup>79</sup> The hedonism of the post-Thatcher dance-drug culture, alongside the commodification of homosexuality via the commercialisation of drugs and sex, has transformed utopia into lifestyle.

The trouble with the transformation of a 'subculture' into a 'lifestyle culture' is that the creation of a self-conscious lifestyle highlights the contingency of its living patterns, and impairs the plausibility of defending one's *fundamental* rights. In addition, this new hegemonic template offers none of the advantages of community (Woods, 1995).

Although the boundaries between a 'gay' lifestyle and a sub-cultural system are blurred, specific forms of speech and fashion, as well as values, have become constitutive of a symbolic vocabulary that responds to the oppression of heterosexism (Chaney, 1996).<sup>80</sup>

But if it is necessary, as Jenkins (1983) has argued, for sub-cultural status to imply a deviant relationship to a dominant culture, and as the concept of lifestyle stresses distinctions *within* a culture, then the lifestyle concept can be employed as a methodological tool for the understanding of the disparate collectivities which, linked by their deviant sexuality, constitute the gay subculture.

The manner in which the symbolic resources of mass culture are appropriated denote power and articulate identity, and the importance of lifestyles 'lies in how we think about the most fundamental themes of what it is to say that individuals are members of

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<sup>79</sup> The impact of American 'cultural imperialism' is clearly visible in representations of homosexual desire and identity within 'metropolitan sex-gender systems' present not only in 'capitalist heartlands of the West', but also in large cities across the world (Sinfield, 1998).

cultures'. In making the distinction between a 'way of life' and a 'lifestyle', Chaney (1996: 85-87) argued that the former is similar to definitions of culture as a form of life associated with the patterns of social order of a stable community. The latter should be understood as local forms of knowledge whose meaning and interpretation are inextricably embedded within the 'particular context of established ways of life.' The gay subculture is composed of members whose gender, ethnicity, religious affiliation, occupation and age imply a multitude of interlocking structural affiliations that can be strategically combined, fused and adapted. In the same way that 'gay' was a bourgeois discourse that made more sense to the middle classes but was nevertheless symbolically shared by working-class homosexuals, we must not reduce lifestyle to disposable income (Healy, 1996). As practices infused with aesthetic and structural significance, lifestyles are not the monopoly of the elites. In fact, much of the innovation in the appropriation of symbolic goods and services arises amongst the disenfranchised enclaves of contemporary society.

'Circuit Queens', 'Gay Skinheads', 'Muscle Marys', 'Assimilationists', 'Queers', 'Anti-Gays', 'Lesbian and Gay Christians', 'Leather Boys', 'Positives', 'Dissidents', 'Beat Queens', 'Professional Gays', 'Disco Bunnies', 'Diesel Dykes' can all be described as different subcultural identities articulated through variant lifestyles. These distinct narratives are constructed in daily performances negotiated through a *bricolage* of possibilities, which can be inclusively or exclusively enacted, but must be filtered through the other cultural and subcultural affiliations (and limitations) of each individual.

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<sup>80</sup> Weeks (1990) argued that the existence of a substantial gay argot indicates culture, and Bronski (1984) has discussed gay male sensibility in movies, theatre, opera and pornography.

These performances might signify a ‘distancing’ as much as a ‘proximity’ to other ‘collective resolutions of desire’, but the central importance of sex as constitutive of the gay subculture must be acknowledged (Dowsett, 1996). The ‘Queer’ theorists of the 1990s, heavily influenced by French poststructuralism and Lacanian psychoanalysis, concurrently recognised the fragmentation of the homosexual experience *and* the central role of sex in its constitution.<sup>81</sup> As such, the homosexual subject is deemed to reinforce the sexual cosmology of modernity as a system of knowledge by turning the categories of ‘gay’ and ‘lesbian’ into disciplinary forces. ‘Queer’, however, failed to reach any sizeable recognition outside of academia not only because of the force of the commercial scene and the assimilationists, but also for its lack of conceptualisation of the social (Woods, 1995; Seidman, 1995).

Contemporary individuals ‘are not posited on a logic of identity’; thus, the ‘ambiance’ of our era stems from the fundamentally paradoxical situation occasioned by ‘the constant interplay between growing massification and the development of micro-groups’. If the mythical ‘gay’ community *does* materialise, as it has been painfully demonstrated by the AIDS crisis, it is because such ‘micro-groups’, or overlapping ‘tribes’ under the rubric of perverse sexuality, partake of a ‘strong component of shared feeling’. Such ‘feeling’ can materialise as a ‘union for confronting together, in an almost animal way, the presence of death, the presence at death’, even if the identification of ‘community’ is achieved ‘through a diffuse union that does not require one’s full presence for the other’. The ‘neo-tribalism’ proposed by Maffesoli (1996) envisions our megalopolises criss-crossed by

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<sup>81</sup> See the anonymous 1991 London leaflet ‘Queer Now’ and ‘Fear of a Queer Planet’ (Warner, 1993).

networks of individuals who share sentiments (*aesthetic*), bonds (*ethic*) and *customs*, and offer ‘mutual aid, conviviality, commensality, professional support and sometimes even...cultural rituals...’ These networks enable individuals to articulate their contingent identities - via such lifestyle practices as taste, music, fashion, manners, body-practices - and to rapidly coalesce into a collective subject whenever their ‘being-together’ is desired or threatened (Maffesoli, 1996:6-73).

My analysis of gay ‘community’, therefore, implies a conceptualisation of identity as fluid and dependent on temporal, spatial, and situational parameters. Mass society - characterised by the ‘conformism of youth, the passion for likeness within groups or “tribes”, the phenomenon of fashion, standardised culture, up to and including the *unisexualisation* of appearance’ - is ‘both cause and effect of the loss of the subject.’ It is within mass society that urban individuals who engage in homosexual behaviour live, thus when the ‘collective spirit’ of gay ‘community’ effervesces, it supersedes ‘aptitudes, identities and individualities.’ However, this ‘community’ continues to be ‘the site of real appropriation;’ it is where ‘both the loss of the individual and the reappropriation of the person’ take place (Maffesoli, 1996:64-66).

#### 4.2.- The Circuit: resisting through ritual

##### 4.2.1.- The Ritualised Lifestyle of the ‘Circuit Queen’

The circuit queen is one of the many sub-cultural identities of the gay 'community'. As such, the circuit queen performs his identity through lifestyle practices that revolve around an international calendar of gay-mega-dance-events: the 'circuit-parties'. Many of the largest parties of the circuit originated as benefits to raise money for the AIDS crisis, and it is widely believed that a great percentage of those who frequent the circuit have received an HIV or an AIDS diagnosis.<sup>82</sup> As Andrew Sullivan, the HIV-positive-British-born-Oxford-and-Harvard-educated former editor of the leading American political weekly *New Republic*, and analyst of American politics for the English newspaper *Sunday Times*, observed in the *New York Times Magazine* (1996):

On the surface the parties could be taken for a mass of men in superb shape merely enjoying an opportunity to let off steam. But underneath, masked by the drugs, there is an air of strain, of sexual danger translated into sexual objectification, the unspoken withering of the human body transformed into a reassuring inflation of muscular body mass (quoted in Signorile, 1997:93)

My argument is that the life-style of the circuit-queen is suffused with significant (quasi) religious qualities, and that the circuit constitutes a 'spontaneous resistance strategy' that challenges the medical definition of the AIDS body as a dying entity.<sup>83</sup> However, before proceeding with a discussion of the quasi-religious aspects of these mega-events, I shall briefly argue for the embodied nature of the *ekstasis* experienced within the context of the 'circuit'. I shall also discuss how the AIDS crisis has pushed the gay/positive body into a ritualised existence.

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<sup>82</sup> Data to corroborate this statement would require further research. However, research conducted by Signorile (1997), Lewis & Ross (1995) and my own participant observation point in the same direction.

#### 4.2.2.- The Gay Body: magic and resistance

The 'gold standard' of human bodily classification has been the white, European, middle-class, heterosexual body. Masculinity, the 'bodily quality or condition that defines a person', is a construct linked to the adjustment of medieval notions of manhood to the emergence of the new bourgeois society of the end of the eighteenth century.<sup>84</sup> The questioning of gender relations allowed by liberal democracy posed a threat to male hegemony, and prompted the abandonment of ancient notions that conceptualised the difference between the sexes as a simple matter of degree. As the biological 'two-sex' model gained credence, the surface and the interiority of the human body were increasingly differentiated in accordance with the emerging model of distinct male and female bodies (Laqueur, 1990). As such, the fundamentals of the contemporary male body emanate from the second half of the nineteenth century, and are shaped by Darwinian notions that define it as vigorous, competitive, assertive, and muscular (Rotundo, 1993; Petersen, 1998).

Gay Liberation stripped the unconditional association of homosexuality with gender deviance, and a process of masculinisation ensued. If the sex-gender system of 'metropolitan gay identity' has abandoned conventional notions of gender hierarchy, such as those of the Latin-American model where manhood is associated with the dominant role, residues of a hostile ideology that conceptualises femininity, and passivity, as

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<sup>83</sup> The term 'circuit queen' is widely applied 'to describe the average repetitive attendee, although few men will label themselves a circuit queen' (Signorile, 1997:33).

<sup>84</sup> Medieval notions of manhood such as chivalry and the institution of the duel lasted into modern times. The word masculinity only appeared in the mid-eighteenth century (Petersen, 1998).

inferior still haunt. Yet, the stigma of femininity is ultimately a consequence of the dominance of men over women, not of 'straight' over 'gay' (Sinfield, 1998). The hyper-masculinity of the (hard) muscular male body, heralded as the hegemonic ideal of an American-dominated internationalised gay subculture, is the result of the subaltern position of (soft) femininity in mainstream society - even if masculinity is 'insecure of its status and even its existence' (Heywood, 1997:171).<sup>85</sup>

The male bodybuilder constitutes the very embodiment of conspicuous and traditional masculinity. Competitive female bodybuilders also strive to embody masculinity in an attempt to dissociate themselves from 'femininity', and from 'immanent passivity' (Ian, 1994). However, the gay bodybuilder destabilises masculinity through the 'eroticisation of gender *sameness*', and by superimposing 'authentic' masculinity onto the feminised body (Bordo, 1997:49). One of the most astonishing sites of a circuit party is the materiality of thousands of masculinised 'buffed' bodies intermingled and intertwined in a vast network of (not so masculine) gestures and embraces. In his parody of the masculine body the circuit queen transgresses conventional masculinity, subverts the traditional codes of representation, and creates opportunities for narcissistic self-identification. This narcissistic self-identification may only denote a superficial level of association, as 'inside that body is a mind that harbours a past in which there is some scrawny adolescent or stuttering child that forever says, "I knew you when..."' (Klein, 1993:41). Thus the 'circuit', by constituting a forum for an articulation of drag that subverts dress and associated gender roles, as well as poses and style of bodily relation,

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<sup>85</sup> 'Body fascism' is the term employed by members of diverse gay 'tribes' to denote the (sub)cultural

constitutes the site where the 'masquerade of masculinity' is epitomised (Healy, 1996). However, another cultural imperative is fundamental in the gay worship of muscularity. The inner quality of the self has been increasingly equated to its outer appearance; when health is a 'virtue' not only does the 'soft' body represent a sign of moral weakness, but also the 'dis-eased' gay body surely constitutes a symbol of personal degeneration.

Loss of self is one of the most fundamental forms of suffering in chronic illness (Charmaz, 1983). The stigmatisation, isolation, loneliness, frustration, and dependency processes triggered by the onset of illness are perhaps masked, but not alleviated, by the 'new compulsive body-building' trend among gay men (Evans, 1988). The compulsive production of the muscular (and, as such, perceived as healthy) gay body is enacted in the hope that the achieved strength of its surface may function as a magical shield against the internal threat that the HIV virus represents. In their research of the gay-dance-party institutions of Australia, Lewis & Ross (1995) recognised the magical thinking involved in the process of 'tricking' the virus. In their sample of sixty-three self-identified gay men who were regular patrons of inner-city gay parties, four reasons related to the obsession of the body-beautiful were identified. Only *one* referred to issues of heterosexual dominance: the 'straighter-than-straight' appearance enabled by a muscular body provides a 'passport' between the dominant culture and the gay subculture. The other three motives related to the production of a muscular physique were concerned with HIV/AIDS: a healthy and muscular body disguises a positive diagnosis; a muscular appearance enables self-denial concerning one's own status, and allows for the possibility

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imperative of the muscular body. Signorile (1997) has argued that 'body fascism' is equivalent to some forms of racism.



of misleading a potential sexual partner into believing that one is healthier than one appears; the possibility to 'trick' the degenerative and infectious capabilities of the virus.

Especially before the discovery of HIV, AIDS-risk was equated to group membership.

With the identification of the virus in 1983 the homogeneity of gay men as a risk-group

was broken. 'HIV status' simultaneously specified individual identities into HIV-

positives and HIV-negatives. As such, the division between the (positive) gay men who

'posed' a risk, and the (negative) men who were 'at-risk', took place. With new

developments in drug therapy, the division between gay men has become more nuanced.

In terms of potential threat of contamination, positive individuals who have trouble

keeping up with their drug regimen, or 'non-compliers' (read: 'very-risky'), are compared

to positive individuals who have never taken anti-retroviral treatment, or 'drug-naïve'

(read: 'not-so-risky') (Flowers, 2001).<sup>86</sup> However, and most importantly, simply by

belonging to a group affected by the only modern plague that 'affronts all technical

values', a gay man is 'polluted' irrespective of his individual health status (Shilts, 1987).

As such, to the 'general public' (unfamiliar with the nuanced issues of anti-HIV therapy)

separate *individual* identities continue to be collapsed into the unified identity of group

membership.

#### 4.2.3.- The Positive Body: ritual and resistance

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<sup>86</sup> Individuals who fail to comply with the requirements of a HAART regime are deemed more likely to develop drug-resistant strains of the HIV virus. As such, they present a bigger threat as they may infect others with strains of the virus that are resistant to the treatment.

The 'coming out' process precedes any genuine engagement in other sub-cultural rites.<sup>87</sup> It is an event that modifies gender behaviour and identity, and places same-sex desire in the core of the homosexual person's identity. Full participation in the gay community can be achieved only through the process of coming out, which is considered the 'key' ritual of gay culture (Herdt, 1992). Oftentimes coming out is linked to a migratory process. A great number of homosexual individuals feel that it is necessary to migrate (or even immigrate) in order to create the social space necessary for the construction of a gay identity.<sup>88</sup> Only post-Stonewall generations have been able to profit from a community whose political and economic power has been translated into gay and lesbian institutions. As such, this process of identity development that has accompanied the formation of the gay and lesbian cultural system of recent decades is a transformational process constitutive of a genuine *rite de passage*. Coming out constitutes a 'collective initiation rite, a public coming-of-age status-adjustment transition into the adult gay community' (Herdt, 1992:31).

Coming out can be seen as a 'technology of the self', a process through which the body is inscribed (Foucault, 1988). The self-disclosure entailed in the coming out process has two conflicting effects: the reinforcement of community and an increased individualisation. In coming out one does not simply renounce the old identity, but forges a new one. The

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<sup>87</sup> The term 'coming out' was first employed amidst the homosexual subculture in order to denote the moment in which an individual became an integral member of the subculture. It was a term that parodied the more acceptable ritual of social recognition accorded to the debutante, and that had none of the contemporary metaphorical associations with the closet (Chauncey, 1991).

<sup>88</sup> A survey conducted by 'Gay Men Fighting Aids' revealed that 77.1% of gay men who live in London have grown up outside of the capital (*Gay Times* 03/1997).

double movement embedded has been recognised in Rose's (1989:240) analysis of the self-confessional event:

In confessing, one also constitutes oneself. In the act of speaking, through the obligation to produce words that are true to an inner reality, through the self examination that precedes and accompanies speech, one becomes a subject for oneself. Confession, then, is the diagram of a certain form of subjectification that binds us to others at the very moment we affirm our identity

AIDS has bestowed new meaning upon the coming out process. In his research on the processes of initiation and socialisation of urban gay youth in the American Midwest, Herdt (1992:21-35) compared the coming out experiences of four different cohorts. The first cohort dated from the turn of the century to the 1930s. The second cohort extended from World War II to the Stonewall Riots, whereas the third cohort comprised the 'sexually-liberated' generation of post-Stonewall activism. The fourth cohort, beginning in 1982, was characterised by the onset the AIDS epidemic. In juxtaposing these different experiences, or 'pathways of adjustment across cultural epochs', Herdt concluded:

where early cohorts lived closeted and in fear, suffering such huge psychosocial costs as the alcohol abuse associated with the bar culture of that generation, and where the third cohort is now besieged frontally with the death and grief of AIDS, today's youths - witness to these preceding life-styles - are in response developing an alternative cultural reality and future life course

Heterosexual sexuality does not need to come out as the major institutions of society sanction its development. The coming out event results from a process of self-acceptance

required only of those individuals whose sexual orientation is stigmatised by the social environment. Sexuality has become fundamental in contemporary identity-construction processes (Foucault, 1981). In this light the closet became a place of terrible darkness, in which the negation of the body was interpreted as the annihilation of the innermost expression of self. Only out of the closet could selfhood be re-appropriated, if not gained for the first time. Van Gennep (1960) argued that all rituals of social transition follow the same tripartite pattern. First there is the stage of 'separation' from secular and everyday relationships, which is followed by the 'liminal' (transitional) period. The process ends when, after a new status and cultural knowledge has been achieved, the individual returns to secular relationships. Occasionally, the liminal phase may detach from this tripartite ritual structure, and in its independent existence will constitute an autonomous 'state of transition'.

This 'state of transition' is populated by members who are 'betwixt and between' normal social roles, and close to some transcendent and sacred core of moral and social value (Turner, 1967). Van Gennep's (1960) tripartite scheme of rituals of social transition can be applied to provide a fuller understanding of the transformation implicit in the coming out process. The severance and withdrawal from usual social roles experienced by the homosexual person, when he or she recognises his or her 'differenceness', illustrates the initial phase of separation described by Van Gennep (1960). This stage of identity construction, which has been described as the 'self-suspicion' phase in the construction of a gay identity, is characterised by introspection, anxiety, and alienation from family and friends (Weinberg, 1983). Although the basic structure of the coming out process can

be considered universal, its shape - according to age, social, ethnic, and geographical variables, as well as cultural era - can vary greatly.<sup>89</sup> A thirty-year-old father who comes to recognise his homosexuality will experience the liminal phase of his coming out differently from a teenager who seeks help within the established institutions of the gay community.

In order to acquire a gay identity, the initiate needs to traverse the liminal stage of the coming out process. In this liminal period he or she will exist in 'timeless ritual space outside normative society, and will unlearn previous belief systems and behaviours (Van Gennep, 1960:75). The 'relearning process' refers to the possibility, enabled by ritual, for previously held ideas and beliefs to be unlearned so that new social roles can be performed satisfactorily (Van Gennep, 1960). The relearning aspect of coming out is fundamental for the successful adaptation into the new moral world of gay culture. After coming out, the gay person experiences a new sense of self. The new self inhabits a different moral world where different social roles are performed, new relationships enacted, and new environments inhabited. Moreover, in being reincorporated as new selves into a subculture within the wider society, and by publicly adopting gay-identified social relationships, initiates are reborn into a new selfhood that can be achieved only through the death of the old (even if the degree of such 'death' varies according to each individual). In many cases the coming out process may lead to literal social death as parents, friends and family reject the new gay-identified individual. However, the death

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<sup>89</sup> Seidman et al (1999:9-11) argue that as the notion of 'coming out' is inseparably linked to the idea of the 'closet', and that as the latter presupposes a narrative which constructs 'gay individuals as suffering a common fate in a society organised around normative heterosexuality', they may need to be rethought as gay and lesbian (and bisexual) identity in contemporary America has been normalised and routinised.

of the old self does not translate into a new identity that is free from the stigmata of homosexuality. Societal oppression and internalised homophobia may continue to scar the development of the gay-identified person. Functioning in society as an openly gay male or female requires much more than the mere unlearning of secrecy, it demands rejection and symbolic reinterpretation of the homosexual stigma. It is because sexuality has come to be placed 'in a more and more distinctively privileged relation to our most prized constructs of identity, truth, and knowledge' that such a *rite de passage* becomes so crucial, and entails much more than simple modifications in self-identity (Sedgwick, 1990:42).

AIDS has created a new form of subjectivity for the homosexual. The legal necessity, the moral obligation, the sexual imperative of 'HIV-disclosure' discourse has constituted a new type of subjectivity for the diagnosed individual.<sup>90</sup> The crossing of the boundary 'seronegative' vs. 'seropositive', 'healthy' vs. 'diseased', shares the same tripartite structure as that described by Van Gennep (1960). Whereas in mainstream society the diagnosis of a serious illness might cause profound isolation, the widespread rate of infection within gay communities may soften the initial reaction to an HIV diagnosis. The liminal phase of coming out about one's HIV diagnosis (to him/herself and/or to others) is characterised by the ambivalence of the individual towards his or her reality as an officially dis-eased individual. The typical development of the syndrome contributes for a liminal phase that can be particularly long, as the first occurrence of an opportunistic

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<sup>90</sup> See chapter seven.

infection might not occur for a long period from diagnosis.<sup>91</sup> In addition, periods of disease may be alternated by long stretches of apparently good health. As such, asymptomatic HIV infection is understood through biomedical explanatory frameworks that present themselves as a metaphysics of an otherwise imperceptible condition. The departure from the land of the living, which characterises the initial phase of the HIV-coming-out process, culminates in the inclusion of the initiate into the land of the dying, or the 'reincorporation' phase of the HIV-coming-out process. Regardless of the stage of development of HIV infection, when an individual comes out to the world as an HIV carrier, his or her old self must be shed, as the reincorporated self is ultimately understood to be a dying one.<sup>92</sup> Such a process of reincorporation is often reinterpreted from the privileged position of 'enlightenment'. Discourses of salvation, rebirth, and biography, which are employed in order to make sense of an HIV diagnosis, serve as important symbolic and narrative reference points between the positive body, the tainted self, and mainstream society.

Homosexual identity was first 'spoiled' by its classification as a mental handicap. Although removed from the list of mental illnesses by the American Psychiatric Association in 1972, the change in the official conceptualisation of homosexuality affected its 'actual' component much more than its 'virtual' one (Garfield, 1995;

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<sup>91</sup> Opportunistic infection (OI) constitutes an infection in an immune compromised person caused by an organism that does not usually cause disease in healthy people. Many of these organisms are carried in a latent state by virtually everyone, and only cause disease when given the 'opportunity' by a damaged immune system.

<sup>92</sup> The laboratory parameters used to monitor the progression of HIV disease, especially T-cell count measurements, present the HIV-infected individual with a picture of gradually diminishing health that will ultimately result in the total collapse of the immune system. See chapter six for a more detailed analysis of

Goffman, 1971). With the onset of AIDS, which we ought to recall was first named G.R.I.D. (Gay Related Immunological Disease), to the deeply discrediting attributes prescribed by the dominant culture to disqualify gay men from social legitimisation was added the stigma of a fatally contagious illness. Consequently, the current knowledge and development of a gay identity is deeply embedded within the larger AIDS cultural agenda. AIDS might seem to be invariably fatal, but its expected fatality can develop so gradually and slowly that its carriers find themselves existing in a liminal space where the boundaries between living and dead, diseased and healthy, are deeply confused and unbearably prolonged. People in crisis often create life-reinforcing celebrations involving the use of music, dance, and intoxicating substances. As such, ritualised behaviour often emerges among a subculture in crisis. In addition, the loss of confidence in mainstream healing institutions to control or prevent communities from being affected by deadly diseases is one of the major contributory factors for the evolution of such rites during times of plagues (Zoja, 1989). The liminality inherent in an HIV diagnosis, when combined with the stigmatisation of homosexuality, and added to the urban and 'culturally plural' character of homosexual communities, has produced a rich collection of contemporary ritualised behaviour. It is thought that only within the institutions of urban marginal groups can contemporary society still provide for some *limited* participation in genuine ritualistic behaviour (Hanna, 1987). Perhaps 'limited' is too narrow a term.

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these tests, and chapter seven for how the perception of such tests impinges upon the subjectivity of the diagnosed.



Durkheim suggested that social groups perform rituals so that common values may be renewed, social bonds strengthened, and communal conceptions reaffirmed (Durkheim, 1955). Rituals have been present in all human cultures. Ritual as a 'symbolic mode of communication of "saying something" in a formal way, not to be said in ordinary language or informal behaviour' describes an 'extraordinary event involving stylised, repetitive behaviour' (Firth, 1973:176; Hanna, 1987:129). Rituals are characterised by 'repetitive behaviour that does not have a direct overt technical effect'. Private rituals are those conducted and observed solely by one person whereas public rituals are performed for at least one other person. Public rituals can be defined as those aspects of certain customs that 'have no direct technological consequences and which are symbolic'. Public rituals 'say something about the state of affairs, particularly about the social conditions of those taking part in the ritual' (Helman, 1996:9). Rituals have two principal functions. The *expressive* function communicates the basic values of the culture in a dramatised language. It can be understood only within a specific cultural and social context, and only by those initiated and conversant in the culture's vocabulary. The *creative* aspect of ritual creates and re-creates the inner and outer boundaries of a society, and provides the categories through which men perceive reality (Turner, 1969).

Processes of industrialisation and modernisation have fundamentally shaken the prominent role of ritual. In traditional societies rituals served as the main vehicle of social renewal, cohesion, and protection against threatening dangers. The process of western 'disenchantment' culminated in a modern existence where the important social, psychological, and symbolic dimensions traditionally fulfilled by ritual were instead

carried out by the nation-state. As civil religion came to substitute the institutionalised kind, pluralistic societies looked to ‘flags, coinage, anthems, uniforms, monuments and ceremonies’ to provide their members with a sense of shared identity and belonging (Smith, 1991:16-17). More recently, however, political and social deterioration, as well as globalisation, have contributed to the decline of civil religion as an alternative focus for value consensus. Eliade (1959) has argued that the disappearance of genuine initiation rituals fundamentally distinguishes the ancient from the modern world. Yet, as we shall see, the amorphous character of contemporary society, unable to provide a clear focus of identity, seems to have reawakened the ancient desire for initiation (Barker, 1992). Contemporary human beings, at least ‘queer’ ones, may not be that different from their ancestors after all.

#### 4.2.4.- The Wider Context: rave culture

Methylenedioxymethamphetamine (MDMA) was first synthesised in 1912 and patented two years later by the German pharmaceutical company Merck. The drug was never marketed and only reappeared in 1953 under the code name ‘Experimental Agent 1475’ when the US army tested its potential (on animals) as a chemical weapon for the Cold War. Unlike LSD, which had also been tested by the American military, MDMA did not make it into the streets and only resurfaced in the mid-1960s when it was resynthesised by drug researcher Gordon Alles and a biochemist from the University of California at Berkeley, Alexander Shulgin. Inefficient as a weapon MDMA was deemed suitable for therapeutic use. However, this ‘penicillin for the soul’ was only utilised by a few

experimental therapists.<sup>93</sup> In the 1970s the drug became known as 'Adam', a reference to the keeper of the Garden of Eden before his original sin, but by the 1980s it had been renamed 'Ecstasy' due to the new name's supposedly greater market appeal (Saunders, 1995; Collin, 1998). In the United States MDMA was made illegal in 1985, but only after a long battle had been fought by its supporters - a 'collective of psychologists, researchers and lawyers' who claimed the drug's 'healing potential should not be lost to the therapeutic community' (Collin, 1998:33).

In Britain, an amendment to the 1971 Misuse of Drugs Act had criminalised MDMA much before its use became widespread (Collin, 1998). Whether as a tool for self-enlightenment or as a hedonistic enhancer, or both, widespread use of Ecstasy in Europe did not happen until the mid-80s. Followers of the Indian guru Bhagwan Rajneesh, and the hedonistic 'crowd' that used to rock the Balearic summers of the notorious island of Ibiza, introduced the drug into the Continent (Saunders, 1995). The combination of Ecstasy and 'House Music' sparked the 'most vibrant and diverse youth movement Britain had ever seen'. Such movement reached within into deep country and spread without national borders; its political and cultural effects were felt 'in music, fashion, the law, government policy and countless other areas of public and private life' (Collin, 1998:4).<sup>94</sup> The roots of 'rave culture' date back to the early-1980s and are to be found

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<sup>93</sup> RD Laing was one of the therapists who reported the positive effects of MDMA during therapeutic sessions. Despite its illegality, there are reports that MDMA is still used by both psychotherapists and unqualified therapists in the United States, Germany and Denmark (Saunders, 1995).

<sup>94</sup> House music originated in black, gay clubs of Chicago in the 1980s. Afro-American 'gays' are doubly discriminated not only by mainstream America, but also as homosexuals are 'prevented from expressing their own identity within their own communities. This contributed to a powerful, pent-up frustration which found its release in the clubs, the only place where they could be themselves...the club became church, bedroom and family' (Collin, 1998:17). DJs who experimented with it in Ibiza brought House music to

both in the warehouse parties of the 'rare groove funk and hip-hop fraternities', and in the coastal holiday camps which hosted hedonistic weekends for the working class 'Soul Mafia' (Collin, 1998:72). However, it was not until the summer of 1989 when Ecstasy met 'Acid House' that 'rave' culture took Britain by storm. As such, 'rave' culture may offer a polysemous forum for the questioning of gender relations, the reassertion of community, the seeking of the religious, or it may simply constitute a site for the production of pleasure and desire (Saunders, 1995).

#### 4.2.5.- The Circuit

British 'rave' culture, which had been inspired by the black, gay clubs of Chicago, was later reimported into the United States where white, heterosexual Americans would create their own 'rave circuit'. A reverse but analogous process happened to the 'subterranean' and 'marginalised' gay 'rave circuit' that had developed in the United States (Collin, 1998:277-278). In the 1990's a global network of gay mega-dance-events – 'the circuit' - flourished in Canada, Australia, the United States, and Europe.<sup>95</sup> In the urban gay neighbourhoods of American life in the 1970s the term 'circuit' had been used to denote 'the institutions that together compose the gay ghetto, especially its social, sexual, and recreational scenes' (Levine, 1998:49). The transformation undergone by the circuit in

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England (Saunders, 1995:205). In Britain, 'House Music' metamorphosed into 'Acid House' (Collin, 1998:58-197).

<sup>95</sup> Some of the events that now comprise 'the circuit', such as 'Mardi Gras' in Australia, which dates back to 1978, existed well before 'rave culture' crystallised into its internationalised form. However, such events have been added to the calendar of 'the circuit' and increasingly marketed to and attended by its 'consumers'. Another example is the Carnival of Rio de Janeiro, Brazil (whose roots can be traced back to the turn of the twentieth century) that has seen some of its 'gay balls' abandon their traditional format and music (samba) in favour of not only Anglo-American music but also environments that reproduce the setting and atmosphere of circuit parties. However, the bulk of 'circuit' events take place in the United States where it is estimated that there are fifty parties a year, generating around five million dollars in ticket

the 1990s reflects not only general processes of economic and cultural globalisation (as well as comparatively easy access to air-travel) but also the relative political emancipation experienced by urban gay communities during the 1980s. Sadly, that which increased the visibility and relative clout of such communities was also what was decimating it. AIDS grants the circuit its singular character:

I love circuit parties, the costumes, the men. It's the place where I mourn the friends I've lost. When a good anthem comes on we go: Oh remember him, this one is for Nick. James threw Paulo's ashes all over me at the Black Party. I thought it was coke up my nose, but James screamed, no it's Paulo! I've done so many ashes; the ashes have been saved for the next party. We get rid of them gradually, in different parties. The next one will be at Trade on the Bank Holiday in August. It's a nice idea, because it keeps the party going... it keeps the thought. Most queens are full of life, silly bastards. It keeps their memory going, if they are a fun person... As I said James and I had a number system: I was number 23. Poor George came number one. You can't be serious about it, you can't... (Interview #12)<sup>96</sup>

Secularisation has decreased the role of religion in public areas of Western life, but since the 1950s both immigration and the appearance of new religious movements (NRMs) have vastly increased the British repertoire of religious belief and practice.<sup>97</sup> The type of mystico-religious experience that I propose the circuit constitutes does not present any answers to fundamental questions of existence, but is evocative of the type of popular

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sales. In addition to the 'circuit', a network of 'minicircuits' - 'the 'hot boy night-club parties' - has developed in the last few years in urban centres around the US and Europe (Signorile, 1997).

<sup>96</sup> Only four members of my sample had ever attended a circuit event. See chapter seven .

<sup>97</sup> NRMs is an umbrella term utilised to denote a plethora of organisations emerging in Britain since the 1950s, which offer answers to questions of a religious, spiritual, or philosophical nature. Although some of these organisations originated in Britain (the Aetherius Society, the Findhorn Foundation), most have been imported from the East or North America (Barker, 1992).

religiosity that existed before the institutionalisation of faith. If we are to understand how these sites perform religious roles we must abandon Christian notions of religion defined by 'interiority' and 'salvation', and realise that much like the ancient 'cult of saints and various other forms of superstition', these events deal with "immanent transcendence" - another way of describing the *puissance* which binds together small groups and communities.' Communal life and survival is the focus of these sites (Maffesoli, 1996:58-59).

Dance has traditionally been one of the major institutions of western gay culture, but the circuit is a phenomenon of a globalised subculture in the shadow of an epidemic. The ritualised combination of sex and drugs as symbols to combat the stress of knowledge of imminent death has been used by many different cultures. The fundamental themes of life and death constitute the building blocks of initiation rites, and often involve the use of dance, sex, drugs and music (Zoja, 1989). Such a combination has often served as liberation pathways from the bondage of the dominant culture's repressive taboos (Tiger, 1971; Evans, 1988; Zoja, 1989; Reaney, 1991; Douglas, 1991; Garber, 1992). The inability of the establishment to provide a solution to the AIDS crisis, and the subculture's subsumption, function as psychological incentives for high levels of drug consumption. Circuit parties can involve tens of thousands of participants who engage in a weekend-long marathon of dance, music, drugs and sexual behaviour.<sup>98</sup> The transformed environments created within these institutions - with the use of lights, music, sets, special effects, costumes, crowds, and drugs - contribute to the feeling of suspended

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<sup>98</sup> The main party is usually preceded and followed by smaller events.

reality and allow for the temporary abandonment of everyday inhibitory constraints. The circuit *may* provide opportunities for the achievement of physical and spiritual ecstasy, as well as positive reaffirmation of self-identity and (sub)cultural values, articulated through sexual behaviour and consumption of mind-altering substances.<sup>99</sup> Moreover, the promotion of some of these parties by AIDS organisations legitimises the practices of drug consumption and multiple sexual encounters as individuals are enticed to attend these parties 'for the cause' - their pilgrimages 'are all in the line of duty and goodwill: They're fighting AIDS' (Signorile, 1997:125).

'Mardi Gras' and 'Sleaze Ball' in Australia, the 'White Party' in Miami and Zurich, the 'Black Party' in New York, or the 'Black and Blue Festival' in Montreal are circuit events which supply social space for the expression not only of explicit homosexual behaviour but also for 'immanent transcendence.'<sup>100</sup> Lewis & Ross (1995) have noted that the 'Mardi Gras' and 'Sleaze Ball' parties in Australia might perform the same symbolic functions as do the Christian celebrations of Easter and Christmas for the religiously-identified. Moreover, the social functions they accomplish are similar to those of the temples of institutionalised religion since their members attend its ceremonies in order to transform and escape reality. The secular context of these sites frames the

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<sup>99</sup> 'For many gay men, rave culture is an incredibly powerful form of communal escapism which enables them to get away from the pressures of today. The combination of clubbing and designer drugs has, for example, been strong enough to help us find a release from the reality of AIDS' (David Meech in Gay Times of 9/1994, cited in Saunders, 1995:183-185).

<sup>100</sup> Efforts to establish a gay-mega-party in London have so far been unsuccessful (the Red Party only ran from 1994 to 1997). However, the gay club Trade, part of the 'minicircuit' and the first nightclub in Britain to be allowed to remain open for twenty-four hours, provides opportunities for weekly 'pilgrimages'. In a recent (08/08/98) Channel Four documentary Trade was compared to a 'church'.

experience of the sacred on the psychological level, but spiritual language is often employed to translate the subjective experience of the transcendence of the self.

Whilst for most communities mourning is an infrequent transitional period during which social life is suspended - and a time where the deceased and the grieving constitute a special group located between the world of the living and the world of the dead - it would appear that circuit queens have been unevenly affected by the AIDS crisis. If these events continually attract a disproportionate percentage of HIV infected individuals it is because these unfortunate men can never be fully reintegrated into the world of the living, and need to continually employ psychosocial mechanisms to remember the deceased members of their community and reassert their own lives:

In ways similar to those of these men, many others talk of the circuit as offsetting the tragedies they experience, particularly with regard to AIDS. They literally look to the circuit as part of their mourning process, as a psychological remedy to the epidemic (Signorile, 1997:90-91)

Recent research suggests that some gay men might be actively procuring HIV infection as an act of solidarity with their fellows, and as a way into the AIDS system.<sup>101</sup>

However, it is more likely that the limitations of safer sex campaigns outlined above, as well as the misguided impression that new anti-retroviral therapies may constitute a cure for the syndrome, represent the most significant factors in the continued spread of HIV

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<sup>101</sup> Continuum, vol4 (5) (1997:22-25). More recently a number of websites and internet discussion groups for 'Bug-Chasers' (as these individuals are known) have appeared. 'Bareback.city.com', which claims a membership of forty-eight thousand, and 'bareback.com', serve as virtual communities for those who want to be infected by those willing to purposefully infect (so-called 'gift-givers) them (Freeman, 2003). My



infections amongst 'men who have sex with men'. The circuit and its related events may contribute to the spread of HIV infection, but the gay 'dance-drug' culture does provide gay men with positive images about self, and opportunities to transcend the negative social, physical and psychological consequences of an HIV diagnosis (as well as plenty of free condoms).

#### 4.3.- The Pilgrimage: dancing for salvation

That circuit parties constitute a highly ritualised social institution is certain. Although it is widely recognised that post-modern pilgrims often voyage beyond the boundaries of explicit religion, can we really affirm that the 'circuit' constitutes a genuine pilgrimage culture (Morinis, 1992; Reader and Walter, 1993)? If it does then this particular manifestation of pilgrimage is indeed characterised by some very remarkable configurations. Pilgrimage is a complex socio-cultural institution occurring outside of the usual, and normally fixed, social realms (Morinis, 1992). Because pilgrimage is such a multidimensional social phenomenon, universal denominators are tenuous and one should think more in terms of unifying themes. A brief conceptualisation of the phenomenon of the circuit within theoretical frameworks of traditional pilgrimage culture grounds the insight necessary for the realisation that this unusual form of pilgrimage can indeed be characterised as a post-modern expression of an ancient practice.

The theoretical perspective on pilgrimage developed by Victor Turner (1969; 1978), which is in direct opposition to functionalist theories that favour the integrative function

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own research has also revealed that some gay men view HIV infection as a way into a specific 'life-style' made possible by the welfare system and the relinquishment of full-time employment (see chapter seven).

of pilgrimage, was based on studies of Christian pilgrimages. For Turner pilgrimage is about *communitas*, that is, the creation of a temporary social space where the main relational basis is grounded on equality. Divested of social roles, individuals exist outside the normal parameters of society in a liminal space that fosters spontaneity and bonding. Such 'anti-structural' interpretation is essentially the reverse of the functionalist approach, which deems pilgrimage as a phenomenon that reasserts the social order and reiterates cultural and national identities. Nevertheless, one could reasonably employ the functionalist framework to argue that the circuit represents celebrations that reaffirm (sub)cultural values by creating and reiterating a sense of (sub)cultural consciousness. Arnold van Gennep's (1960) work on initiation rites, rites of passage, and their transitional character, is reflected in Turner's conceptualisation of pilgrimage culture. As we have seen, Van Gennep identified the tripartite nature of ritual characterised by a process of separation, transition and reincorporation. In the context of pilgrimage culture such tripartite structure is distinguished by the separation stage, which is characterised by the pilgrim's departure from profane society; the liminal phase, composed of a two-tier process of 1) transition within-the-profane-to-the-sacred and 2) transition-within-the-sacred-to-the-profane, and which represents the actual pilgrimage; and the final stage of reincorporation within the profane, or secular society (Crumrine and Morinis, 1991).

Turner's theoretical framework has been widely criticised (Werbner, 1977; Morinis, 1984; Sallnow, 1987). Fieldwork in Sri Lanka (Pfaffenberger, 1979), Morocco (Eickelman, 1976), Nepal (Messerschmidt and Sharma, 1981), North India (Van der Veer, 1984), the Peruvian Andes (Sallnow, 1981), and in West Bengal (Morinis, 1984), have all

refuted Turner's theory. Instead such research has pointed towards the integrative character of pilgrimage (Eade and Sallnow, 1991). The invalidation of Turner's model by these studies suggests not the uselessness of his conceptualisation, but the inherent limitation of a structuralist model in grasping the multidimensionality of the phenomenon. In order to overcome the simplistic dichotomy embedded in the structuralist foundation that frames the Turnerian approach, which favours the subversive character of anti-structure; and the functionalist explanation, which highlights the role of pilgrimage in reiterating the social order, we must view pilgrimage 'not merely as a field of social relations but also as a *realm of competing discourses*' (Eade and Sallnow, 1991:5). In this light, Turner's theoretical effort should be understood not as an empirical description of pilgrimage but as one of the many competing discourses attempting to grasp it. Or, as has argued Morinis (1992), pilgrimage's wealth of content impedes its analysis from a unified and recurrent factor.

Besides the empirical evidence against the experience of *communitas*, Turner's (1969) theory has also been proven flawed in its contention that pilgrimage is an experience articulated on the collective level. In fact, it has been demonstrated that pilgrimages are highly individualistic practices that covet a direct connection with the divine (Morinis, 1992). However, the applicability of Turner's theoretical framework (or discourse), when one considers that 'transcendence' and the 'divine' are experienced through the relationality of a collective of individual sexualised bodies, seems remarkably suitable to the analysis of the circuit as constitutive of a genuine pilgrimage culture. If *communitas* involves the creation of an egalitarian bonding between individuals outside of, freed

from, the normal structures of society, *and* the formation of a temporary community and field of social relations that appears as an alternative to the normal structures of society, then in the context of these mega-parties a sense of *communitas* is indeed achieved (Turner, 1969). Circuit queens enter into a great variety of social and sexual relationships taking place in anti-structure - the out of time and out of space environment created with the aid of music, drugs, decoration, costumes - and replace normal social ties by a temporary but intensive bonding in which the individual directly experiences a sense of belonging, and an affirmation of sub cultural values. The psychosocial boundaries created by the physical protection provided by these institutions against the homophobic prejudice of mainstream society is enhanced by the communal use of illegal drugs, shared behaviours, and bodily practices that reinforce group solidarity.

Pilgrimages taking place within the realm of popular culture are often related to death and heroic figures. Whilst temples, shrines, and straightforward conceptions of the divine are not essential elements of popular pilgrimages, the sacred potential of the profane world is revealed in the transformation of secular sites into quasi-religious locales. These sites provide not only a focus for the crystallisation of cultural identities that may transcend any national boundary, but also promise a potential glimpse onto the transcendent. The circuit provides its pilgrims with the opportunity to engage in ritualised emotional cathartic processes and supplies them with a route to a liminal world where their tainted social personas may be cleansed, renewed, and healed. Access to the sacred is achieved through remembrance of the dead and of the dying heroes, who constitute a significant percentage of the pilgrims. The *individual* nostalgia of the post-modern world is

exponentially magnified within the AIDS crisis (wherein the untimely death of members of so-called 'risk-groups' reaches epidemic proportions), and the longing for what might have been (and for what was in the pre-AIDS past) is thus articulated on the *collective* level. These pilgrims simultaneously enact the role of mourner, actor and observer.

The sacred in the secular world is marked by a fluidity that permits individuals to impose culturally demarcated meanings upon pilgrimage sites, which can accommodate a plurality of discourses and practices. Functioning as a 'religious void' such polyvalent ritual spaces, which contain pilgrims as a social body, traditionally derive their power from the contrasting discourses of miracle and sacrifice. 'Miracle' discourse focuses on the potential for the dramatic healing of incurable disease whereas 'sacrificial' discourse, by converging on the doctrine of the physical resurrection of the untainted body of the redemption, challenges the traditional boundaries between the physical and the spiritual and sanctifies suffering (Eade and Sallnow, 1991). Healing miracles, a major focus of traditional Christian pilgrimage centres, has become increasingly obsolete with the advent of allopathic medicine. However, allopathic medicine has largely failed the circuit queen.<sup>102</sup> Thus the forefront position of 'miracle' discourses in his pilgrimage culture. In this light, however, not only the dead but also the dying heroes of AIDS come to embody both contrasting discourses. If in traditional pilgrimage culture individualised diseased bodies represent a proximity to the sacred realm, performing a mediating role between the ideal and the human, the circuit embodies liminality *per se*. The circuit reflects the diseased state of an *entire* subcultural enclave.

Popular pilgrimages are deemed to have accompanied the relative cultural shift characteristic of contemporary religious expression in which after-life salvation has been gradually substituted for 'in-life' emotional fulfilment (Reader, 1993). In the context of the circuit, acute concerns for survival frame the idealised motive of the perfectly healthy dimensions of the gay body: its lived, its political, and its social elements. It is the pursuit of the coveted ideal that defines the sacred journey (Morinis, 1992). Even if the traditional hardships, which characterised sacred voyages of the past, have been eliminated by the accessible and efficient modes of transport of the modern age, the heretical ideal at the centre of this pilgrimage culture is today more demonised than in ancient times. The very experience of the circuit offers stigmatised and diseased bodies opportunity to embody (even if only briefly) the ideal of multidimensional health, and/or its utilisation for instrumental goals. The healing of the *lived* body - our material physicality - represents the pilgrim's hope that the experience of pain, suffering, and illness might be alleviated not only by the magical shield of a muscular body strong enough to 'trick' the virus, but also by the celebration of his very embodiment. Such a celebration is enacted during these pilgrimages through sexual behaviour, and the sheer physicality of these dance marathons. The procurement of the healing of the *political* body is articulated through the resistance against moral norms that these pilgrimages represent. The political body represents the body both as an instrument of power and as the site of struggles over power. The circuit provides an arena where 'domesticated bodies' resist internalised 'technologies of power' (Foucault, 1979; 1981).

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<sup>102</sup> Although 'combination therapy' was initially claimed as a 'cure' for AIDS, recent studies have shown that between 30% to 50% of patients will experience failure of the treatment within one year of initiation

Could it be then that these pilgrims are, by assuming the chronic (even if ultimately fatal) sick role, protesting against the social controls imposed upon them by the mainstream society that engulfs them? Illness may be a highly expressive political act, but it is often ineffective due to the inability of the diseased to make their voices heard (McGuire, 1996).<sup>103</sup> However, even if illness as political resistance represents but a palliative, it can at times occasion healing by the mere articulation of social and political contradictions. The *social* body, the physical cradle of metaphorical meanings, is dictated by dominant ideologies, socially compelled and religiously legitimised, which have the potential to inflict negative self-images, alienation and suffering. Moreover, as in the case of the ‘non-innocent’ victim of HIV infection, such ideologies can rob the individual of the validity of his own experience: infected gay men are responsible for their fate due to their own behaviour. The circuit provides its pilgrims with the opportunity to ritually realign and reinterpret body metaphors. In the process of positive re-identification with the gay body, in all its freedom and nakedness, the circuit queen is permitted a metaphorical recontextualisation of his social body and experiences a feeling of wholeness and healing:

It was the first time I ever felt proud of being gay...that huge space filled with all these beautiful, strong, powerful men. (Interview # 51)

In order to understand the nature of healing we need to distance ourselves from the Cartesian dualism of allopathic medicine, and conceptualise the self as a unitary

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(Pink Paper, 01/05/1998). See chapter six.

phenomenon constituted by the intermingling of body, mind, and society. We should regard the body as a biological entity shaped by cultural directives. This organic being, who functions on the physical, cognitive and symbolic levels of social existence, is compounded by equally significant social and environmental contexts upon which the body/mind act and are acted upon. Within such a perspective the circuit could be understood as the 'body/mind/self experiencing a spiritual transition in an emotionally and socially shared cultural practice, which is simultaneously an intense physical, mindful and socially meaning-laden journey' (McGuire, 1996:113). This perspective would suggest that circuit parties do not simply symbolise an idealised nirvana of health and equality, but that the actual dimensions of the unitary self are actively engaged in resisting and transforming power structures. 'Conscious' or 'unconscious' pilgrims circuit queens might be, but determinedly engaged in the ritualistic process of transcending a reality they wish were otherwise (Bowman, 1993).

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<sup>103</sup> In the case of HIV disease, however, patients have significantly impacted processes of 'knowledge-making' concerning their disease (Epstein, 1996). See chapter six.



## **Chapter 5:**

### **Queer Spirituality: Resisting the Demonisation of the Homosexual Body**

Nothing that is of us can be alien to our theology

(Collins, 1979)

#### **5.1.- The Spiritual Discourses of the Queer**

The pluralism encountered in the industrialised societies of the so-called developed world extends to most facets of social life. If alternative religious cosmologies continue to occupy a subjugated space in relation to the universalistic claims of the Judaeo-Christian tradition embedded in the capitalist system, the (post-modern) climate of the emerging century is one of challenge to traditional secular and religious discourses. However, despite being conducted from a multitude of subject positions, contemporary inquisitions of mainstream social structure and practice are nevertheless ultimately homogenised by their encapsulation within the paradigm of traditional heterosexuality. In Britain, the replacement of the religious by the medical model of homosexuality was widely accepted by the late 1950s (Weeks, 1990). Two decades later, the onset of the AIDS crisis revealed how easily the relative 'safety' that secularisation had apparently bestowed upon the homosexual body could be replaced: homosexuality once again met with the wrath of God (or, at least, of some of His most zealous followers). Such adverse social context reveals the persistent heterosexism of mainstream society, which frames the development of the theological reinterpretations of the experience of homosexuality that constitute the theme of this chapter.

In the present analysis I shall describe the ‘conscious’ resistance project that ‘Queer Spiritual Discourse’ (QSD) represents.<sup>104</sup> Under the umbrella term of QSD I describe the two main perspectives around which this elite-produced resistance project has based its cultural and theological production. Such perspectives I have termed ‘Queer Theology’ and ‘Gay Soul’. The two perspectives diverge inasmuch as each approaches the problem of the religiously defined axiom of the inherently sinful homosexual body from different theological paradigms. Queer Theology constitutes a queer hermeneutics of the Bible; conducted mainly by gay theologians, ministers and scholars within the Judaeo-Christian tradition, Queer Theology should be understood as an attempt to uncover ‘subjugated knowledge’, and to reinterpret biblical texts accordingly.<sup>105</sup> On the other hand, Gay Soul reflects the religious pluralism of western societies and conducts its resistance effort from within a *melange* of other religious systems that mainly borrow from the New Age as well as Eastern and Aboriginal tradition. However, these categorisations constitute definitional strategies that attempt to neatly delineate social phenomena that often overlap; they should be understood not as exact translations of complex social realities, but as analytical tools. Despite the fundamental differences in cultural content, both Queer Theology and Gay Soul merge on the level of their goals. Hence, QSD constitutes a ‘micrological’ resistance project with the objective of not only challenging the traditional religious demonisation of the homosexual body, but invalidating it.

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<sup>104</sup> The polysemous ambiguity of ‘queer’ (rather than the fixedness of ‘gay’) enables the continual deconstruction of identity; as such it more aptly captures the kind of spiritual discourse that I will be analysing.

<sup>105</sup> Such reinterpretation is conducted within a ‘contextualising’ framework, which, by rejecting any universal claims of truth, recognises that truth is a relative concept and that biblical interpretation can only be conducted in relation to specific historical and cultural contexts.

## 5.2.- Liberation Theologies

The modern social processes of pluralism and secularisation have enabled traditionally oppressed social groups to assert their own world-views, and to rationally challenge the institutional and religious cosmologies of their oppression. Radical challenges to traditional readings of the Bible have been conducted, and minority-specific hermeneutics of the Holy Book proposed: feminists, Latin-Americans, blacks from Africa and North-America, gays and lesbians have all been engaged in challenging religious legitimisation of patriarchal, eurocentric, and heterosexist systems of social organisation. As such, Liberation Theology emerged in the 1960s in Latin America where specific cultural and socio-economic configurations propelled local theologians to conduct a radical reflection on faith. As a source of theological production, Liberation Theology constitutes a coherent form of religious discourse surrounding issues of human liberation. However, Liberation Theology is not only a set of doctrines but constitutes a social movement with anarchic tendencies. As a social movement, Liberation Theology subjugates its doctrinal aspirations to the social and proposes the mobilisation of disenfranchised constituencies for collective action aimed at producing effective social change. Despite cultural and social differences, Liberation Theology can be used as an umbrella term to describe unique and distinct theological efforts of varied oppressed cultures in different societies. Such localised liberationist theologies find their differential matrices overshadowed by the commonality of their main themes, and the similarity of their social expectations.<sup>106</sup> Liberation theologies that may cut across a myriad of

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<sup>106</sup> South African Black Theology, for example, was in its origins minimally affected by Latin American Liberation Theology. However, as a social movement the Black Theology of South Africa has been constituted through the interplay between its internal cultural and socio-economic conditions and the external influence of the Latin American situation (Kretzschman, 1986).

specific cultural experiences of socio-economic oppression all endeavour to contextualise biblical texts, and provide multi-cultural, gender polyvalent basis for identification with the Holy Book. Black churches reject any interpretation of Scripture that legitimates racism, while Latin American priests are silenced for defending a socially engaged interpretation of the Bible; a queer hermeneutics of the Bible finds in the stories of Ruth and Naomi, and David and Jonathan, the two finest examples of committed love.

The emergence of an institutionalised gay subculture in the 1970s substituted the 'impoverished cultural unit' (Simon & Gagnon, 1967:183) that had represented gay life before the 1960s, where threats of impeding sanction limited 'cultural and structural elaboration' (Levine, 1992:73). This improved social situation replaced the self-loathing social networks whose primary social functions had been the facilitation of sexual contacts and the management of stigma (Humphreys, 1979). It resulted from the social movements of liberation of the Sixties whose origins can be traced to the relative moral loosening of the Roaring Twenties (Greenberg, 1988). Consequently, 'impoverished cultural units' across the western world were replaced with the establishment of a multitude of cultural, social and economic institutions attended by gay-identified individuals undergoing a process of relative socio-political enfranchisement. Such developments, along the same lines of feminism and other emancipationist movements, provided the ground upon which QSD could begin to be formulated. As such, it can be argued that such a discourse is fundamentally embedded within the wider cultural movement of debunking oppressive meta-narratives of so-called universal religious systems. A queer slant on Liberation Theology rejects the homophobic and heterosexist

ethos of the Judeo-Christian tradition, and forsakes notions that equate the AIDS crisis with divine punishment. QSD does constitute an integral element of liberation theologies, but its effect in terms of creating social change may not be analogised by some of its most successful relatives. More research is needed to assess the role of such a resistance project in the lives and subjectivities of ordinary gay individuals.<sup>107</sup>

### 5.3.- Queer Theology: resisting the Judeo-Christian tradition

#### 5.3.1. 'Texts of Terror' and the Theology of St. Aelred

Homosexual practices are very rarely mentioned in the Bible; much more numerous are the references to adultery and heterosexual fornication. There are five undisputed Biblical passages that refer to homosexual acts between males: two of them are found in the 'Holiness Code' of Leviticus (LEV. xviii. 22; LEV. xx. 13); the other three in the New Testament (ROM. i. 27; I COR. vi. 9-10; I TIM. i. 9-10). There is one passage, which occurs in St Paul's Epistle to the Romans (ROM. i. 26-27), that refers to female homosexuality. In addition, there are two passages which *could* be directly referring to homosexuality; one upon which 'homosexual significance by marginal reference' *may* be imputed; and, finally, six passages which, when translated into English, have assumed (not necessary) homosexual connotations. There are also the stories of 'Sodom and Gomorra', and of 'Gibeah', upon which 'tradition has imposed a homosexual interpretation based on *a priori* considerations' (Bailey, 1955:29). It is, however, the

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<sup>107</sup> See chapter seven for an analysis of my research as it relates to issues of the queer spiritual discourse.

story of Sodom and Gomorra in Genesis 19:1-28, which has been traditionally interpreted by religious and political institutions as the most legitimate proof of divine acquiescence to the exclusion of homosexuals from the portals of heaven.

The story is well known. When Lot parted from his uncle Abraham, he decided to settle in the infamously wicked city of Sodom, which neighbored Gomorra. The story tells how God, unhappy about the evil reputation of the twin cities, sends two angels to investigate the reality of such a claim. If true, the cities must be destroyed. Abraham, who had interceded with God for the sake of his nephew, accompanied the angels to the gates of the city. There, Lot met him and the angels. Lot urged them to accept his hospitality, and had the angels and his uncle stay in his house for the night. Upon hearing about the unusual visitors the people of Sodom and Gomorra, an unwelcoming bunch oblivious to ancient hospitality rules, beset Lot's house in order to 'know' them. Unsuccessful, the enraged inhabitants threatened them with violence and even rape. Horrified, but appeasing, Lot offered his own daughters to the eager mob. But Sodom and Gomorra wanted angels, not girls, and they refused Lot's bid for human sacrifice. These coveted angelic creatures responded by blinding their aggressive hosts. The next morning the visiting angels, angelic mode regained, rescued Lot and his family. Soon after that, God overthrew the twin cities with brimstone and fire from heaven. Sodom and Gomorra were no more.

Sodom and Gomorra is but one of many 'texts of terror' which have been used not only to terrify gay individuals across the globe, but also for political and religious

discrimination.<sup>108</sup> However, Queer Theology employs Foucauldian genealogical methods to uncover ‘subjugated knowledges’, and comes up with a reinterpretation that reveals the role of the heterosexist power system that has imbued the construction of the Sodom and Gomorra myth with homophobic elements. According to the queer reinterpretation, before the first century witnessed the Jewish philosopher and biblical commentator Philo of Alexandria offered his imagination upon such text, it had had no previous association with homosexuality. The acts of bestiality and homosexual behaviour described by Philo of Alexandria are not directly referred to in Genesis 19, and the only possible linkage of the text with homosexuality appears to be the use of the Hebrew word *yadha*. *Yadha*, which can be employed to express multiple meanings, is usually understood as ‘to have thorough knowledge of’; however, it often signifies the intent to ‘examine the credentials of visitors’. In its less utilised form *yadha* implicitly conveys sexual intercourse (Swicegood and Perry, 1990:340). In the context of the tale of Sodom and Gomorra, *yadha* is employed in order to signify the wish of their people for Lot to reveal his angelic guests so that its citizens may ‘know’ them (Wilson, 1995). Traditionally it is claimed that the term signifies a demand from Sodom’s citizens, the sodomites, to engage in coitus (Bailey, 1955).

Such ‘knowing’ might indicate an intention to rape the angels of destruction; an act of physical violence and not one of homosexual behaviour. ‘Anal phallic penetration’ was the customary ritual of welcome to trespassers of ancient societies, performed in order to

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<sup>108</sup> In her book ‘Texts of Terror’ (1984) Phyllis Tribble first used the expression in order to describe biblical passages that justified violence toward women. Subsequently, Robert Goss in ‘Jesus Acted Up’ (1993) identified analogous texts for gays and lesbians: Genesis 19; Leviticus 18:22 and 20:13; Romans 1:26-27; Corinthians 6:9; and Timothy 1:10 (Swicegood and Perry, 1990).

demonstrate subjugation (Dover, 1978). This fact illustrates the oppressiveness of traditional biblical interpretation that understands in an act of heterosexual male dominance committed against men and women alike, the divine condemnation of same-sex relationships engaged in by mutually consenting, self-identified gay individuals living in contemporary society.<sup>109</sup> In addition, further complications of an argument that asserts that Sodom and Gomorra constitute a condemnation of *homosexual behaviour* are highlighted by the fact that, besides Lot's offering of his own female offspring for such 'knowing', the subjects of such potential violence were angels who traditionally escape gender classifications. Even if *yadah* were indeed employed to convey some sort of sexual innuendo, it would be difficult to justifiably equate the condemnation of rape with the sinful nature of all other non-violent homosexual acts and relationships (Wilson, 1995).

Radical reinterpretations of biblical texts conducted by feminists and gay individuals regard the revival of the concept of friendship, expressed in the Christian doctrine of the Trinity, as the main relational basis between God and humanity. The doctrine of the Trinity in classic Christian theology constitutes the foundation of the act of creation, and is understood by Queer Theology as validation of gay relationships, not heterosexual ones, as the ideal representation of God's love.<sup>110</sup> As God's nature is expressed through connectedness with each member of the Trinity, 'Be fruitful and multiply' (Genesis 1:22-28) comes to signify not the articulation of love confined to heterosexual parameters of

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<sup>109</sup> Gay theologian Robert Goss, for example, sees no difference between the rapes of Genesis 19 and the rape of the concubine in Judges 19:92 (Goss, 1993).



the family unit but its qualitative and quantitative expansion (Cleaver, 1995).<sup>111</sup> Within this framework friendship is viewed as a form of social relationship, which abandons the hierarchical forms of relating characteristic of patriarchal Christianity, in order to favour values of equality and mutuality. Such ‘theology of friendship’ is traced back to the work of the twelfth century Abbot of Rievaulx, St. Aelred, who challenged the dualistic division of flesh and spirit espoused by the traditional Christian view of ‘platonic friendship’. His work *De Spirituali Amicitia* (On Spiritual Friendship) reflects the liberal stance of an ancient member of the Church, one of many ‘uncovered’ homosexual ancestors, who could express his views without fear of condemnation by religious authority. A tolerant Church and State are supposed to have allowed Aelred to permit the development of ‘particular friendships’ among his monks whom, within the limitation of celibacy vows, were encouraged to physically express their affection for each other (Wilson, 1995).

Queer Theology argues that the sanctioned celebration of same-sex spiritual and physical relationships by a medieval monk dismystifies the equation of homosexuality with sin (or disease), and lends a gay face to the image of God. As such, the ‘theology of friendship’ presents contemporary gay individuals with a relational model.<sup>112</sup> Interestingly, the demands of some gay and lesbian individuals to have their relationships acknowledged

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<sup>110</sup> The heterosexual person is deemed unnatural as his or her relational models are conditioned by societal approval. Only gay relationships are constituted through the expression of truly divine qualities, and not as a result of external programming (Gearhart, 1974).

<sup>111</sup> Theologian R. Cleaver understands Genesis (1:22, 28) to suggest that love should expand from couples to groups (Cleaver, 1995:66).

<sup>112</sup> Aelred’s *Spiritual Friendship* describes the importance of intimate friendships in developing a spiritual life. Aelred, who permitted the physical demonstration of affection among his monks, is generally considered by queer theologians to have entered into homosexual relationships (Cleaver, 1995).

through the legalisation of same-sex marriage are deemed to be an internalisation of the hierarchical relational modes of heterosexuals. In contrast, a relational mode that emphasises friendship, ‘expressed and nourished sexually’, is regarded by Queer Theology not only as the most favoured contractual basis for homosexual relationships but also as one of the greatest lessons gays and lesbians can teach humanity (Stuart, 1992:8).<sup>113</sup>

### 5.3.2.- Was Jesus ‘Queer’?

The ‘theology of friendship’ is ultimately embodied in the life of Jesus Christ, who is deconstructed by a queer hermeneutics of the Bible of an imposed asexuality, the social purpose of which is the promotion of ‘a moral/political dualism that subordinated women and denigrated sexual pleasure’ (Goss, 1996:69). Moreover, Christian discourse about God promoted the idea of an apathetic divine entity stripped not only of pleasure and desire but also of any passion (*patheia*).<sup>114</sup> A queer reinterpretation of christological discourse endeavours to refocus the story of Jesus through the lenses of his *basileia vision* (Schussler-Fiorenza, 1989). God’s reign (*basileia*) was the symbolic marker of the divine liberation of the people - the destitutes, the persecuted, the children and the outcasts who would inhabit the kingdom of Heaven (Perrin, 1976; McDonalds and Chilton, 1987). As such, Jesus is viewed as a radical political creature whose tactics of

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<sup>113</sup> The political analogy of this theological perspective regards marriage as contrary to the main objectives of the lesbian and gay movement, i.e., the validation of many forms of relationships within the context of a liberalised gay identity. In addition, state intervention in private relationships would not only extend the scope of the ‘gaze’, but also increase the sexual oppression of gay and lesbian individuals who would continue to choose to engage in sexual relationships outside of the institution of marriage.

<sup>114</sup> Apatheia: ‘Apathy is a form of the inability to suffer. It is understood as a social condition in which people are dominated by a goal of avoiding suffering that it becomes a goal to avoid human relationships and contacts altogether’ (Soelle, 1975:36 quoted in Goss, 1993:65).

*basileia* proposed a completely different vision of power relations (Goss, 1996).<sup>115</sup> In addition, the notion of an apathetic God is rejected through the reinterpretation of Jesus as an individual whose divinity is expressed through the sensual experience of his humanity.

The asexuality of Jesus has also been questioned by contemporary mainstream theology: because 'Jesus lived in his body, as other men do', he is deemed to have had sexual and emotional urges similar to those of other human beings (Driver, 1965:241). Yet, the sexualised Jesus is delimited by heterosexual relational modes as his sexuality is placed within a framework of heterosexual marriage.<sup>116</sup> Queer Theology reclaims Jesus' sexuality as a reflection of the divinity of same-sex desire. The argument towards the homoerotic nature of some of Jesus' sexual feelings was first articulated in the late 1960s by the Anglican canon Hugh Montefiore (Montefiore, 1969).<sup>117</sup> The debate surrounding a gay-identified Jesus was appended by the Episcopal priest, Malcom Boyd, for whom Jesus' androgynous character epitomises 'gay spirit' and the expression of liberated sexuality, and followed-up with accounts of the homoerotic nature of his relationship with Lazarus (Williams, 1992; Wilson, 1995; Goss, 1996). Such interpretation challenges traditional readings of the Bible that regard John (son of Zebedee), and not Lazarus, as Jesus' 'beloved disciple' (Eller, 1987; Boyd, 1990).<sup>118</sup> Queer Theology deconstructs the

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<sup>115</sup> Jesus' egalitarian ethos is well illustrated by the following biblical passage in Luke 22:24: 'For which is the greater, one who sits at the table, or one who serves? Is it not the one who sits at table? But I am among you as one who serves' (Goss, 1993:74).

<sup>116</sup> Phipps (1975) has claimed that scriptural evidence supports his argument that Jesus was married. Meier (1991) has challenged this view.

<sup>117</sup> *Newsweek* August 7, 1967 p.83.

<sup>118</sup> Boyd, M. (1990) 'Was Jesus Gay?', *The Advocate* [December 4, 1990 (90)].

traditional christological discourse, which by emphasising the superiority of an asexual male figure immaculately conceived legitimises oppressive structures based on gender stereotypes, and rejects notions of physical and sexual pleasure.

As Christianity came to pervade Roman civilisation, the ancient Greco-Roman techniques of self-mastery were transformed into austere mechanisms of social control that abominated pleasure and disdained the body (Foucault, 1986). The notion of the apathetic God was thus diffused. These two building blocks of traditional christological discourse (a spiritless and asexual male God) legitimised a system of social relations and institutions based on patriarchal and authoritarian values. Maleness came to be associated with 'superior rationality, spirituality and authority, whereas femaleness was considered inferior and associated with emotions, embodiedness, and sensuality' (Goss, 1996:67). Queer Theology disrupts notions of biblical validation of such social systems by proclaiming that it is in Jesus' practice of *basilea*, as well as in the expression of his divine sexuality grounded in friendship, that evidence is to be found of a radically political personage whose social utopia was much closer to the egalitarian values of 'gay spirit' than to the oppressive norms of heterosexual society.

### 5.3.3. Ancient Queers: the historical evidence

Effective revaluation of same-sex relationships within biblical texts can only take place if their existence can be demonstrated. Historical evidence, revealed by the historian John Boswell and utilised by the proponents of Queer Theology, seems to suggest that in Europe religious ceremonies that celebrated same-sex unions date back to 400 BCE, and

existed throughout the Middle Ages (Boswell, 1994).<sup>119</sup> In the Greco-Roman world there were four broad types of same-sex relationships: male slaves who were exploited by their male owners; homosexual concubines, whose main purpose was the sexual fulfilment of the master before his heterosexual marriage; and homosexual lovers, who could (or could not) consummate their relationship into a legal and spiritual bond that represented the same-sex alternative to heterosexual marriage (Boswell, 1994).<sup>120</sup> In his analysis, Boswell asserts that the modern stereotypes of Greco-Roman homosexuality are faulty historical constructs, and that the range of homosexual relationships extended far beyond 'formal, brief interactions between an older "lover" and a "beloved" who is always considerably younger and generally somewhat passive. That this was the cultural myth, at least in fourth-century Athens, is beyond doubt.' Moreover, and perhaps most surprisingly, same-sex relationships between males were inextricably enmeshed with the military and democratic apparatus of such societies, which idealised love between two men as the most 'stable' and 'heavenly' of all human liaisons (Boswell, 1994:57).<sup>121</sup>

Despite the advance of Christianity, which overshadowed all other ancient religions in Europe, social structures and relational modes continued to be largely defined by ancient custom and religion. Although eroticism and sexual love were notions contrary to the emerging religion, the sexual abstinence of the devout Christian was considered futile by

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<sup>119</sup> The Vatican and the Eastern Orthodox Church have refuted such evidence.

<sup>120</sup> Classical antiquity saw four broad types of heterosexual relationships: use, concubinage, marriage, and romance (Boswell, 1994:29).

<sup>121</sup> The stability of homosexual love between males was proposed in the Hellenistic debate *Affairs of the Heart*. It would appear that the Hellenistic debate was influenced by Plato's *Symposium*, which characterises heterosexual relationships as vulgar, and their same-sex counterparts as heavenly (Boswell, 1994:74).

the pagans, and morally questionable by the Jews.<sup>122</sup> It took Christianity one thousand years to substitute priestly celibacy, monastic community life, and voluntary virginity (even within marriage) for the biological family as the ideal of human existence.

Consequently, marriage did not become a domain of church affairs until the tenth century, and only after the Fourth Lateran Council in 1215 did the church declare it a sacrament requiring ecclesiastical involvement (Boswell, 1994).

In the East, however, marriage had become a public liturgical function for some time before 1215. The earliest Greek liturgical manuscript, *Barberine 366*, contained four types of ceremonies celebrating sacramental union, one of which consisted of a 'prayer' for uniting two men.<sup>123</sup> *Barberini 366* is not the only example of a ceremony celebrating the union of same-sex citizens from societies that existed before the twelfth century. The monasteries of Paris, Petersburg, and St. Catherine on Mount Sinai; the Greek basilian monastery of Grottaferrata; and the Vatican all celebrated the union of same-sex couples. These ceremonies continued throughout the sixteenth century and across the entirety of the Christian world, and were featured in some of the oldest Greek liturgical manuscripts known. Yet, after the twelfth century, and for reasons not well understood, Western Europe was swept by an increasingly negative attitude towards homosexuality. However, even as late as 1526, the Ottoman sultan Suleiman granted his same-sex partner, the count of Siebenburgen, the governance of half of the city of Budapest (Boswell, 1994).

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<sup>122</sup> The difference between pagan and Christian attitudes is illustrated by the small number of vestal virgins, and by their reduced obligation towards virginity. In addition, pagan virgins were offered by their parents as children and did not enter freely into virginhood. Only marginal movements within Judaism, such as the Essenes, practised sexual abstinence. Rabbinic Judaism obligated reproduction (Boswell, 1994).

<sup>123</sup> The other three ceremonies for sacramental union contained in *Barberini 336* were: two separate 'prayers' for heterosexual unions, and a ceremony for heterosexual betrothal (Boswell, 1994).

Despite the influence of Boswell's work in the articulation of Queer Theology as a resistance project, the openly gay historian has been accused of being an 'advocacy scholar' whose 'pro-homosexual' research does not stand the scrutiny of mainstream historical method (Weeks, 1980; Wright, 1984, 1989; Payer, 1984; Brundage, 1987; Wright, 1994; Broton, 1996; Mark, 1997). Critics have found issue with almost all of Boswell's arguments. In his 1994 book *Same-Sex Unions in Premodern Europe* Boswell endeavoured to set the context of religiously legitimised unions of same-sex couples in ancient times. Boswell starts by showing that marriages in Greco-Roman antiquity constituted loveless dynastic arrangements in which all members of a household were thoroughly subordinated to a free-born male. In addition, as the sexual needs of free men were often not fulfilled within the marital environment it was quite common for satisfaction to be sought outside of the blessed union. For that a whole assortment of concubines, slaves, and other lovers of either sex were easily available. The norm of classical homosexual relationships was that of an older man taking an 'active' role in the education of his younger, 'passive' boy. However, homosexual relationships between equal adults were not necessarily disapproved of. In fact, as Plato suggested in *Symposium*, homosexual relationships between two free men might constitute the highest form of friendship.<sup>124</sup>

It has been argued that several of Boswell's translations in *Same-Sex Unions in Premodern Europe* are wrong, and that as a 'tendentious' historian he conveniently

ignored the context of the ancient texts he examined (Brooten, 1996; Mark, 1997). Amongst many examples there is the apparent misinterpretation of a Greek regulation for monks which, had it been correctly translated would invalidate a central notion of Boswell's argument concerning the similarity between heterosexual and same-sex ceremonies. As such, the term *adelphopoiesis* is deemed wrongly translated; it does not mean 'same-sex' union, but a ceremony for 'brother-making'.<sup>125</sup> It does appear that the Church, especially the Eastern Churches, did officially approve and regulate the ceremony of *adelphopoiesis*, and it may have been the case that the ceremony of *adelphopoiesis* was used at times to bind together pairs of men who had homoerotic relationships. The contention is with Boswell's claim that *adelphopoiesis* was officially approved by the Church as a 'same-sex union' for homosexual liaisons between men.<sup>126</sup> Not everybody disagrees with Boswell's work (Duberman, 1980; Moore, 1981); whether one agrees or disagree the important point for my argument is that Boswell's research has been widely influential in the construction of a theology that resists the idea that to be gay is to be a sinner.

#### 5. 4.- Gay Soul: resisting homophobia

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<sup>124</sup> Although Boswell provides several examples of such relationships, he fails to mention that elsewhere, both Plato and Aristotle, insist that homosexual activities should be forbidden in an ideal community (Scroogs, 1983).

<sup>125</sup> The correct translation should have been 'Monks are forbidden from sponsoring children at baptism, serving as the best man at a wedding, or taking part in a rite of', but Boswell's version reads 'Monks must also not select boys at baptism and make same-sex unions with them' (Boswell, 1984:29; Norton, 2002:46).

<sup>126</sup> Contrary to Boswell's claims, there is evidence that in the Balkans, where the ceremony persisted after dying out elsewhere, an *adelphopoiesis* celebrated several kinds of 'brother-making' unions: between a man and a woman, between several men simultaneously or between one man and several others serially (Norton, 2002).



Whereas Queer Theology tends to emphasise the similarity of the metaphysical dimension of the human condition of homosexuality, the theological efforts I have identified as *Gay Soul* are articulated outside of the Judeo-Christian tradition. The dimensionality of traditional religion that allows for the unity of Queer Theology is not analogised in the plethora of spiritual discourses characteristic of the ‘religious supermarket’ of the pluralistic societies of the West. Thus, *Gay Soul* is usually articulated within an assemblage of specificity that renders a unifying analysis of the spiritual experiences of homosexual men and women simplistic and erroneous. Moreover, extensive work on lesbian spirituality, which has been heavily influenced by feminist theology and hermeneutics, has been conducted elsewhere.<sup>127</sup> Another clarification that needs to be made is that the focus of my analysis is not the countless spiritual practices of urban gay men, but the recurring themes observable across the realm of spiritual techniques and practices in which such individuals engage in. Until recently, spiritual self-questioning in gay communities was not really prolific. However, the AIDS crisis has given it considerable impetus as many of the members of the subculture, besieged by death and suffering, have sought answers for their predicament in the spiritual realm.

5.4.1.- Reclaiming the Shamanic Past

By proposing the notion of a *separate* spiritual identity, *Gay Soul* shifts the hierarchical patterns of social interaction between gay selves and mainstream society by positing that only through the realisation and appreciation of the unique attributes of an *essentialist*

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<sup>127</sup> See, for example, Gearhart and Johnson (1974).

spirit can gay-identified individuals realise their full human potential. In this process of spiritual and social re-empowerment, contemporary homosexual identity is linked to a mythological past enchanted by spiritual predecessors embodied in the gender-bending, homosexual individuals of traditional societies upon whom shamanic powers were once bestowed (such as the *nadle*, 'the changers' of the North American Indian tribe Navajo). The shaman of traditional societies occupied a specialised role that was conferred upon him or her after profound experiences of 'sickness, dreams and ecstasies' had been endured. Such individuals were initiated into rituals where techniques of the sacred were learned, and special status as spiritual guides and agents of transformation thus achieved (Eliade, 1964).

Gay Soul argues that only the gay-identified individual is able to partake, on a (sub)culture-wide level, in the shamanistic inner journey of symbolic death and rebirth. Such transformation is experienced twice: first in the 'coming-out' process whereby the old, specious social self sheds its skin in order for the rectified, self-identified gay individual to be (re)born; second, in the fundamental association of AIDS with the subculture's identity, the shamanistic journey is experienced both on the individual level and on the socio-cultural dimension through collective representations of the health crisis. Generally, the deep experiences of pain and alienation internalised during the process of growing-up as the 'other', in conjunction with the unparalleled levels of stigma and suffering occasioned by AIDS, endow gay individuals with a 'knowing' that is unique and exclusive to their (sub)culture. Gay Soul rescues gay individuals from patriarchal damnation and unrepented death by bestowing upon them a *luminous* quality of being, an

'otherness' that accentuates the gifts of compassion, empathy, healing, interpretation and enabling (Thompson, 1987). More specifically and expressly modelled on the figure of the Native American shaman *berdache*, the quasi-religious group Radical Faeries was established in 1979. The berdache was usually a man who exhibited feminine behavioural traits. However, the less frequent instance of the female berdache, a woman who presented masculine behaviour, also existed. The philosophy of the Radical Faeries focuses on the transformative role that gay individuals perform inasmuch as they constitute a third gender. Its founder Harry Hay is the same man who established the first American gay political organisation, the Mattachine Society, thirty years earlier.

Gay persons are separated from the rest of society not only by their deviant sexuality but also by the intensity of their own human and spiritual experience: thus, they occupy a liminal social position from which to enlighten the rest of society. The inherent liminality of homosexuality - produced by its location somewhere in between, as well as beyond, mainstream sexual identifications - is intensified by an epidemic that places gay bodies at the very frontier of life and death. It is not only the soul of the gay individual that finds salvation but its repository as well. Despite, or perhaps as a result of, the gay body's continual association with sin and disease, *Gay Soul* repeatedly and emphatically presents it as the sacred repository of divine essence. As such, the gay body functions as a metaphor for the subculture's proposed earthly mission of saving the planet through mediating, restructuring and reinventing the social structures which regulate the relationship between the physical and the social body. In linking the secular process of 'coming-out' to an inner process of shamanistic spiritual discovery, *Gay Soul* contends

that philosophical and metaphysical answers to the condition of being gay cannot be answered solely with reference to the social level. Sexual self-acceptance, within the context of 'safer-but-free' discourse of the AIDS generation, represents the only pathway to the integration of flesh and spirit without which the social and spiritual potential of the gay self cannot be realised.<sup>128</sup> Salvation is thus articulated both on the personal and society-wide level.

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<sup>128</sup> In the beginning of the AIDS epidemic cultural gay discourse preached safe sex and the reduction of sexual partners and encounters (if not monogamy) as the most efficient prevention against HIV. Such discourse has been subtly transformed into one of 'safer sex' (the parameters of what constitutes 'safe' sex have not only been widened but also questioned) without its pairing with a reduction in sexual activity.

## Chapter 6

### AIDS Dissent: Resisting (Re)medicalisation

I'm afraid you've got an alternative illness

(NB)

#### 6.1.- AIDS Activism: setting the ground for future resistance

In his book *Impure Science*, Epstein (1996:14-19) analyses the social processes through which the opposing knowledges and 'truth-claims' about HIV and AIDS have been constructed. In attempting to delineate the 'pathways' through which certainty has been established, and how the nexus knowledge/power has been articulated in the context of the American health crisis, Epstein argues that knowledge about AIDS has emerged out of 'credibility struggles'. Scientific credibility - 'the capacity of claim-makers to enrol supporters behind their argument, legitimate those arguments as authoritative knowledge, and present themselves as the sort of people who can voice the truth' – has been problematised by the political nature of HIV/AIDS. Multilateral 'credibility struggles' have broadened the spectrum of potentially plausible pathways, as well as the range of pertinent truth-claimers, and thus muddled the boundary between 'scientific' and 'folk' knowledges to the point where 'the very mechanisms for the assessment of credibility' are being questioned. Competing cultural narratives that often overlap, subvert and/or reinforce each other surround acquired Immune Deficiency Syndrome (AIDS). These multiple stories, constructed and compounded upon that traditionally meaning-laden entity, the body of the male homosexual, have generated an 'epidemic of signification' (Treichler, 1988). As such, the synchronous dispute over the biological, social, moral and

etiological dimensions of AIDS can be grouped into two main areas of contest: *causation* and *treatment*.

In the beginning of the AIDS crisis networks of local initiatives and political action groups emerged within 'gay communities'. Such grass-root organisations played a very important role in the unfolding of the (localised) epidemic inasmuch as they constituted the only source of support for those first affected by the syndrome. Moreover, in their strongly critical stance on governmental and media attitudes these organisations provided a basis for the development of AIDS activism, or the AIDS Movement. AIDS activism constitutes the ground for what has been called 'politics of treatment', i.e. the contested political, socio-economic, and scientific processes, through which allopathic anti-HIV treatment has found its way into the bodies of HIV-diagnosed individuals. Although this politics of treatment was not the first in challenging medical authority, no other group of treatment-activists has ever been able to achieve such a degree of modification in the politics and methodologies of scientific research and practice. AIDS activism has altered the conduct of clinical research by changing the 'ground rules for the social construction of belief' through the questioning of the processes via which medical trials are interpreted. As such, AIDS activism has occasioned a relative but substantial modification in the stringent rules of the American 'gatekeeper' federal body Food and Drug Administration (FDA) (Epstein, 1996:181-329).

The resistance project embodied by such a 'politics of treatment' represents a highly successful initiative inasmuch as it has not only fundamentally altered processes of

scientific research, but has also simplified access routes to allopathic treatment. By resisting established norms of scientific conduct, the HIV-positive activists of the AIDS movement have achieved unparalleled successes in producing significant social change. As such, these individuals have been able to directly benefit from the articulation of their desired goal of ‘drugs into our bodies now’ (Epstein, 1996). In the present chapter I shall focus on another ‘micrological’ strategy of resistance. The Dissident Movement also concerns itself with scientific issues around HIV/AIDS, but its transformative goals go well beyond issues of easier access to treatment. The dissident movement claims that the scientific procedures that have established the truth(s) about AIDS rest on shaky ground. Consequently, the movement constitutes a radical initiative that challenges the very scientific notions which have constructed the knowledge(s) of HIV and AIDS. However, it is important to note that as a sociological analysis the present chapter makes *absolutely* no claim on the scientific credibility or veracity of either the medical or the dissident ‘truth-claims’. My goal here is simply to analyse the social processes through which such claims are accepted, rejected, or contested.

6.2.- Is it Cancer? Is it GRID? No, it’s AIDS: what a difference a name makes

The contraction of the severe pneumonia caused by *Pneumocystis carinii* by five ‘active homosexuals’, announced by the CDC’s *Morbidity and Mortality Weekly Report 30* on the fifth of June of 1981, rang the first alarm bells of the impending AIDS crisis. These five men had a lot in common: they all lived in the American state of California; they were all young (twenty-nine to thirty-six years old); they all suffered from candidiasis;

they were all infected with cytomegalovirus (CMV); they all used 'poppers'.<sup>129</sup> One of them was an intravenous drug user, and three of them showed a significant depletion in their T-lymphocyte population (in the other two, lymphocyte population had not been studied).<sup>130</sup> Three of these individuals had been patients of Joel Weisman, a Los Angeles physician whose clientele was mainly composed of gay men. Since late 1979 Dr. Weisman had noticed a marked increase in cases of a mononucleosis-like syndrome among his gay patients. Such a syndrome was characterised by fever, weight loss, and swollen lymph nodes. These patients also suffered from diarrhoea, and from oral and anal candidiasis. Initially, Weisman thought his patients were suffering from cytomegalic disease, which since 1956 had been linked to CMV. Although it was known that 94% of the Californian homosexual community was infected with CMV at the time, the widespread virus only caused fatal lesions in immunologically impaired newborns. There was no effective treatment for the mononucleosis-like syndrome, but Weisman's patients had so far recovered spontaneously (Grmek, 1990).

In February of 1981 one of Weisman's patients did not spontaneously recover from the fevers and the diarrhoea, and was hospitalised in the immunology division of the University of California at Los Angeles (UCLA) hospital. Once this patient had been hospitalised, it was found that his lymphocyte profile was severely damaged; PCP was

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<sup>129</sup> Candidiasis is a benign fungal disorder of the mucous membranes. Cytomegalovirus (CMV) is a virus that belongs to the herpes virus family; the great majority of American homosexuals had been infected by it before the onset of AIDS (Grmek, 1990). 'Poppers' (a reference to the sound of breaking made when the original medicinal ampoules were cracked open) are nitrites, a salt or ester of nitrous acid, that were first used to dilate blood vessels in the treatment of angina. 'Poppers' were (and still are) widely used as aphrodisiac inhalants. The sale of 'poppers' has been banned in the USA, but in the UK and Europe it continues to be widely available (Shenton, 1998).

<sup>130</sup> See discussion of T-lymphocyte cells CD4 and CD8 in 6.4.2.



also diagnosed. Soon it was discovered that another four gay men, with exactly the same diagnoses of Weisman's patient, had been recently hospitalised in the Los Angeles area. The severity of the disease frightened the doctors (and the patients). Despite the intensive treatment directed mainly against the PCP, two of them rapidly died, and the other three showed no signs of recovery. The first 'active homosexual' died in March of 1981. He had been diagnosed with Hodgkin's disease in 1978, and treated successfully with radiotherapy. Yet, at autopsy no trace of Hodgkin's disease was found. Had the *ante mortem* diagnosis been wrong? What indeed had caused the fierce death of such a young man? The CDC report 30 speculated that as 'the occurrence of pneumocystosis in these five previously healthy individuals without a clinically apparent underlying immunodeficiency is unusual' there must have been 'an association between some aspects of homosexual lifestyle or disease acquired through sexual contacts and *Pneumocystis* pneumonia in this population.' Infection by CMW was hypothesised as the most probable etiologic cofactor (quoted in Grmek, 1990:5).

As soon as 1979 the rumour that a 'gay cancer' was spreading among the homosexual communities of New York and San Francisco began to spread. Dr. Linda Laubenstein of the haematology division of New York University's Medical Center had, in the fall of 1979, diagnosed Kaposi's sarcoma (KS), a rare form of skin cancer, in a young homosexual man. Soon after that another case, again in a young homosexual man, was recognised in the Brooklyn Veterans Administration (VA) Medical Center. Interestingly, both patients had friends in common. By March of 1981 eight cases of an aggressive form of this sarcoma had been identified in three New York hospitals. Still, the

appearance of eight cases in two years in a city as huge and diverse as New York would not necessarily raise many eyebrows. Until then KS had been a relatively benign chronic disorder that invariably afflicted mostly (90%) older males of specific ethnicity.

However, these eight cases were completely anomalous: they were acutely malignant (of the first eight diagnosed individuals four were already dead), and they were all in homosexuals. In San Francisco, the first diagnosis of KS was made in April of 1981.

*Morbidity and Mortality Weekly Report* 30 of July, 4 1981, entitled 'Kaposi's sarcoma and *Pneumocystis* pneumonia among homosexual men – New York City and California', informed the medical community that since early 1979 KS had been diagnosed in twenty-six men, twenty in New York and six in California. Of these twenty-six men eight had died in less than two years; twenty-five were white; six suffered from pneumonia (PCP pneumonia in at least four); four from toxoplasmosis of the central nervous system; one from cryptococcal meningitis; twelve tested positive for CMV (the other fourteen had not been tested); and none of them was heterosexual (Grmek, 1990).

Initial medical theorising about the syndrome had been framed by the notion that it was *not* an infectious disease. The first time such a model was proposed was in an article published in the *New York Times* on July 3, 1981. In his 'Rare Cancer Seen in 41 Homosexuals', Dr. Lawrence Altman, medical reporter for the newspaper, first articulated what would arguably become the most common theme in mainstream media coverage of the syndrome. A highly sexualised life-style, or a sexual promiscuity responsible for a succession of sexually transmitted infections, seemed to be the strongest

link between male homosexuality and the disease.<sup>131</sup> The plausibility of the ‘immune-overload’ hypothesis was grounded on the appearance of the syndrome (mainly) among homosexuals.<sup>132</sup> However, the implicit assumption that the new disease was *essentially* associated with (homo)sexuality related to the notion that the promiscuity of homosexuals was inherently linked with (the) illness. In addition, the notion of a ‘homosexual hazard’ in disease causation, as well as the reported increase of drug use among gay men, was deemed sufficient to explain why the syndrome was taking hold of such a social group at that specific time.<sup>133</sup> As such, the ‘immune overload’ model, grounded on the normalising function of an epidemiological science that ignored heterosexual cases of AIDS, was initially favoured over the hypothesis of a single infectious agent.

The problem with this hypothesis, also known as ‘antigen overload’, was that it did not explain why the apparently new syndrome had not affected homosexuals of other eras. Moreover, by concentrating on the health hazards of gays in the ‘fast lane’ the ‘immune overload’ hypothesis failed to extend its aetiological framework to include other, soon to be significantly affected, ‘risk-groups’. The ‘promiscuity paradigm’ would have seriously detrimental consequences not only for the public perception of homosexuals, but also for

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<sup>131</sup> At this point, lesbians’ exclusion from the syndrome was deemed to be the result of a sexuality much less ‘promiscuous’ and much more contained than that of their male counterparts (Epstein, 1996).

<sup>132</sup> One of the central voices of the ‘immune overload hypothesis’ was the community doctor Joseph Sonnabend, whose practice in New York’s Greenwich Village focused on the treatment of sexually transmitted diseases of male homosexuals. Such a bombardment to the immune system, in conjunction with drug abuse, was deemed to be the cause of the immune collapse observed in the affected homosexuals. (Epstein, 1996).

<sup>133</sup> See 6.5.3.2. for a discussion of the notion of the ‘homosexual hazard’.

the self-conceptualisations of homosexuals themselves (Epstein, 1996).<sup>134</sup> The ‘immune-overload’ hypothesis lost ground when, in the December 10, 1981 issue of the *New England Journal of Medicine*, Gottlieb et al described the appearance of the disease in two exclusively heterosexual males; in one of them CMV had been found in the sperm. It was hence hypothesised that repeated reinfection with CMV was the cause of destroyed immune function. However, as it was a well-established fact that most American homosexuals were infected with CMV this hypothesis was also inadequate in explaining the syndrome. A cofactor, ‘the veritable cause’, had to be the culprit. Another aetiological model for the disease was thus proposed: a multifactorial model where equal weight was given to the role of infection, drug use, and genetic predisposition.<sup>135</sup> The diagnosis of the syndrome in heterosexual individuals (8% of total cases) suggested a role for blood in the transmission of the infectious agent. It seemed increasingly plausible that the infectious route was similar to that of the hepatitis-B virus (Grmek, 1990:15).<sup>136</sup>

The notion that Acquired Immune Deficiency Syndrome (AIDS) was probably transmitted by a viral agent through the blood system was strengthened by the

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<sup>134</sup> Chapter seven explores the issue of how such conceptualisations affect the construction of the homosexual identity within the context of my empirical data.

<sup>135</sup> This multifactorial model, however, could not explain what kind of chemical substance homosexuals were more exposed to. ‘Poppers’ was utilised by many, but no evidence existed of the role of nitrates in the destruction of the immune system. Also, it was equally difficult to explain how repeated reinfection could exhaust the immune system; the notion that semen, when inserted into the rectum, might act as an immunosuppressant was first proposed (Gmerk, 1990).

<sup>136</sup> The term virus was first employed in the nineteenth century to ‘describe any substance capable of multiplying within an organism and making it sick.’ It was applied to all pathogens. In 1903 Emile Roux published a review of the nine pathogens known which were ‘inframicroscopic’. The term virus, subsequently only applied to these ‘so-called invisible microbes’, refers to pathogens that can reproduce like other like forms when in contact with appropriate living cells. As such, viruses are fundamentally different from bacteria. Bacteria live off their host, but have their own metabolic and reproductive mechanisms. Viruses are absolute parasites, which reproduce through foreign cellular elements (Grmek, 1990:49-50).

identification of the syndrome in haemophiliacs in the summer of 1982. Haemophilia constitutes a rare hereditary bleeding disorder. Factor VIII, the blood-clotting agent injected in haemophiliacs to treat their condition, is filtered to remove bacteria, fungi, and protozoa. With all the known pathogens removed from factor VIII the causal agent could only be a virus. A viral hypothesis for AIDS had been favoured from the beginning, and the notion that an animal virus had become pathogenic to humans seemed plausible.<sup>137</sup> It was hypothesised that pigs brought from Angola by Cubans might be responsible for AIDS, but AIDS patients tested negative for these agents. Whatever was causing AIDS nobody knew but the frightening fact was that by late 1982 the syndrome had begun to spread among heterosexuals. However, most such heterosexuals belonged to the 'Five-H Club'; an unenvied collective composed of Haitians, heroin addicts, haemophiliacs, and hookers.<sup>138</sup> As such, so far AIDS really afflicted only 'marginal' groups, stigmatised *a priori* by deviant behaviour, ethnicity, or genetic flaw.<sup>139</sup> The discovery of HIV would not happen until 1984 but by May of 1982 the CDC issued a protocol hypothesising that the new syndrome was a sexually transmitted viral infection. The causative agent was postulated to be 'a common virus producing new effects as a result of certain environmental factors, or one of several novel agents, e.g., mutant or recombinant strains of human or animal pathogens' (Grmek, 1990:32).

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<sup>137</sup> CMV had seemed as the most likely culprit, but also the Epstein-Barr, which causes mononucleosis and Burkitt's lymphoma in Africans virus, had been suspected (Grmek, 1990). The problem with the attribution of AIDS to infection with CMV, or with Epstein-Barr, was that both were well-established viruses with well-known pathological manifestations. Such a fundamental change in their disease-causation properties would virtually amount to the birth of a completely new virus.

<sup>138</sup> In 1982 researchers from the University of Miami noticed that a number of Dade county residents presented the symptoms of AIDS. None of these individuals were homosexual, or addicts; they were all, however, Haitian. Later it was established that many such Haitians had entered into homosexual relationships not by personal preference, but due to economic necessity (Grmek, 1990).

In the beginning of 1982 the 'gay cancer' had been identified in fifteen American states, by the end of that year AIDS had become a global 'epidemic' present in thirty-three countries (Garfield, 1995). The public perception of the syndrome had evolved from a disease of poorly regarded minorities to a potential threat to mainstream society. The first allopathic therapeutic response would not emerge until two years after the discovery of HIV in 1984. Consequently, for the first three years (at least) of the health crisis AIDS patients and the possibly at-risk population of the 'worried-well' had to look elsewhere for at best a 'cure', at worse a 'palliative' (Hay, 1984).

6.3.- Holism and AIDS: beginning to resist the medical model

6.3.1.- The Role of AIDS in the Advancement of Holistic Medicine

The anthology of aetiological speculation surrounding the looming prospects of the AIDS threat was abruptly brought to a halt in 1984. That which the religiously-inclined had interpreted to be the prophesized juggernaut of doomsday was in fact just a virus. However, simple as that virus might have been its isolation did not translate into a relatively efficacious treatment until the development of Highly Active Antiretroviral Treatment (HAART) twelve years later.<sup>140</sup>

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<sup>139</sup> 'Innocent victims' of the disease, i.e., recipients of blood transfusions and newborns infected in utero, were excluded from such undesirable membership (Grmek, 1990:32).  
<sup>140</sup> Only with the introduction of HAART in 1996 did the medical system finally devise a 'truly important' therapy for HIV and AIDS (Standish et al, 2002: xiii).

The first Federal Drug Administration (FDA) approved antiretroviral drug for HIV infection was Zidovudine (AZT). The actual benefits of AZT were highly contested, and many critics argued that AZT was not only worsening the disease but hastening the deterioration of the immune system and causing death (Hodgkinson, 1996; Epstein, 1996).<sup>141</sup> Treatment with AZT and AZT-like drugs (known as nucleoside analog drugs) remained the mainstay of HIV medical treatment until the development of antiretroviral therapy (ART) in 1996.<sup>142</sup> ART involved the combination of two or three drugs in the treatment of infection; an increase not only in the quantity of the ingested drugs but in their quality as well. A newly developed antiretroviral class of drug, the powerful protease inhibitors (PI), had been developed and was used in the new ‘combination therapies’, commonly referred to as ‘drug cocktails’. ART soon evolved into HAART, a ‘cocktail’ of as many as four different types of antiretroviral drugs, which should be

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<sup>141</sup> AZT emerged out of the effort by the American National Institute of Health, the so-called VirusCancer Program of the 1950s and 1960s, to develop a chemotherapy to fight cancer. AZT, invented in 1964 under the VirusCancer program, was one such drug. When AZT was tested on cancer-ridden mice it failed to cure the cancer, and further research on the compound was abandoned. The drug, however, did destroy all the rat’s healthy growing tissues, and they all died from extreme toxicity. AZT, a DNA terminator, suffocated all cells, cancerous or not. When HIV was identified, the drug was rediscovered in the shelves of its manufacturer, Burroughs Wellcome. The political pressure of AIDS activism for a quick solution facilitated the FDA approval of AZT without the enactment of its usual stringent scientific procedures (Cohen, 1987; Lauristen, 1990). The claim that AZT actually caused death remains controversial. However, AZT does cause anemia, peripheral neuropathy, and serious gastrointestinal complications (Standish et al, 2002). Moreover, symptoms attributed to HIV infection can be caused by consumption of AZT (Kremer et al, 1996).

<sup>142</sup> AZT, also called retrovir or azidothymidine, is used to block the enzyme reverse transcriptase, which the HIV virus is thought to use in order to convert viral genes in DNA messages inside the nucleus of white cells. Although the inefficiency of AZT in treating HIV infection was suggested by the highly contested Concorde trials, many remained unconvinced of the drug’s harmfulness (Hodgkinson, 1996; Epstein, 1996). Critics argue that AZT is a highly toxic drug absorbed through the DNA gamma-polymerase into the energy centres of *all* body cells, the mitochondria. In addition, AZT is perceived amongst many HIV-infected individuals to be highly toxic, and to have been responsible for many of the deaths attributed to AIDS. ‘Combination therapy’, which uses a combination of new protease transcriptase inhibitor drugs has been heralded as a new cure. Since 1995 ‘improved therapeutic regimes and developments’ have allowed the shift from the monotherapy of AZT to the ‘combination therapy’ of protease inhibitors. As such, the ‘management and monitoring’ of HIV patients has undergone fundamental changes. The new approach, unlike reverse transcriptase inhibitors such as AZT, blocks HIV protease, which is used by the virus in

taken before the development of any symptoms. The medical system's inability to deliver a substantive palliative to the greatest health threat of modern times for the fifteen years that lapsed between 1981 and 1996 caused a serious questioning of orthodox medicine as a universal model of healing. Hence, the 'void' that opened when medicine failed was, to a certain extent, filled by the alternative or complementary medicine paradigm. These unorthodox medical systems did not claim to be able to heal AIDS; what they claimed to offer was a comprehensive approach that would concentrate on the 'healing' of the 'person' rather than the 'cure' of the 'patient'. The new medical system, moreover, offered hope when the 'HIV=AIDS=death school of thought seemed endemic in conventional medical settings', and acceptance at a time when most AIDS patients were treated as pariahs (Standish et al, 2002:1). As such, many HIV-infected individuals searched for salvation, and resisted the demise of their allopathically-condemned lives, in the hands of 'holistic' healers whose very existence was a direct outcome of the New Age Movement.

6.3.2.- The New Age: a time for healing

The New Age Movement constitutes a blend of pagan religions, Eastern philosophies, and occult-psychic phenomena. The movement's ultimate goal is the transformation of the self and, consequently, of society as a whole (York, 1995). As an international social movement the New Age emerged in the late 1960s. However, this modern movement is more adequately conceived as the latest manifestation of the 'cultic milieu'. The 'cultic

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assembling virus particles from building blocks made inside cells. However, resistance often occurs and 'combination therapy' is often also ineffective (Batsis, 2000:22).



milieu' bloomed with the Enlightenment, especially after Protestantism and the first major movements of religious sceptical thinking had destroyed any plausible remnants of medieval magic. Such metaphysical and occult traditions have traditionally accompanied Christianity (Campbell, 1972; Melton, 1991). The scientific thought of the eighteenth and nineteenth century provided fertile ground for the 'cultic milieu', whose leaders eagerly adopted enlightened ideas of natural law and evolution to create a new alternative spiritual cosmology.<sup>143</sup> Modern New Age metaphysical practices, whose western genesis can be traced to the ascendancy of Eastern religion and transpersonal psychology in the 1960s, trudged on to become a successful movement that reflects non-conventional forms of religiosity. These unusual expressions of religiosity are articulated through loosely connected networks of ideologically related groups and organisations.<sup>144</sup> The decentralised movement is concerned with ecological issues, holism, empowerment politics, and new understandings of education and of citizenship. Yet, the New Age's primary focus is the transformation of the self through healing.

New Age transformation comes in the form of healing: healing of the body, mind, of relationships, as well as of the effect of spiritual traumas. These unorthodox healing modalities are often procured after the failure of physicians of the more culturally

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<sup>143</sup> Examples of early metaphysicians whose work was heavily based on scientific ideas include Swedenborgianism, Mesmerism, and Theosophy. Emanuel Swedenborg, one of Sweden's leading scientists, the first to hypothesise the nebular origin of the universe, analysed the relationship between the material and the spiritual word through his occult practice of Swedenborgianism. Mesmerism was the creation of the Viennese physician Franz Anton Mesmer who attempted to articulate a scientific model of a healing power stemming from sacred spiritual energy. The Theosophical Society, founded at the end of the nineteenth century, combined the latest scientific findings and the principles of the metaphysical movement in order to elaborate a pseudo-scientific world cosmology (Melton, 1991).

<sup>144</sup> More than ten million Americans draw on resources provided by the New Age movement. In Britain there are at least thirteen New Age publications whereas in the United States at least one hundred such magazines exist (Heelas, 1996: 113).

accepted variety, be they medical doctors or psychiatrists. As the New Age Movement developed, it accepted into itself a concurrently developing movement that was taking a fresh look not only at traditional alternative healing arts, but at the possibility of treating conditions with which orthodox medicine and Freudian psychiatry were having the most difficulty. Many of these alternative medicines had ‘a common ideological base and shared common beliefs with the New Age Movement, hence their merger seemed logical’ (Melton, 1991:169). As such, the central idea which linked the holistic health movement and the New Age was the notion of self-responsibility. The individual self is understood as entirely responsible for his or her actions, and for the necessary steps in order to achieve a transformation, an improvement, a healing of one’s life.<sup>145</sup> The New Age might have started off as a utopian movement typical of the 1960s whose long-term influence might have been analogised as an ephemeral spiritual Woodstock; yet, its offshoot has had a considerable effect in altering notions of health throughout the western world.

6.3.3.- The Growth of Holism

Since the 1970s ‘many holistic health methodologies have enjoyed a marked increase in acceptance among the established medical community’ (Melton, 1991:170). Holism had

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<sup>145</sup> The notion that the individual is responsible for his/her own disease contains the possibility for the healing of disease as long as the person correctly modifies whatever patterns of behaviour, and/or removes the physical blockages, which are impeding the presence of health. Especially in the early years of the health crisis this was a very encouraging perspective to AIDS patients who had been left with no clue not only about what caused the disease but also on how to palliate it. On the other hand, the same notion of self-responsibility could also mean that gay men were responsible for their plight due to their inherently warped characteristics, and as such deserve their fate. The work of Louise Hay, a spiritual healer from Los Angeles who wrote the immensely popular book ‘You Can Heal Your Life’, attracted a great following of gay men in the late 1980s. Her approach offered AIDS victims and what she called the ‘worried well’ the hope that by changing thought patterns healing could occur. At the same time, Hay’s work also attracted a lot of criticism for ‘blaming the victim’ (Hay, 1984).

been a debated concept within the philosophy of science much before the holistic health movement, spurned by a number of serious books on the emerging concepts of health, emerged in the late 1960s (Dubos, 1968; Montagu, 1971; Carlson, 1975). The emergence of these new (in the West) conceptions of health translated into the appearance of a number of holistic health centres whose foundations arose from the free clinic movement of the 1960s.<sup>146</sup> The first holistic health centre, modelled on the Greek healing temples of *Aesculapius*, the Greek god of healing, was founded in California in 1958. In Britain, the ground was also fertile for the evolution of the holistic health movement; in 1959 the Westbank Healing and Teaching Centre was founded in Scotland and the Naturopathic Research Group established in England. In 1974 an organisation dedicated solely to the research and development of natural therapies, the Healing Research Trust, was started in Surrey. The turning point for the movement, however, was the founding of the American Holistic Medical Association (AHMA) in 1978 (Melton, 1991:169-173).

The evolution in western conceptions regarding 'alternative' medicine reflects the unexpected process of enfranchisement that such non-western systems underwent in the 1990s. In the 1970s and 1980s these disciplines were mainly provided as an alternative to conventional health care and hence became collectively known as 'alternative medicine'. The medical system initially viewed such systems of healing as an exotic and primitive moil of notions which would stand no ground under the scrutiny of scientific methods. However, as an increasing number of patients – especially HIV patients – continued to resort to these obscure systems of healing, the initial disdain which characterised most of

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<sup>146</sup> Holistic health clinics differed from free clinics inasmuch as the latter were physician-centred and the former client-centred. The client-centred approach enabled patients to pick and choose among all the

the attitude of western medicine evolved into a more positive stance of co-operation.<sup>147</sup> As such, HIV physicians, whose many patients were also avid consumers of ‘alternative’ or ‘holistic’ medical systems, became increasingly aware of the many benefits bestowed upon their patients by these previously unfamiliar healing systems. Thus ‘alternative’ medical systems began to be utilised in conjunction with what now became known as ‘complementary’ medicine, a term that developed as the two systems began to be used alongside (to ‘complement’) each other. Such relational shift, where the understanding of ‘complementary’ or ‘alternative’ medicine (CAM) has evolved from the subjugated relation between unconventional and conventional healthcare to a categorisation of the unconventional disciplines themselves, has produced what is now viewed as a legitimate system of healing.<sup>148</sup> Hence the emerging integrative medicine movement was spawned.<sup>149</sup> The full integration of holistic and allopathic medicine – the ‘integrated care model’ – is currently still just a vision (or a mirage rather). However, that such a possibility can even be envisioned attests to the influence of the New Age movement where a legitimised CAM represents the movement’s most fruitful derivative (Melton, 1995).

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available treatments (Melton, 1991).

<sup>147</sup> 70% of HIV-diagnosed individuals in the United States use some form of alternative medicine to treat their HIV disease (Standish et al 2002:xiii). One in five people in the UK use some form of complementary medicine (Wright, Johnston, and Bennet; 2003).

<sup>148</sup> 16% of GPs in Britain say that they have prescribed some type of complementary medicine in their careers (Wright, Johnston, and Bennet; 2003).

<sup>149</sup> The motion towards integrative medicine has been thrust forward by health consumers who are beginning to demand that many complementary and alternative medicine (CAM) practices be included in conventional health settings, be they within the parameters of a nationalised health service like the NHS or privately organised and paid for like in the US. However, as an emerging movement the goals of the integrative medicine movement are far from being neatly defined. Does integrative medicine aim at providing patients with multiple modalities, or should it constitute a collaborative effort between two

#### 6.3.4.- Holistic Health and AIDS: practicing what it preaches

Holistic or alternative medicine is grounded on the essential principle that dis-ease is a product of some kind of imbalance in the three dimensional structure that constitutes a human being: the physical, the emotional, and/ or the spiritual dimensions. Patients are viewed as people not as a collection of impersonal symptoms. As such, living systems constitute a gestalt and no disease can be reduced to its physical symptoms. Holistic medicine became a buzzword for any therapeutic technique which did not fit the mechanist conception of the human body espoused by western medicine. To be truly holistic a therapeutic strategy must include a combination of practices which address the physical, emotional, and spiritual requirements of each particular individual. Founded on the conception of human beings as an integral component of nature, and of a nature constantly engaged in a flux of rebalancing and regeneration, holistic medicine argues that dis-ease will take hold when nature and its processes are warped. Analogously, if the 'life-energy' or 'vital energy' is blocked or tainted by unnatural antigens or products, as well as by emotional or spiritual distortions, health may only be re-established once these physical or ethereal blocks have been cleared. Blockages are removed through a plethora of techniques, many of which come together in 'naturopathy', a holistic system which uses healing practices limited to natural means. Such techniques and their associated remedies - be they nutritional substances, body manipulation, psychological techniques,

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independent fields? Another issue is that by fusing with conventional medical practices and settings CAM might be appropriated by a medical system that functions under a completely different set of assumptions.

or spiritual healing – are conceptualised not as direct healing agents but as agents of the universal life force.<sup>150</sup>

In the first years of the epidemic AIDS victims (as they were then called) ‘dropped like flies’. Their deaths were painful and their physical deterioration ghastly; the social ostracism they encountered then is unimaginable today. So-called ‘innocent’ victims, such as children or haemophiliacs who had not acquired the disease through (homo)sex, were submitted to much prejudice. Children were barred from school, dying patients were refused medical treatment, and landlords expelled their sick tenants. Gay men in particular, whose presumed promiscuous nature had apparently triggered the spreading disease, were exposed to magnified intolerance as they were considered ‘guilty’ of their own predicament. In the early years of the health crisis medical and governmental agencies showed very little interest in a disease that seemed to only affect disenfranchised sections of society. The alternative medicine community responded to AIDS in a different way. Some within such community traditionally distrusted the hugely profitable pharmaceutical companies and their expensive drugs whereas others questioned the idea that a virus caused the syndrome. The important factor in the evolution of the close association between HIV and complementary medicine was that many desperate patients looked towards the alternative medical paradigm for some sort of solution to their problem. At a time when people with AIDS faced bigotry and rejection from most factions of mainstream society many New Age therapists, AIDS healers, or alternative therapists were willing to provide AIDS patients with more than potentially

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<sup>150</sup> Holistic medicine includes dozens of alternative therapies and medical systems such as: Chinese medicine, ayurvedic medicine, macrobiotics, osteopathy, hydrotherapy, psychosynthesis, gestalt therapy,

beneficial compounds such as Chinese herbs; they treated the victims like people and gave them hope.

In a typically holistic perspective it had been postulated that as gay individuals had such internalised levels of hatred it was not surprising that they should have been so disproportionately affected (Hay, 1984). The only way to heal oneself from AIDS would thus be through 'inner work'; only when the spirit was mended could health be physically manifested. Such a multidimensional model proposed to treat AIDS victims by focusing not only on their physical well-being but also, perhaps mainly, on their emotional and spiritual dimensions. Alternative therapies constitute non-invasive, gentle techniques where individual attention is given to each patient. These techniques attempt to balance the individual's vital energy by creating a safe environment where the patient, with the help of the practitioner, may be able to access his/her own healing powers. The momentum of CAM in the last decades is directly related to its mobilisation around the AIDS issue. The fundamental fact to remember is that during the first years of the AIDS crisis the holistic health movement constituted the most important tool to resist the medically-imposed model of AIDS=death. The subsequent discovery of HIV and the consequent medical appropriation of the meaning of AIDS changed all that. Yet, the medicalisation of AIDS did not cause the demise of CAM in the context of the needs of people living with HIV. In fact, had the AIDS crisis never occurred, the current initiative to integrate the medical system and the holistic paradigm might have never emerged (Standish et al, 2002).

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Jungian therapy, herbalism, homeopathy, therapeutic touch and many others.

### 6.3.5.- The Gentle Approach: does it 'really' work?

The 'Bastyr University's Alternative Medicine Care Outcomes in AIDS' (AMCOA) represents the most comprehensive American investigation of the use of holistic medicine among HIV-positive Americans to date. One-thousand-six-hundred-and-sixty-six HIV-diagnosed individuals who self-identify as complementary and alternative medicine (CAM) users were studied between 1995 and 1997. Such individuals reported using a total of one-thousand-four-hundred-and-ninety-two CAM therapies for HIV disease. However, a staggering low number of these therapies have been clinically evaluated: *forty-five* randomised clinical trials have *ever* been conducted, and within these trials only *twenty-four* of the one-thousand-four-hundred-and-ninety-two CAM therapies for HIV disease have been appraised.<sup>151</sup> The close relationship between AIDS treatment activism and the holistic health movement helped to occasion the mainstreaming of a small number of CAM therapies which are now prescribed by allopathic physicians, covered by insurance companies, and offered free of charge at the National Health Service.<sup>152</sup> In addition, in 1992 the National Institutes of Health (NIH) in the United States established the Office of Alternative Medicine (OAM) to scientifically study alternative medicine. Despite the fact that the OAM opened ten research centres in the United States between 1994 and 1997 (including the Bastyr centre), and that the use of CAM is widely diffused among the infected population, the fact remains that the scientific community's ignorance

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<sup>151</sup> This data refers to studies published in peer-reviewed journals which had an abstract in English despite the country of publication. Only some of these studies were also placebo controlled (Standish et al, 2002).

<sup>152</sup> The most common CAM therapies to have been mainstreamed are Chinese Medicine (including herbs), some forms of body manipulation such as therapeutic touch, and nutritional medicine.



of the potentially adverse or beneficial effects of CAM therapies in HIV disease still lingers.<sup>153</sup>

Medical research on AIDS faces many obstacles. If the research approach is allopathic there are several complicating factors: the putative causative agent (HIV) is thought to be mutable; there are several contributory factors to the pathogenesis of AIDS; and immune supportive therapeutic strategies are debatable inasmuch as there is much controversy surrounding the connection between presumed immunological targets and the appearance of disease. Even greater difficulties are faced in the determination of CAM's efficacy in HIV disease since CAM's underlying holism blurs the dimensional boundaries typical of allopathic medicine. CAM research is further hampered by structural elements (such as the relative scantiness of literature and funding), but CAM's intrinsic logic of individualisation, holism, and combination constitutes the greatest hurdle for its evaluation from a clinical perspective. In addition, 'replicability' - the hallmark of the scientific method - requires that a clear specification of whatever is being tested be articulated so that the studied substance and/or procedure can be described, stabilised and generalised. However, the definitions, qualities, and parameters of most CAM practices, practitioners, and substances have not been standardised and are thus not fitting for generalisation. Moreover, in evaluating non-material interventions, which characterise many CAM systems (e.g. acupuncture), not only might controls be difficult to select if a blind experiment is the goal but also placebos may be very problematical to define.

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<sup>153</sup> The initial euphoria caused by the apparent success of combination therapies in the late 1990s overshadowed the interest in CAM therapies and research in HIV disease, but the number of HIV-positive CAM users did not significantly diminish. Once the adverse effects of HAART began to emerge the interest in CAM rebounded as these side-effects needed to be tackled (Standish et al, 2002).

The fact that many CAM practitioners tend to use a combination of substances and/or therapies in their practices significantly obscures issues of standardisation, clinical indications, therapeutic targets, and potential toxicities. Despite such difficulties in establishing the scientific validity of many CAM therapies, some clinical trials have indeed shown the efficacy of particular CAM approaches. One of the most thoroughly researched CAM practices within the context of HIV disease has been Traditional Chinese Medicine (TCM), whose modalities include dietary therapy, massage therapy, heat therapy, exercise, meditation, and acupuncture. A number of completed controlled trials of Chinese Medicine have all demonstrated the efficacy of TCM in treating symptoms of HIV infection (Burak et al, 1996; Cohen et al, 2000; Weber et al, 1999). In addition, nutritional approaches to HIV disease have also been clinically evaluated to demonstrate the positive effects of such approaches in maintaining health (Muller, 1992; Grimble, 1997; Allard et al, 1998). In addition, integrative treatments for HIV disease are already being implemented with considerable success (Kaiser, 1993). As such, the utilisation of CAM in the treatment of HIV disease continues to increase as their difficult-to-scientifically-prove dimension is contrasted to personally experienced benefits.<sup>154</sup>

#### 6.4.- The Appropriation of the Meaning of AIDS

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<sup>154</sup> An American study found that over 90% of 120 experienced and credentialed providers of CAM in the context of HIV disease claimed that their therapies ‘were “somewhat” to “very effective” at all disease stages and on all disease measures, including symptom management (96%), maintaining quality of life

#### 6.4.1.- The Discovery of HIV: a surreptitious appropriation

The turning point for the medical appropriation of the syndrome came in April of 1984. Aetiological speculation was extinguished almost overnight with the announcement made by the US Health Secretary that the National Cancer Institute (NCI) oncologist Robert Gallo had identified the probable cause of AIDS. Gallo claimed to have isolated a new virus, which was said to be the third human variant of the cancer-causing retrovirus family, which he had discovered in the 1970s. The new virus was named HTLV-III.<sup>155</sup> The 'collaborative' role of the French Pasteur Institute was briefly mentioned (Epstein, 1996). However, American science could not bask in its glory for too long. A year after the announcement, a US Department of Health and Human Service's Office of Research Integrity (ORI) investigation declared Gallo guilty not only of scientific misconduct, but also of making false statements in published scientific papers (Shenton, 1998).<sup>156</sup> The work of the Pasteur Institute's chief of viral oncology, Dr. Luc Montaigner, had been somehow 'appropriated' by Gallo.<sup>157</sup>

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(98%), raising or maintaining CD4 lymphocyte levels (66%), slowing progression to AIDS (69%), and extending survival (73%)' (Calabrese and Werner, 1998: 281-287).

<sup>155</sup> Howard Temin and Satoshi Mizutani, two biologists from the University of Wisconsin and from the Massachusetts Institute of Technology respectively, won the Nobel Prize in 1975 for their discovery that the transcription of RNA into DNA was possible. Until then it was thought that DNA makes RNA and RNA makes protein; it was not thought that the mechanism could operate in the opposite direction. A virus genome usually integrates into the genome of the host in the form of DNA. In the search for a viral cause of cancer, it was hypothesised that the viral genome, once inserted into the genome of the host, would constitute an oncogenic sequence. As such, cell division rather than viral reproduction would take place. However, in the 1960s this hypothesis ran into a stumbling block: the viruses thought to cause avian sarcoma virus and feline leukaemia (animal cancers) were filled with RNA, not DNA. The discovery of the two American biologists demonstrated that RNA viruses, with the help of a specific enzyme known as reverse transcriptase, can be transformed into DNA and then penetrate the nucleus of a cell. The name retrovirus stems from this inverse capability of some such pathogens (Grmek, 2000).

<sup>156</sup> The initial verdict was subsequently dropped as the Department's appeal board, not its scientists, redefined the criteria for scientific misconduct (Shenton, 1998).

<sup>157</sup> Gallo's history of 'appropriation' of other people's work dates back to the 1970s. Just as Temin and Baltimore discovered reverse transcriptase, Gallo was researching a group of related enzymes, called DNA polymerises of blood cells. Gallo immediately understood that the new discovery could aid him in his efforts to establish a connection between viruses and cancer. 'At that time, only the retroviruses causing

In 1982 Montaigner and his team had been able to show the presence of reverse transcriptase, the enzyme which is thought to characterise retroviruses, in samples of a lymph tissue from a gay male with chronically swollen lymph glands, a condition known as 'lymphadenopathy syndrome'.<sup>158</sup> Lymphadenopathy Syndrome was believed to be a precursor to AIDS.<sup>159</sup> Montaigner had informed Gallo of his discovery before the simultaneous publication of a paper from the former, and two papers by Gallo, in the same issue of *Science* (220) of May 1983. Gallo had offered to abstract Montaigner's paper, and in doing so claimed that the virus discovered by the French team of scientists, which was named LAV, was a 'C-type retrovirus' similar to Gallo's previously isolated HTLV. In fact, what Gallo had actually 'discovered' was a virus with a 99% degree of genetic similarity to the French LAV: a matter of accidental contamination or purposeful misconduct (Epstein, 1996; Maggiore, 1996)?

In his *Science* paper 'Isolation of Human T-Cell Leukemia Virus in Acquired Immune Deficiency Syndrome (AIDS)', Gallo had claimed that the leukaemia virus HTLV he had previously identified was responsible for causing AIDS. In 1984, in another May issue of *Science*, Gallo and his American collaborators published the paper 'Frequent Detection

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cancer in animals were known, and all ambitious oncologists dreamed of finding a human oncogenic retrovirus.' Gallo and his collaborators tried for five years; in 1980 one of Gallo's colleagues, Bernard Poiesz, isolated such a retrovirus. Gallo soon published Poiesz's (a trainee at the NCI) findings as mostly his own. During the decisive period of his trainee's discovery Gallo was travelling, and absent from the laboratory (Grmek, 1990:56).

<sup>158</sup> The evidence that reverse transcriptase (RT) is constituent of a retroviral particle has been challenged by the dissident critique. Some of its proponents claim that as the presence of RT is proven indirectly, and as other cellular DNA polymerases can also produce RT, this hypothesis cannot be ascertained (Papadopulus-Eleopulus et al, 1996).

<sup>159</sup> Lymphadenopathy can appear as the result of a broad range of causes such as the flu, mononucleosis, lymphoma, and HIV infection. It is characterised by swollen, firm and possibly tender lymph nodes.

and Isolation of Cytopathic Retroviruses (HTLV-III) from Patients with AIDS and at Risk for AIDS'. In this paper Gallo completely abandoned the notion of a leukaemia virus, and referred instead to a new 'discovery'. After having been unable to find HTLV in AIDS patients and, perhaps more significantly, after having received a sample of LAV from the Pasteur Institute, Gallo suddenly changed his rhetoric and 'discovered' yet another virus: HTLV-III. In his 1984 *Science* paper Gallo was not only claiming someone else's findings as his own, but he had also subtly renamed and reclassified the entire family of viruses, which he had identified in the 1980s as the leukaemia-causing 'human T-cell leukemia viruses' (HTLV-I and HTLV-II). Now the AIDS-causing HTLV-III, and its assumed related leukaemia cousins, were all reconceptualised as 'human T-lymphotropic retroviruses'.<sup>160</sup> The press announcement made by the US Health Secretary, which had proclaimed to the world the efficacy of President Reagan's scientists, and established HTLV-III as the causal factor in AIDS, had disregarded the usual standards of scientific procedures. None of Gallo's scientific hypotheses had been peer-reviewed and his 'findings' had yet to be independently replicated (Epstein, 1996).

A 12-point investigation from the National Institute of Health's Office of Scientific Integrity found Gallo guilty of scientific misconduct, and accused him of hampering research efforts. These charges were, however, later withdrawn through a series of legal efforts. Yet, the Human Retrovirus Subcommittee of the International Committee of the Taxonomy of Viruses discarded Gallo's HTLV-III, and re-baptised the virus in 1986 (Epstein, 1996; Shenton, 1998). After accusing Gallo of stealing its virus, the Pasteur

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<sup>160</sup> The name was a reference to the lymphocyte depletion observed in AIDS patients.

Institute sued the U.S. government in 1985. The dispute was only resolved when the presidents of both countries, Jacques Chirac and Ronald Reagan, met in Frankfurt to sign the 1987 agreement whereby the two nations conceded in splitting the royalties for the antibody tests (US\$ 35 million by 1994) (Shenton, 1998). In 1989 the *Chicago Tribune* published an exposé of Gallo's science, and concluded that Gallo had obtained HTLV-III from the Pasteur Institute either by 'accident or theft'. Soon after that Montaigner's laboratory asked for a renegotiation of the 1987 agreement, and for US\$20 million in reparation.

The 'doctrine of specific etiology', developed from the work of Pasteur and Koch, demonstrated that specific germs produced specific diseases in the human body. Later this model was extended beyond infectious diseases, and disease was explained by the lack of a specific element such as a vitamin or a hormone. Despite the achievements of such theory, it has rarely provided a complete account of the causation of disease (Dubos, 1959). Epstein (1996) performed a content analysis of scientific articles dealing with the isolation of HIV in seven major journals during the period 1984-1986, the pivotal years as far as the institutionalisation of the HIV hypothesis is concerned. Epstein wanted to verify the notion that 'by repeatedly citing each other's work, a small group of scientists quickly established a dense citation network, thus gaining early (if ultimately only partial) control' of the meaning of AIDS (Treichler, 1992:76 quoted In Epstein, 1996:81). He concluded that by 1986 '62% of the articles cited Gallo to make unqualified claims, and only 22% did so in conjunction with qualified claims.' Epstein also observed that 'expressions of doubt or scepticism – let alone support for other hypotheses – were

extraordinarily rare throughout this period'. 'Serious doubts' were voiced in passing, or in 'short letters to journals'.<sup>161</sup> Nevertheless, and despite Gallo's 'discovery' having become established fact 'simply because it's true', it institutionalised the viral aetiology of AIDS and framed the subsequent treatment research and strategy by the anti-retroviral model (Treichler, 1992:76). Yet, the isolation, the discovery, the harmfulness, and even the very existence of the HIV virus continue to be disputed to this day.

The medical appropriation of AIDS was firmly established with the discovery of HIV. As new antiretroviral treatments slowly emerged they subsumed the significance of the holistic medical systems that had been serving the needs of people living with HIV and dying of AIDS for over a decade. In addition to their health-producing function, these alternative paradigms had also served as resistance strategies against the medically established 'truths' surrounding AIDS. Despite the orthodox advances in its quest to find a cure for AIDS, medicine is still far from a real solution. As such, the holistic paradigm of CAM continues to resonate with many individuals whether in a complementary or absolute role. In addition, a new resistance project has been gaining increased momentum. Although the origins of this emerging micrological strategy can be traced back to early in the health crisis, only recently has it begun to constitute a problem for the mainstream institutions that deal with the problem of AIDS. This resistance project, which bases itself on the original 'immune overload' model of AIDS, is thus framed by holism. However, such a resistance project questions the core knowledge(s) of AIDS not

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<sup>161</sup> In a letter to the medical journal *JAMA*, published in September of 1984, Arthur Ammann called for a 'cautious appraisal...(as) there is no historical precedent for believing that a single infectious agent is capable of abolishing a normal immune system' (quoted in Epstein, 1996:83).

through the language of an 'alternative' paradigm but through the very language which has established these knowledge(s) in the first place.

#### 6.4.2.- The Orthodox View on AIDS: first things first

The dissident critique has posed a series of challenges to the scientific knowledge that constructs the phenomenon of AIDS. Such challenges have been articulated from the same biomedical perspective, and within the same scientific language, with which the orthodoxy asserts that HIV is the cause of AIDS. As such, the dissident critique utilises 'reverse discursive practices' in order to credibly challenge science. I have no intention (or ability) of engaging in the scientific merit of either argument. Furthermore, my argument is a sociological one and as such totally pervious to the assumptions of either medical model. However, failing to briefly sketch the main points of contention between the orthodoxy and the dissidents would greatly impoverish the present argument. As such, I attempt to describe a certain amount of medical data only inasmuch as it is a necessary framework for the further development of the analysis of the social processes that surround the construction of scientific (un)certainly associated with HIV/AIDS, and the resistance it has sparked. Hence, in order to provide a framework for the dissident critique I shall briefly describe the orthodox view on AIDS. It could be said that I am basing my argument on 'contested' and partial scientific evidence, as I do not offer the orthodox rebuttal to the dissident critique. Yet, as I have already mentioned, this chapter is not on the merits of the science of AIDS, and I am not claiming that the dissident view is the correct one. However, dissidents argue that the orthodoxy has continually failed to answer any of their challenges. Although the reasons for such alleged failure remain open



to speculation, the orthodoxy has justified it on the grounds that any public engagement with dissident theories risks their legitimisation (Hodgkinson, 1996; Epstein, 1996).

Most of the information on the AIDS 'epidemic' developed in this section has been gathered from the United Nations programme on AIDS (*UNAIDS*), and from the National AIDS Manual (*NAM*), Britain's leading publication on HIV and AIDS. This data represents the official view. As such, it is endorsed by the World Health Organisation (*WHO*), by the Communicable Disease Surveillance Centre and the Scottish Centre for Infection and Environmental Health in Britain, and by the Centers for Disease Control and Prevention (*CDC*) in the United States. Moreover, this view is supported and reproduced by all leading AIDS service and advocacy organisations and by all of the established representatives and institutions of medical research and science around the world.

The human immune system has evolved over millions of years; it operates in part through the independent circulatory system known as the lymphatic system. This system is composed of organs and tissues such as the bone marrow, the thymus gland, and the spleen, which together create our main immunological weapon: white blood cells. Some of these cells directly attack invading organisms (cell-mediated immunity), and others act by producing antibodies (humoral immunity). Our immune system is capable of both non-specific and specific immunity. Non-specific immunity constitutes the more basic function of the system as it deals with a range of common microorganisms that constantly challenge the health of our bodies. The cells responsible for non-specific immunity are

called *phagocytes*, 'eating cells' that literally swallow invading antigens (foreign bodies). On the other hand, specific immunity can, to a certain extent, cope with uncommon organisms through the production of immune globulins (commonly known as antibodies), i.e. key proteins produced by cells to deal with antigens. A range of cells known as *lymphocytes* carries out specific immunity, the dimension of the immune system that deals with HIV infection. Lymphocytes are classified as B-cells, responsible for producing antibodies to defend the body against bacteria and other foreign antigens, and as T-cells, which are in charge of cell-mediated immunity. Although antibodies can effectively cope with the free-floating viruses circulating in the bloodstream, most viral infections occur within the host's cells without the pathogen freely roaming the circulatory system. Antibodies cannot reach within cells; for that to happen cell-mediated immunity, where T-cells identify and destroy the body's own infected cells, is necessary. T-cells are divided into CD8 cells (cytotoxic T cells) and CD4 (T 'helper') cells. CD4 cells do not act directly upon the destruction of infected cells but are essential for optimal immune function. CD4s can be directly infected by HIV, or depleted in indirect ways. CD4 depletion has been considered to be the most harmful effect of HIV infection responsible for 'paralysing normal immune responses and leaving the body prey to opportunistic infections' (King, 1994:31-45).

LAV ('Lymphadenopathy Virus'), or HTLV-III ('Human T-Cell Lymphotropic Virus Type III') was first isolated by French scientist Barré-Sinoussi, a female member of Luc Montaigner's team of scientists at the *Institute Pasteur* in Paris in May of 1983. From 1986 onwards the virus has become widely known as 'The Human Immunodeficiency

Virus', or HIV. HIV is present in blood, semen, vaginal fluids, saliva, breast-milk; it is mainly transmitted through unprotected anal or vaginal sex, blood to blood contact, and from mother to baby during the course of pregnancy, birth or breast-feeding. Several cases of 'HIV-free AIDS' were reported at the 8th International Conference on AIDS in Amsterdam in 1992, but 'strictly speaking, a person who does not have HIV infection cannot have AIDS, because HIV is part of the case definition of AIDS. If somebody is immunosuppressed but does not have HIV, they do not have AIDS.' It is expected that the vast majority of HIV infected persons will eventually develop AIDS (UNAIDS fact sheet: 1-5). Although there are several reported cases of HIV-infected individuals who have not developed AIDS fourteen years from infection, generally a few years after infection the immune system begins to show signs of stress (Buchbinder et al, 1994). Initial infection is usually followed by a transitory flu-like illness, which is immediately attacked by the immune system, before a period of variable dormancy sets in.<sup>162</sup> The HIV diagnosis is based on tests for the antibody; in Britain the ELISA test is standard whereas in other countries a confirmatory 'Western Blot' must follow a positive ELISA. Second-generation ELISA tests have been improved in order to reduce the possibility of the false positive reactions, which had occurred in the earlier generation of tests. The improved ELISA tests employ fragments of highly purified laboratory-cultivated HIV proteins (synthetic peptides) deemed to produce reliable HIV antibody reactions. However, the likelihood of the Western Blot producing false positive results is one of the reasons the test is not used for confirmatory purposes in the UK (King, 1994).

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<sup>162</sup> It was initially thought that the virus remained inactive for many years, but recent research has suggested otherwise (Ho et al, 1995).

Surrogate markers, i.e. laboratory tests employed to monitor disease progression, unlike clinical evidence of disease, indicate the statistical likelihood that an HIV-infected individual will develop an opportunistic infection and/or progress to a full-blown AIDS diagnosis. Constant surveillance of the functions of the immune system is 'motivated by the underlying benefit of early intervention or prophylaxis', and to help doctors decide when to prescribe treatment drugs. Although the CD4 count is 'not a straightforward, unambiguous reflection of the healthiness of the immune system... (as) the counts can vary on a number of factors'; it constitutes one of the main surrogate markers of progression of disease. More recently, however, the role of CD4s as immunological markers, as well as parameters against which to measure the efficacy of antiviral treatments, has been questioned (King, 1994: 40-45). Such modification in the conceptualisations of surrogate markers are related to new technological developments (viral load technology) which can measure the levels of virus found in lymph nodes and in the blood system. As such, 'viral load' measures have been favoured over clinically observed immunodeficiency and/or the presence of opportunistic infections as markers of disease progression. The main goal of antiviral treatment has thus become the reduction of levels of HIV in the body, which can now be measured by the new technology. Reduction in 'viral load' indicates whether combination therapy is working or not.<sup>163</sup>

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<sup>163</sup> Virological tests include p24 antibody and antigen, HIV culture, SI/NSI phenotype, and DNA/RNA amplification. The retrovirus HIV consists of a single stranded RNA whose viral envelope protein, gp120, adsorbs to the surface of both CD4 cells and monocytes. Viral entry and uncoating subsequently occur whereby the enzyme, reverse transcriptase (RT), duplicates the single-stranded RNA into double stranded DNA. Viral integration into the host DNA proceeds, causing the transcription and translation of HIV genes.

## 6.5.- The Dissident Movement

### 6.5.1. The Dissident Critique and the Dissident Movement: a close relationship

The 'Dissident Critique' is comprised of a series of specific challenges to many of the scientifically established truths that have framed the appropriation of the meaning of AIDS by the medical system. The critique has been articulated from within the bio-medical orthodoxy by a number of scientists, researchers, and medical professionals. The work of 'dissident' scientists is supported and disseminated by dozens of lay organisations around the globe. Many of these loosely connected institutions have been set up exclusively and autonomously to engage in the propagation of such ideas, and to achieve the overturn of the medical model of AIDS as it is currently constructed.<sup>164</sup> Despite the unstructured linkages among these organisations, a broader movement that functions through this loosely connected array of dissident organisations has coalesced.<sup>165</sup> As such, the appearance of an emerging social movement organised around the arguments of the 'dissident critique', the 'Dissident Movement', began to take place

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Chronic infection and ultimate cellular destruction will ensue in these cells, contributing to the progressive destruction of CD4 cells (King, 1991).

<sup>164</sup> Such organisations are: Academy of Nutrition Improvement (Nagpur, India); ACT UP San Francisco; ACT UP Hollywood; ACT UP Toronto; Alberta Reappraising AIDS Society; Alive and Well (Eugene, Oregon); AMG (France); Continuum magazine (London); The Forum for Debating AIDS South Africa (FDASA); Fundacion Arte y Ciencia (Colombia); Health Education AIDS Liaison (HEAL) Network (New York City, Denver, Hartford, Portland, San Francisco, San Diego, Seattle, Washington DC', Hawaii, Toronto, Uganda); International Forum for Accessible Science (IFAS Switzerland); Joint Action Council Kannur (JACK); New York Rethinking AIDS Society (NYRAS); and Students Against the HIV Causes AIDS Hypothesis (SATHIVCAH).

<sup>165</sup> Such coalitions have resulted in some unlikely partnerships. AIDS Coalition to Unleash Power (ACT UP), whose activities started in New York City and are today articulated in many chapters throughout the United States and abroad, constitutes the most public direct-action group of AIDS activism. ACT UP 'shares the most basic characteristics of a new social movement, articulates a mix of instrumental, expressive, and identity-oriented activities (Gamson, 1989:351-360). Although the majority of the chapters of ACT-UP accept and disseminate the notion that HIV is the cause of AIDS, and contest the 'politics of treatment' of the health crisis, recently a few ACT-UP chapters have associated themselves with the

in the 1990s. The movement's institutions are densely interconnected in their efforts to transform the political, economic, and socio-cultural relationships that characterise the global problem of AIDS. As a social movement the 'dissident movement' functions within the emerging 'embryonic global public sphere', which provides a forum and a voice for non-state global actors (Devetak and Higgott, 1993:491). The system of relationships in which the movement is embedded is characteristic of 'network society' (Castells, 1996), which is increasingly substituting the nation-state as the main focus of civil loyalty and fostering the evolution of 'cosmopolitan politics' (Vertovec and Cohen, 1999). However, despite the 'transnationalism' of the movement, the social resistance they articulate is delimited by the socially structured discursive spaces through which dissident individuals navigate. Transnational politics still maintain traditional axes of discrimination (Guarnizo and Smith, 1998:3-34).

For reasons of space, I shall describe only, and briefly, three of the most relevant dissident organisations of the Anglo-Saxon world. I begin with the 'mission statement' of one Britain's most vocal representatives:

At the 12<sup>th</sup> World AIDS Conference in Geneva, 1988, it was concluded at an official meeting that such a virus as 'HIV' has not been isolated and may well not exist. At the onset of the 'epidemic', the hysteria that resulted from the linking of sex, death and 'an infectious virus' created a climate where to question the 'facts' was considered reprehensible. Many of those who dared to do so were silenced or ridiculed. Since the growth of the orthodoxy, those who question have also had to contend with the weight of vested interests. Continuum is a unique forum for those in the scientific

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dissident critique. As such, these ACT-UP chapters have moved beyond simply challenging the appropriateness of allopathic HIV treatment to question the causation of the syndrome.

community challenging the orthodoxy and those whose lives have in some way been touched by the hypothesis (continuum.com)

The first issue of *Continuum: changing the way we think about AIDS* was published in London in October of 1992. *Continuum* began as a newsletter whose objective was to encourage ‘those affected by an HIV diagnosis to empower themselves to make decisions about care and treatment choices’. *Continuum*’s founder was Jody Wells – a man who had refused to take anti-viral medication despite having lived with an HIV diagnosis for many years.<sup>166</sup> Today, *Continuum* is a voluntary organisation, run (mostly) by HIV-diagnosed individuals, which relies on (approximately 500) subscriptions and donations for its survival. Through its four annual issues, and occasional public meetings, *Continuum* functions as a forum for the dissemination of ‘information we believe is necessary for the fuller understanding of HIV, AIDS and immunity’ (continuum.com).

*Reappraising AIDS*, the US published monthly pamphlet of ‘The Group for the Scientific Reappraisal of the HIV/AIDS Hypothesis’, is another important forum for dissident ideas. This collective of ‘medical scientists, physicians and other professionals from around the world encourage a serious reappraisal of the HIV-causes-AIDS model’, and believe that they ‘have identified solid scientific reasons to conclude that ... HIV may be entirely harmless... (and that) ... people diagnosed with “AIDS” may be sick not from HIV infections but from other factors’ (*Reappraising AIDS*, 09/1999:4).

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<sup>166</sup> Jody Wells eventually died from complications usually associated with AIDS.

Another major organisation dedicated to alternative views on AIDS is *Health-Education-AIDS Liaison* (HEAL), which was founded in New York City in 1982 in order to provide information on alternative and holistic approaches to AIDS. Today, in addition to HEAL chapters in twenty-three American cities, HEAL has expanded its activities and educational programmes to include Mexico, Canada, Germany, Switzerland, Spain, and Uganda. HEAL chapters are separate and independent organisations which nevertheless share similar goals, mission statements, guidelines, and objectives. Whilst HEAL does not officially endorse any particular view. The 'mission statement' of such organisation reads as follows:

After more than 15 years working with AIDS and AIDS related problems, HEAL is of the opinion that the whole thrust of AIDS 'testing', research and treatment urgently needs to be reconsidered. HEAL believes that safe, healthy, responsible behaviour can be promoted without terrorism and disinformation (*rethinking AIDS website*)

The co-operation between these institutions is enacted in their publications, through virtual discussion groups, mailing lists, and occasional international meetings. Dissident organisations have generated a great deal of literature that reproduces the scientific papers of the 'dissident critique', which would otherwise only reach the tiny minority that reads scientific or academic journals. In addition, a plethora of books, videos, and tapes that deal with dissident issues have also been published. Another important site for dissemination of dissident views is the Internet. The role of the institutions of mass media in the interpretation and adjudication of scientific controversy is undoubted. The filtering of scientific information as well as the construction of public images of scientific



certainty concerning HIV/AIDS have been ascertained by the overwhelming majority of the institutions of the mass media. However, as dissident organisations have their own media vehicles, a certain degree of destabilisation of mainstream information on AIDS has been achieved. Such destabilisation, and the circulation of dissident information, contravenes traditional 'top-down' models of expert knowledge dissemination. As such, dissident publications, as well as dissident Internet sites, are constitutive of the critique.

In the articulation of the 'dissident critique' the 'dissident movement' employs a mix of constitutionally sanctioned and disruptive and confrontational action. The most important constitutionally sanctioned action of the 'dissident movement' is the organisation of the 'Dissident Conference' alongside the International AIDS Conference, the most important biennial meeting of the AIDS establishment.<sup>167</sup> The first time a 'Dissident Conference' took place simultaneously to the mainstream international event was during the 11<sup>th</sup> International AIDS Conference, which took place in Geneva, Switzerland, from June 28<sup>th</sup> to July 3<sup>rd</sup> of 1998. The Geneva conference represented an important milestone for the 'dissident movement' as it was the first time that some of their views were presented in the most important international forum for HIV/AIDS.<sup>168</sup> However, constitutionally sanctioned action does not preclude disruptive and confrontational action. On the steps that led participants into the Geneva conference the Spanish dissident group *Cobra* staged

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<sup>167</sup> The International AIDS Conference is organised and sponsored by the multinational pharmaceutical companies that manufacture HIV drugs, such as Glaxo-Wellcome. The linkages between pharmaceutical companies and the International AIDS Conference, however, go beyond simple sponsorship. A covert collaboration between the pharmaceutical company Dome and an activist group that aggressively lobbied for greater access to Crixivan, an anti-HIV drug manufactured by Dome, was revealed during the 12<sup>th</sup> International AIDS Conference in Geneva. During the 13<sup>th</sup> International AIDS Conference in Durban the pharmaceutical company Boehringer Ingelheim, which manufactures the anti-HIV drug Nevirapene, funded an activist group to lobby for greater access to its drug (SAPA 13/06/00).

a hunger strike to protest 'the institutionalisation of the HIV virus on the basis of inadequate scientific evidence' (Continuum (4) 6:21). The latest dissident conference 'Making Sense: Alternative Views on the Origins and Causes of AIDS in Africa' took place at the end of August 2000.<sup>169</sup>

The proponents of the dissident critique want a *reappraisal* of AIDS science – not the abandonment of the scientific method, but what is thought to be the appropriate and necessary review of the science surrounding AIDS.<sup>170</sup> Such a critique has been articulated beyond the scientific community by the organisations of the 'dissident movement'. The grassroots of the movement is composed of HIV-diagnosed individuals who attribute their well-being to their disbelief in the bio-medical paradigm of AIDS.<sup>171</sup> Such individuals are the ones who keep the loosely connected network of dissident institutions functioning, usually on a voluntary basis. However, it is important to understand that such institutions began to coalesce after (and around) the work of the scientists who comprise the 'dissident critique'. Despite the proximity of the 'dissident

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<sup>168</sup> Dr. Eleni Papadopulus-Eleopulus, of the 'Perth Group', presented her views on the unreliability of HIV tests. See 6.5.3.1.

<sup>169</sup> In this conference, which took place in Uganda a month after the mainstream International AIDS Conference had been held in South Africa, the delegates called for the suspension of HIV testing and an immediate halt to the provision of anti-retroviral drugs to HIV positive pregnant and breast feeding women (South African Guardian 17/09/00).

<sup>170</sup> The dissident critique bases its arguments on the narrowness of the biomedical paradigm. Yet, in their use of 'reverse discourse' these sceptics demand that scientific principles and methods be followed. This is particularly evident in their critique of the failure of the orthodoxy to follow Koch's postulates.

<sup>171</sup> Most biomedical research into HIV/AIDS focuses on the efficacy of allopathic anti-retroviral treatment in reducing viral load or augmenting CD4 counts (see below). Fewer studies concentrate on the reasons why some individuals, despite having been infected with HIV for over a decade, do not seem to develop the syndrome. These supposed unusual (or abnormal) individuals, who contradict the biomedical notion that HIV should invariably lead to AIDS, are classified as 'long-term survivors' or 'non-progressors'. What these studies have found is that 'long-term survivors' share one thing in common: they have never used anti-retroviral drugs to deal with HIV infection (Hogervorst et al, 1995; Munoz, 1995; Pantaleo et al, 1995; Root-Bernstein, 1995; Yunzen et al, 1995; Garbuglia et al, 1996; Montefiore et al, 1996).

critique' and the 'dissident movement', the former should not be collapsed with the latter as the 'critique' constitutes a scientific endeavour not a social movement.

#### 6.5.2.- The Dissident Movement as a Genuine Social Movement

Post-modernist accounts of social reality have described the substitution of meta-narratives for the contingency and specificity of social structure and action. In a theorisation that reflects such perspective a distinction between 'old' and 'new' social movements has been postulated. The debate of whether 'new' and 'old' social movements constitute a fundamental break, or are better conceptualised as a continuum, has been extensively argued elsewhere.<sup>172</sup> Such distinction, however, seems increasingly sterile: 'the continued theoretical investment in gnawing again and again on this bone of contention is producing rapidly diminishing returns' (Cohen and Rai, 2000:4-10). As such, my goal here is not to argue for the inclusion of the dissident movement in either categorisation but to demonstrate how such a resistance project can indeed be looked at from the perspective of an emerging movement.

A social movement is characterised by three basic features. It must constitute an organised attempt to change social structure; be composed of 'culturally degraded' and 'politically oppressed' individuals stripped of 'any real influence over the major decisions that affect their lives'. In addition, social movements make use of tactics that simultaneously include 'disruption and confrontation with co-operation, legality, and consensus building'. The 'dissident movement' fulfils all such criteria. As a social

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<sup>172</sup> For a detailed discussion see Hannigan (1991), Zirakzadeh (1997), and Porta et al (1999).

movement it is attempting to change social structure; its constituency is mostly comprised of 'culturally degraded' individuals; and its tactics simultaneously include 'disruption and confrontation with co-operation, legality, and consensus building' (West, 1993:29). Still, there is an essential difference between being a social movement and being a *successful* social movement. The success of social movements is directly connected to their ability to secure and manage resources as well as to 'the social networks from which movements draw human and material support' (McAdam, 1982:36). Whether the 'dissident movement' will have any success in changing social structure can not be ascertained. The movement's material resources are negligible and its social networks are not richly elaborated.

Any social movement represents an act of social resistance. Whereas the target of change desired by the dissident critique is not specifically the state, 'nation-states' are implicated inasmuch as their institutions support not only the AIDS establishment and its industry, but also the scientific processes that have established that AIDS is an infectious disease. The network of loosely connected organisations of the 'dissident movement' remains largely unelaborated in terms of organisational and material resources. Most dissident organisations are under-funded, and staffed on a voluntary basis. Such lack of institutionalisation resonates with the marginal position of any counter-cultural movement, but also reflects the complexity of the different sets of relationships between dissident science and dissident groundwork. Although scientists of the 'dissident critique' are intimately connected to the genesis and the articulation of dissident ideas, they are not officially affiliated with the 'movement'; they are affiliated with mainstream institutions

such as hospitals or universities. It can be argued that despite the process of disenfranchisement that some scientists associated with the 'dissident critique' have suffered as a result of their production of and public engagement with dissident views, they still lend their remaining prestige and social connections to it. However, most of the individuals responsible for the organisation, the political activity, and the dissemination of dissident information are representatives of a segment of society known as 'nonelite' (McCarthy and Zald, 1977). The nonelite is constituted of people who 'in their daily lives lack substantive political clout, social prestige, or personal wealth, and whose interests are not routinely articulated or represented in the political system (Zirakzadeh, 1997:4). However, 'social movements amount to far more than individual participants, formal movement organisations and material resources...and many scholars now favour approaches which give priority to the cultural content and ethos of movements' (Zirakzadeh, 1997:4-5). As such, scholars are increasingly searching for concepts 'which adequately reflect the diffuseness, fluidity and indeterminacy which supposedly characterize today's social movements.' Notions of 'collective action' and 'mobilization' increasingly juxtapose the concept of social movement (Melucci, 1996; Beckford, 2000). The 'dissident' movement then constitutes a social movement indeed.

### 6.5.3.- The Scientific Controversies

### 6.5.3.1.- The Perth Group: HIV has not been isolated

The National AIDS Manual (NAM) publication 'HIV & AIDS Treatments Directory' states in its 1994 issue that:

Usually HIV infection is detected by an HIV antibody test. The first test to be done, usually on blood, but possibly on saliva is an ELISA... Since this test can sometimes be positive even when someone is not infected – a 'false positive' – a second test called the Western Blot is done.<sup>173</sup> This can confirm an ELISA.... (However) the likelihood that some people will falsely test positive for HIV antibodies by the Western Blot method is widely known amongst virologists and is one reason why the test is rarely used for confirmatory purposes in the UK... (The Western Blot) relies on a subjective judgement of the intensity of the bands of antibody which form in response to particular antigens... so false positive results are possible with this method just as with any other laboratory test (King, 1996:2-31)

In the Western Blot there are about ten HIV proteins located at different spots on a paper strip; once serum is added some of the spots on the paper strip will darken. A positive result is defined by a certain combination of such darkened bands, but the definition of the required combination for a positive result varies according to national frontiers.

Whereas four bands are required in Australia; in Canada and the United States three bands are sufficient; and in Africa only two are necessary (Turner, 1996).<sup>174</sup> In addition,

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<sup>173</sup> Diverse phenomena may produce a false positive ELISA: vaccinations (hepatitis B, tetanus, flu); organ transplants; viral infections such as herpes simplex I and II; AIDS-defining diseases like tuberculosis and mycobacterium avium; underlying conditions (haemophilia) and behaviour (receptive anal sex) often associated with AIDS patients may all produce false positives (Johnson, 1996). Semen is a foreign protein which, when accumulated in the blood through receptive anal sex, might produce a positive result in HIV tests (Papadopoulos, 1992). Recent generations of ELISA tests have, however, been vastly improved.

<sup>174</sup> The US's FDA has relaxed its requirement of three reacting bands for a positive result as in the first licensed kit of the Western Blot less than half of AIDS patients tested HIV positive. Production processes

the 'subjective judgement' implicit on the interpretation of the Western Blot has been shown to be informed by *a priori* cultural categorisations which defy scientific objectivity. According to Britain's Public Health Laboratory Service (PHLS), 'an accurate diagnosis' should be achieved through the juxtaposition of clinical specimens to a range of "risk-factor" information on fifteen categories including sexual orientation and national origin' (Continuum 4 (3):2).

The potential ambiguity of the Elisa and Western Blot tests has been acknowledged by the medical orthodoxy. However, the so-called 'Perth Group', a team of medical scientists from the Royal Perth Hospital in Western Australia, has made a much more radical claim (Turner, 1998:38).<sup>175</sup> In the June 1993 issue of *Bio/Technology* the Perth Group argued that the Western Blot test used to confirm an HIV diagnosis could not be relied upon at all. The Australian scientists argued that test was flawed in the four essential dimensions of a scientifically viable antibody test.<sup>176</sup> A couple of years later the Perth Group articulated another astonishing claim; the scientists argued that there is no proof that HIV exists inasmuch as HIV-identification processes have not followed the

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for the test strips are not standardised; variations occur not only between different manufacturers but also within lots from the same manufacturer (Hodgkinson, 1996).

<sup>175</sup> The team's main scientists are Dr. Eleni Papadopulus-Eleopulus, Dr. Val Turner, and Dr. J. Papadimitrou.

<sup>176</sup> According to the Perth Group, Western Blots are unreliable tests because of:

1. The lack of a source of HIV-specific antigens (as HIV has never been isolated these tests employ complex procedures that involve a series of assumptions in determining a positive result);
2. Cross-reactions producing 'positive' results on the test;
3. The impossibility of reproducible results across different laboratories due to the interpretative framework of the test;
4. The inability of the test to measure up to the 'gold standard' of scientific testing reliability, i.e., an independent method of ascertaining the infection, which the test is deemed to identify (Hodgkinson, 1996).

accepted method of retroviral isolation (Papadopolus-Eleopolus, 1997).<sup>177</sup> As antibodies are never disease-specific, an accurate antibody test can only be devised if viral isolation has been accomplished.

Viruses are only capable of multiplying when inside a host cell, but through an electron microscope they are observable as independent particles constitutive of a unique stretch of genetic material (the virus genome). The procedures for isolation and purification of virus genomes, which developed out of the work of American scientists experimenting with malignant muscle tumours in chickens in 1911, were standardised between 1940 and 1970, and reiterated at a 1973 meeting of the Pasteur Institute (Rous, 1911; Papadopolus-Eleopolus, 1997). Briefly, unpurified biological material made up of various biological particles is spun through a density-graded centrifuge, which bands the similar particles at characteristic densities – the higher the density, the lower its ‘banding’ in the test-tube. This procedure isolates and separates the different particles at characteristic density bands, and enables scientists to photograph the isolated particles in an electron microscope. If the photographic images of these isolated particles resemble the viral particles observed in hosts’ cells then a virus may have been identified.<sup>178</sup> The 1973 Pasteur Institute meeting established that photographing at the 1.16 band of density gradient was essential for retroviral isolation. The Perth Group argues that the

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<sup>177</sup> Most claims of ‘isolation’ were based on the detection of reverse transcriptase (RT), which alongside protease and integrase constitute the three enzymes involved in the replication of HIV. Originally thought to be exclusively associated with retroviral activity, it has been subsequently demonstrated that all cells are capable of RT (Hodgkinson, 1996).

<sup>178</sup> This simplified explanation of the procedure is sufficient for the purposes of this analysis.



photographs of virus particles published by Gallo and Montaigner were not of viral particles at the 1.16 band, the density that defines retroviruses.<sup>179</sup>

In March of 1997, researchers from the US National Cancer Institute and from Franco-German groups did publish the first photographs of HIV in the correct density gradients (Gluschankok et al, 1997; Bess et al, 1997). However, the authors of these studies stated that the great majority of the 'banded' material which appeared in their photographs was non-viral. In addition, argued the Perth Group, it seemed that the few retroviral particles that had been photographed could not be described as retroviruses unless the very definition of retroviruses was changed.<sup>180</sup> According to the Australians, all electron microscope photographs of HIV ever published are of non-purified cell cultures and may contain 'cellular debris' which resemble, but are not, retroviral particles (Papadopulos-Eleopulus, 1997). The orthodoxy responds with the argument that HIV cannot be detected by conventional molecular biology techniques due to its inactivity (only one in anything from 10,000 to 100,000 lymphocytes of infected people is actively replicating the virus). For the Perth Group, on the other hand, HIV has never been isolated and as such it may not exist. If HIV does exist, then it is in 'a very different category from most other viruses for which diagnostic testing has been developed' (Hodgkinson, 1996:256).

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<sup>179</sup> In a 1997 interview Dr. Luc Montaigner admitted that the sample from which his initial claim to HIV isolation originated did not 'contain particles with unique retroviral morphology' (Tahi, 1998).

<sup>180</sup> This argument is defended on the basis that these photographed particles, which contain from 50% to 750% more mass than retroviral particles, violate the definition of retroviruses that takes into account a 'fixed amount of RNA and protein' (Papadopulos-Eleopulus, 1997).

### 6.5.3.2. - AIDS: toxic or infectious disease?

The institutionalisation of the HIV hypothesis did not undergo the usual processes of scientific validation and reproduction. The ‘moral panic’, which characterised the beginning of the AIDS crisis, is one of the contributory factors to the relaxation of the strict scientific criteria normally required before a hypothesis may be declared a proven scientific fact (Epstein, 1996). In addition, as a result of the close association between gay lib and the motto of sexual liberation, sex stood at the centre of the newly articulated gay identity. A monocausal, microbial model for AIDS removed the potential for blame and guilt that a life-style disease might have provoked, *and* allowed for the reaffirmation of sex-positive attitudes through the invention of ‘safe’ sex. However, as the new syndrome rapidly spread across the world it seemed increasingly plausible that the culprit was a transmittable virus. Yet, the hypothesis that behind each affected ‘risk-group’ there was a separate epidemic, each with its unique etiological causes, was never completely discarded.

In the 1970s the gay liberation movement encouraged a sexualised lifestyle across a number of large American cities. The enactors of this ‘liberated’ gay life-style developed a hitherto unheard of level of venereal diseases. As such, the medical profession identified the ‘homosexual hazard’, i.e. inherent characteristics of the homosexual personality which led to an increased likelihood of contracting some types of disease such as ‘gay bowel syndrome’.<sup>181</sup> Such conceptualisations echoed recently outdated ideas of homoerotic behaviour as mental disorder as well as the more ancient notions of

homosexuality as personal degeneration. Much before AIDS, and soon after it officially lost its status as a mental illness, homosexuality came to be considered a 'risk factor' in the causation of *biological* disease. As such, GRID constituted the 1980s' version of medicine's traditional regulatory efforts towards homosexual behaviour. Hence, images of amyl-nitrite-inhaling-homosexual-predators (who had 'as many as ten sexual encounters each night up to four times a week'), devouring antibiotic drugs as prophylactics against the parasitic consequences of unbounded sexual pleasure, came to embody popular notions of homosexuality at the onset of the crisis (Epstein, 1996:46).

An article that appeared in *Cancer Research* in March of 1987, posed the first credible challenge to the theory that HIV was the cause of AIDS (Dues berg, 1987).<sup>182</sup> Its author was the German-born scientist Peter Duesberg, a member of the faculty of the Department of Molecular and Cell Biology at the University of California at Berkeley. Duesberg was one of the pre-eminent experts on retroviruses; he had mapped their genetic structure, and co-discovered the first known oncogene.<sup>183</sup> In 1971 Duesberg was named California Scientist of the Year; in 1986 the National Institute of Health awarded him with the special research grant 'Outstanding Investigator Award', and he was elected into the National Academy of Sciences (NAS) – the premier congregation of America's top scientists. In his *Cancer Research* paper Duesberg argued that HIV could not be the

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<sup>181</sup> Irritable Bowel Syndrome is a relatively common condition, which causes the intestines to be over sensitive. In the 1970s it was hypothesised that gays had a particular form of the disease associated with lifestyle and sexual behaviour.

<sup>182</sup> Other challenges to the HIV hypothesis, which had mainly been articulated through the New York gay newspaper *Native* since 1983, had failed to achieve any credibility.

<sup>183</sup> Oncogene theory arose within the 'War on Cancer' climate of scientific research of the 1970s. This theory, which has been subsequently challenged on many levels, argued that certain genes within each

causal factor in AIDS due to the disparity between the estimated number of infected individuals, and the people who actually had AIDS (for example, in the US the ratio infected/sick was 0.3, and in Africa less than 0.01). Duesberg argued that HIV was harmless as it was only present in one of every ten thousand to one hundred thousand T-cells of HIV positive individuals. As such, the T-cell depletion observed in AIDS patients would be more than offset by the natural rate of T-cell regeneration.

In order to determine if a specified *infectious* agent causes a certain disease it is usually required that the 'Koch's postulates' are met.<sup>184</sup> The postulates require that the causal agent be found in all cases of the disease, and that the agent be isolated from a carrier and grown in pure culture. In addition, when the culture is injected into a laboratory animal the animal must contract the disease; and then the causal agent must be found in the diseased animal (Epstein, 1996). Duesberg argued that the Koch's postulates have not been met. First, HIV antibodies can only be found in 80% to 90 % of AIDS patients. Secondly, argued the scientist, out of the 80% to 90% of AIDS patients who do test positive for HIV in only 10% can the actual genetic material of the virus (rather than antibodies to it) be found.<sup>185</sup> Thirdly, as undisputed evidence of experimental or accidental injection of HIV as causative of disease in animals or health care worker has

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human cell caused cancer. Linked to oncogene theory was the idea that retroviruses contained genes that could turn normal cells into cancer cells (Epstein, 1996).

<sup>184</sup> Robert Koch was the nineteenth century German microbiologist who first identified the cause of tuberculosis (Shenton, 1998).

<sup>185</sup> Duesberg has argued that even patients with full-blown AIDS fail to demonstrate appreciable levels of active virus: 'There is no report in the literature describing the virus ever to be active in a patient, only in cell culture' (quoted in Hodgkinson 1996:138).

never been ascertained – the fourth postulate remains untested.<sup>186</sup> Consequently, Duesberg argued, HIV itself is harmless and constitutes but one of the multitude of infections present in AIDS patients (Duesberg, 1988). Duesberg's alternative aetiology of AIDS, the 'risk- AIDS hypothesis', was first articulated in 1990. In his view, which incorporated and expanded the notion of 'immune overload', AIDS resulted from malnutrition, recreational drug-abuse, the long-term immunosuppressive effects of antibiotics, pathogens present in transfused blood, and the potentially carcinogenic anti-HIV drug AZT (Shenton, 1998).<sup>187</sup> The Perth Group has also defended a non-infectious model for AIDS (Papadopoulos, 1997).<sup>188</sup>

### 6.5.3.3. - The Haemophilia Puzzle

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<sup>186</sup> Scientists began injecting HIV-infected cell cultures into chimpanzees as long as fourteen years ago, but no animal has yet developed an AIDS-like condition (Continuum (5) 5:3). The dissident argument finds support in experiment conducted by Ter-Grigorov et al (1997) 'A new transmissible AIDS-like disease in mice induced by alloimmune stimuli, the only animal model similar to human AIDS', that suggests a 'non-infectious *modus operandi*' for the development of AIDS (Papadopoulos-Eleopoulos, 1997:31).

<sup>187</sup> The 'risk-AIDS hypothesis' was first articulated in the pages of the right-wing American publication *Heritage Foundation Policy Review*. Duesberg, who provided no sources for his data, appears to have borrowed many of his assumptions about the life-style risks of homosexual life from the 'homosexuality as a health hazard' literature of the 1970s (Epstein, 1996). If Duesberg had initially maintained that HIV remained inactive even in patients dying from AIDS, he later changed his mind. Duesberg came to believe that HIV did become active but that the appearance of antibodies was an effect rather than the cause of their immune deficiency. Consequently, campaigns to promote safe sex and sterile needles were misguided efforts in dealing with a 'toxic' syndrome, and as such could potentially foster the spread of the disease by focusing attention on condoms rather than on the inherent danger of the risk factors (Shenton, 1998).

<sup>188</sup> The 'Oxidative Stress Theory,' first developed to determine what makes a cell cancerous, argues that cardiovascular disease, cancer and ageing are caused by perturbation of the cellular redox level and its oscillations. Alterations in the cellular redox occur when the quantity of free radicals (molecules with an unpaired electron that take electrons from other molecules) that the body has to cope with exceeds the availability of antioxidants. Free radicals are highly reactive molecules created in the body, which in excess can damage tissues and cell structure. They are formed as by-products of the body's normal cell metabolism, but are also produced by environmental hazards such as air pollution, cigarette smoke, food additives, radiation, and chemicals. Free radicals, which are associated with disease, are combated by humanly produced antioxidant enzymes and by antioxidant nutrients. Antioxidants help protect the body by neutralising excess free radicals, and thus help reduce their damaging effects. The Perth Group has extended 'oxidative stress theory' to explain AIDS as a result of oxidative stress caused by semen received through receptive anal intercourse; nitrites; recreational drugs; the blood-clotting Factor VII used in haemophilia; antibiotics; and antiviral drugs such as AZT.

Haemophilia is a rare hereditary bleeding disorder treated with the injection of the blood-clotting agent Factor VIII, which is necessary for blood coagulation. The conviction that haemophiliacs have turned HIV-positive through injection of infected Factor VIII has legitimised serious litigations across the world. By 1990 well over one thousand individuals had claimed compensation for having been infected in Britain. In France and Japan health officials have been put in jail for allowing the administration of HIV-infected blood to haemophiliacs (Johnson, 1995). Numerous studies have demonstrated the apparently definitive association between HIV and AIDS in haemophiliacs (Becherer, 1990; Hassett, 1993; Gjerset, 1991; 1994; King, 1998). Still, not everybody agrees.

Although the role of HIV in haemophilia had been questioned as early as 1988, it was Peter Duesberg's challenge to the idea the HIV was responsible for causing AIDS in haemophiliacs that prompted the greatest controversy (Papadopoulos-Eleopoulos, 1988; Duesberg, 1988). According to Duesberg (1988), haemophiliacs with or without HIV were equally immune deficient, and both groups developed the diseases associated with AIDS. Duesberg's argument noted that 75% out of the 20,000 haemophiliacs residing in the US tested positive for HIV antibodies and, as over the five previous years 2% (300) of them had developed AIDS, the risk for an American haemophiliac to develop AIDS amounted to 2% each year. However, according to the postulates of the HIV-AIDS hypothesis, the virus was latent from one to ten years. As such, 'at least 50 per cent of the 15,000 HIV-positive American haemophiliacs would have developed AIDS or died from AIDS' by the time his article was published in 1992. Yet, according to the evidence presented by, a 2% annual risk of developing AIDS indicated that an average

haemophiliac would have to wait twenty-five years for HIV to produce its associated illnesses. The median age of American haemophiliacs had increased from 11 years in 1972 to 20 years in 1982 and to 25 years in 1986 despite the fact that, since the development of HIV tests in 1984, HIV appeared to infect over 75% of the American haemophiliac population. It was possible, then, Duesberg concluded, to make the argument that HIV had in fact *increased* the lifespan of haemophiliacs (Duesberg, 1989:201-77).<sup>189</sup>

An epidemiological study of British haemophiliacs, the ‘Oxford Haemophilia Study’ published in *Nature* in September of 1995, established that in the period 1985-1992 there were 403 deaths in HIV-positive haemophiliacs. The death rates from HIV-negative individuals would have predicted only sixty deaths; thus, 85% of the deaths in the HIV-positive group were caused by HIV infection. The Perth-Group, however, and along the same lines as Duesberg, disagreed with the study and wrote a paper that refuted the evidence presented by the Oxford study. The publication of the Perth paper, which was vetoed by *Nature* but published in the dissident journal *Continuum*, concluded that out of the 403 deaths of the Oxford study 235 deaths were merely assumed to be of AIDS (Papadopoulos-Eleopoulos, 1995). No evidence substantiated that these deaths had actually been caused by HIV infection. In addition, the Perth Group also argued ‘that what has been called HIV infection in haemophiliacs is not caused by an exogenous retrovirus to which haemophiliacs have been exposed to but by the *administration* of Factor VIII preparations’ (Eleopoulos-Papadopoulos, 1995). This was suggested by the fact that some

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<sup>189</sup> Duesberg also argued that, according to CDC statistics, the rate of development of AIDS-defining illnesses observed in wives of haemophiliacs was too small to corroborate the hypothesis that HIV was

haemophilic children who present no risk factors, and whose carefully controlled factor VIII has systematically tested negative for HIV antibodies, become HIV-positive. A positive antibody test in haemophiliacs, hypothesise the Australian scientists, results from the amount of foreign protein in Factor VIII. In its original formula factor VIII contained 99% of impurities and only 1% of clotting factor. The quantity (dose-related) and time (age-related) of Factor VIII product administered to each individual would be the other two relevant variables in an HIV diagnosis in haemophiliacs.<sup>190</sup>

6.5.3.4.- Kaposi Sarcoma: the mistaken signifier

Kaposi's sarcoma (KS) was first identified in 1872 by the Viennese dermatologist Moritz Kaposi, in males living across the Habsburg Empire. However, by the middle of the twentieth century KS was reported to be common among elderly men of tropical African, Sicilian, and Ashkenazy Jewish descent (Christie, 1996).<sup>191</sup> But now, at the end of the twentieth century, KS was attacking homosexuals; so far it had killed eight out of the twenty-six first diagnosed (Epstein, 1996). KS is a cancer of the blood vessels, which develops internally as well as externally. Its characteristic purple lesions, which appear throughout the surface of the body, became the most identifiable stigmata of AIDS, the visible confirmation of the physical and moral degeneration of its bearers.<sup>192</sup> The harrowing skin lesions caused by KS made visible the inherent 'hazard' of being a homosexual. KS materialised the imagined linkage of fortuitous appearance of disease

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sexually transmitted (Shenton, 1998).

<sup>190</sup> When given improved versions of Factor VIII (which contained 99% clotting factor and 1% impurities and cost twice as much as the 'dirtier' version), the health of haemophiliacs improved dramatically (Shenton, 1998). For a series of other studies supporting this argument see Hodgkinson, 1996.

<sup>191</sup> For reasons yet to be discovered KS is fifteen more times common in men than women (King, 1996).



with the perceived cultural-ethnic properties of its victims. Yet, the medical theories that supported the notion of putrefying lesions as the sign of intrinsic rot were disputed almost as soon as they were proposed.

If KS were indeed caused by an infectious agent why had there been no cases of KS amongst haemophiliacs? The largest UK study of AIDS among haemophiliacs did not identify one single case of KS, and an American study revealed that, of the thirteen HIV-positive children with KS, all (but one) descended from African populations where KS is endemic (Beral, 1990; Darby, 1995). The epidemiological classification of KS identifies four main types. There is the *sporadic* KS of Sicilian men and Ashkenazy Jewish males, which usually appears in relatively old age. There is the *endemic* (and mostly ubiquitous) KS of tropical Africans between the ages of 2-15 and 25-45, the *iatrogenic* KS of organ transplant recipients who have been given immunosuppressive drugs, and the *epidemic* KS of gay men from 1980 onwards. Yet, in the words of Gallo's team published in *Science* as early as December of 1984, 'the absence of detectable HTLV-3 sequences in Kaposi's sarcoma tissue of AIDS patients suggests that this tumour is not directly induced by infection of each tumour cell with HTLV-3' (quoted in Hodgkinson, 1996: 360). Simply, because HIV is not found in the cells of KS lesions, it cannot directly cause KS.

Once it was firmly established that HIV could not directly cause KS, it was hypothesised that HIV's immune suppressive effect was its indirect cause. However, the laboratory

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<sup>192</sup> In the Hollywood Aids-epic 'Philadelphia' the sight of the protagonist's body, covered with KS lesions, epitomises the suffering caused by AIDS.

abnormalities (alterations in T4 and T8 cells) that defined the immune suppression thought to be caused by HIV infection were also found in (HIV-negative) heterosexuals. In the latter, as well as in HIV-positive and HIV-negative homosexuals, these immunological abnormalities were also associated with a wide range of causes such as blood transfusions, infections, and antibiotics. In 1988 the US's military Walter Reed Army Institute of Research decided to drop KS from its list of AIDS-defining illnesses:

In our system the presence of opportunistic infection is a criterion for the diagnosis of AIDS, but the presence of Kaposi's sarcoma is omitted because the cancer is not caused by immune suppression (Redfield and Burke, 1988:262).

Two years later, a team of scientists from the CDC proposed a new hypothesis: a yet unidentified sexually transmitted agent caused KS in persons with AIDS (Beral, 1990). The Perth Group disagreed, and argued that it was inconsistent with the current knowledge of other neoplasms (tumours) to assume that KS is exceptional by having a single cause in all individuals. Again the Australians proposed an alternative etiological model to explain the stupendous rise of KS amongst AIDS patients (20,000 times more likely to appear in AIDS patients than in the general population). KS was attributed to different oxidising agents in the various affected groups. Once more the dissident notion that the complex of diseases associated with AIDS has a toxic rather than infectious genesis was reiterated (Papadopoulos-Eleopoulos, 1992). In a 1994 meeting of the American National Institute on Drug Abuse (NIDA), dozens of HIV-free cases of KS among gay men were reported (Hodgkinson, 1996). Today, all HIV/AIDS experts, including Gallo, accept that HIV has no direct or indirect role in KS (Christie, 1996).

However, KS when found in an HIV-positive patient still produces an AIDS diagnosis.<sup>193</sup>

#### 6.5.3.5.- An Epidemic in the Western World?

Since the beginning of the health crisis the Centers for Disease Control (CDC) have revised the definition of AIDS four times. Whereas in 1983 two diseases comprised the syndrome by 1985 the CDC had declared that another eight diseases should be added to the list, and included *specific* reference to HIV as a pre-condition of AIDS. In 1987 the spectrum of diseases that constituted the syndrome was expanded even further to a total of forty-two diseases. Again, in 1993 the disease spectrum was broadened with the addition of pulmonary tuberculosis, cervical cancer, and recurrent bacterial pneumonia, or a CD4 count of less than 200.<sup>194</sup> All the diseases that comprise AIDS had previously existed, none are new diseases. It is widely believed that the four redefinitions of what constitutes AIDS have been necessary adjustments that reflect the developing epidemiological nature of a syndrome whose scope is continually increasing (King, 1998). However, some have argued that what these redefinitions actually do is disguise the fact that the 'epidemic' is in fact shrinking (Fumento, 1990; Lauristen, 1993; Hodgkinson, 1996; Maggiore, 1996; Shenton, 1998).

The 1993 redefinition, broadened to encompass individuals who may have no actual disease (even if they have a depleted T-cell count), doubled the number of American

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<sup>193</sup> In its factsheet about skin cancers CancerBACUP, the UK's leading cancer information service, states that 'AIDS-related KS is the commonest and most quickly developing form of the disease' (cancerbacup.org.uk).

AIDS cases overnight.<sup>195</sup> Before the 1993 redefinition, AIDS cases had actually levelled off in all risk groups. However, after the redefinition ‘more than half of all AIDS cases reported for 1996 (62%) were among people meeting the non-illness criteria for AIDS.’ If the first (1983) AIDS definition had continued to be employed, by 1996 AIDS would only have afflicted 8,200 new Americans. According to the CDC’s latest available AIDS data, the *HIV/AIDS Surveillance 1998 Year-end Report*, the number of ‘persons living with AIDS’ (or AIDS prevalence) was 270,841 in 1997 ([www.cdc.gov](http://www.cdc.gov)). Although there is no data to inform us how many of those people actually have any manifestation of disease, if the 1996 proportions above were kept unchanged only 102,920 individuals would have actually been sick with one (or more) of the forty-five diseases which comprise AIDS. Interestingly, the US’s National Organisation for Rare Disorders (NORD) defines a rare disease as any that affects fewer than 200,000 Americans ([www.rarediseases.org](http://www.rarediseases.org)). Moreover, in every year through 1994 AIDS prevalence fell below 200,000 (Maggiore, 1996).

Current official estimates calculate that 34 million people are infected with HIV worldwide, of whom 24 million are in sub-Saharan Africa (Durban Declaration, 2000). Official 1996 statistics estimated that 21 million adults were living with HIV/AIDS, and that while heterosexual intercourse accounted for more than 70% of such infections homosexual intercourse was responsible for between 5%-10%. Transfusion of HIV-infected blood or blood products was deemed to account for 3%-5%, and drug-use for

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<sup>194</sup> European countries have adopted the 1993 CDC definition, but have excluded the less-than-200-CD4 criteria.

<sup>195</sup> An individual’s CD4 cells can vary greatly within a 24-hour period according to a variety of different factors, and are not predictive of AIDS (King, 1994).

5%-10% (UNAIDS website). In the western world, however, AIDS has not significantly spread beyond the so-called risk-groups. In the US, for example, 94% of all AIDS cases remain confined to gay men and IV drug users. Michael Fumento's *The Myth of Heterosexual AIDS* first challenged the notion that AIDS was 'going from heterosexual to heterosexual through intercourse, that it was epidemic among non-drug-abusing heterosexuals' (1990:14). Fumento showed that only 'about nine tenths of 1 percent' of all AIDS cases in the US was accounted for by 'whites who are thought to have become infected through heterosexual intercourse'. Fumento argued that heterosexual transmission is usually associated with being the sexual partner of an IV drug user. As such, an even smaller percentage of these cases belonged to the white middle-class.<sup>196</sup> AIDS cases in whites thought to have become infected through heterosexual intercourse (not excluding those exposed to 'high risk partners') account only for 6% of all AIDS cases. Moreover, if we include only the cases of white heterosexual transmission, without evidence of 'high risk partners', that percentage will drop to 0.3% (PHLS, 9/1998 – Table 1). As such, the 'de-gaying' of the epidemic might have been a benevolent tactic to secure funding to research a disease remote from mainstream society but its unanticipated effect was

the ultimate triumph of politics over science. Indeed, it is the triumph of politics over reality, with what is "right" or "correct" determined not by what is scientifically right or correct, but by whatever happens to fit a specific agenda and whatever is socially acceptable. It shows the ability of the state, the media, and various special interests to shift an entire nation's perception – indeed of several nations – of the spread of the disease (Fumento, 1990:14)

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<sup>196</sup> The great majority of IV drug users come from the lower classes (Fumento, 1990).

Epidemiology is a normalising science; it reinforces 'unexamined notions of normality to measure and classify deviations from the norm.' This normalising function underpins the fabric of the epidemiological data used to classify HIV-infected persons under specific 'exposure categories' constructed through 'hierarchical representation' (Epstein, 1996).

As it is often difficult to establish the route through which an individual has become infected with HIV

where there has been exposure to HIV infection by more than one route, allocation to the summary categories used in these tables is based on a judgement as to which is the most probable route.

Those exposed to infection, for instance, both through sex between men and injecting drug use, are usually allocated to the summary category of sex between men because of the greater frequency of HIV infection in that group in the UK (Public Health Laboratory Service AIDS Centre, 1998)

Hierarchical representation 'de-emphasizes and underrepresents every patient characteristic *except* homosexuality'; it highlights the moral function of medical science, which in 'its statistical misrepresentation of reality' presumes the most 'sinful' to be the most 'dangerous'. In the US, for example, it is estimated that 25% of gay men with AIDS are also IV drug users. This 25% figure, which is equivalent to 19% of the totality of US AIDS cases, ends up classified under the 'homosexual-exposure' category rather than the 'IV-drug-use category'. If such cases were classified under IV drug use, and were added to those of heterosexual IV drug users (17% of total AIDS cases), the percentage of American AIDS cases attributable to IV drug use would rise to 36% of the total (Lauristen, 1993:57-63).

## 6.6.- Suppressing Resistance

The veracity and exactness of the information produced by the 'dissident critique' and the 'dissident movement' is not the concern of this analysis. So far my goal has been the introduction of the movement's cultural content, its ethos, tactics, resources and constituency. The highly counter-cultural ethos of the dissident movement makes it an obvious choice for counter-resistance strategies from the mainstream institutions which it attacks. It is thus not surprising that the movement has encountered significant opposition.

### 6.6.1.- Suppressing Dissent Information

Publicly relevant engagement with the dissident critique often has significant consequences. Michael Fumento's *The Myth of Heterosexual AIDS* was one of the first exposés of the political manipulation of the health crisis. The controversial message of the book was an elaboration of an article, which Fumento had written for the *New Republic* magazine in 1988. In it Fumento criticised AIDS lobbyists and health educators for exaggerating the risks of the epidemic, and denounced conservative politics for using the epidemic to promote their own political agenda. The book's main message was that AIDS posed no threat to the 'general population'. The publication of this article cost Fumento his job as an AIDS analyst for the US Government's Commission on Human Rights (Hodgkinson, 1996).

Robert Root-Bernstein, who was associate professor of physiology at Michigan State University, was the second youngest recipient ever to receive the five-year MacArthur fellowship. The fellowship, known as the 'genius grant', is awarded to unusually promising experts of various fields. In April of 1990, Root-Bernstein's 'letter-to-the-editor' was published in the *Lancet*. In it Root-Bernstein entertained several hypotheses: AIDS may not be a new disease; AIDS might be caused by other factors besides HIV; HIV may constitute an infection that takes hold of previously immuno-supressed individuals. Such ideas occurred to him as a result of his research which demonstrated that before 1970 around 20% of all Kaposi's sarcoma cases fit the pattern that was generally believed to have arisen only after the appearance of HIV. Bernstein's 1993 book *Rethinking AIDS: The Tragic Cost of Premature Consensus*, which argued for the fundamental role of co-factors in the development of AIDS, was totally ignored by the lay and scientific press in the UK. Neville Hodgkinson, the *Sunday Times*' science correspondent, was criticised by the mainstream media for the mere fact of having reviewed Bernstein's book. This review marked the beginning of a series of articles reporting on dissident views, which Hodgkinson began to publish in the *Sunday Times* in 1993. In the end, Hodgkinson's reporting on dissident ideas cost him his job as well (Hodgkinson, 1996:206).

The television production company 'Meditel' first got involved in the questioning of the scientific validity of the HIV/AIDS hypothesis with the documentary *AIDS: The Unheard Voices*. The Channel 4 documentary, which centred on an interview with Duesberg, explained the scientist's critique of the HIV/AIDS model. Three years later, the Meditel



team produced another documentary, *The AIDS Catch*, which was shown in the 'Dispatches' series on Channel 4 in June.<sup>197</sup> The film expanded on the ideas of the first documentary, and reported on Duesberg's 'risk-AIDS' hypothesis and its radical corollary: that AIDS was not an infectious, sexually transmitted disease. *The AIDS Catch* also featured the first interview in which Luc Montaigner revealed his doubts about HIV's harmfulness without the presence of co-factors. The controversy caused by the documentary was tremendous.<sup>198</sup> Despite protests from Channel 4 and the Independent Television Commission, the BCC found that the program had been unfair in its treatment of the subject. The BBC, however, stated that although it could not discuss the scientific arguments. Meditel went on to produce *AIDS in Africa* in 1993. This film challenged the idea that heterosexual AIDS in Africa was rampant, and suggested that it was the availability of international funding for HIV that encouraged the classification of other illnesses as AIDS. In 1994 Meditel produced yet another controversial documentary, *Diary of an AIDS Dissident*, where viewers of Sky News were shown efforts of the AIDS establishment to suppress dissident publications. Meditel's last documentary - *HIV Testing* (1998) – which had been commissioned by Channel 4's news editor Jim Gray to be aired during the 1998 World AIDS Day was, however, altogether banned at the very last minute due to pressure from the medical profession (Walker, 1999).

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<sup>197</sup> *The AIDS Catch* received the Royal Television Society Award for the best international current affairs documentary in 1987 (Hodgkinson, 1996).

<sup>198</sup> *The Independent* published a letter of protest, which was signed by several of the UK's leading figures in the fight against AIDS. David Lloyd, Channel 4's commissioner of the two Meditel documentaries on AIDS, replied by arguing that these two forty-minute documentaries represented the only television broadcasting time which had ever been dedicated to the dissenting opinion in Britain. The drugs manufacturer, Burroughs-Wellcome, and the AIDS organisation, the 'Terrence Higgins Trust,' took Meditel to the Broadcasting Complaints Commission (BCC).

Meditel's 1990 documentary *The AIDS Catch* prompted the first serious rebuttal of Duesberg's work. By then Duesberg had argued not only that HIV was harmless and not sexually transmitted, but also criticised the reliability of ELISA tests and of the main therapeutic drug used in the treatment of HIV infection (AZT). The publishing of a two-page commentary in *Nature*, which followed the broadcast of *The AIDS Catch* in the beginning of 1990, was pivotal in the National Institute of Health's refusal of Duesberg's application for renewal of his five-hundred-thousand-dollar-a-year 'outstanding investigator' grant. However, although *Nature's* commentary constituted the first effort from the orthodoxy to respond to Duesberg, it was deemed to be 'an emotive "commentary" rather than a scientific rebuttal' (Hodgkinson, 1996:167; Epstein, 1996). Duesberg fought for the following two years to have the NHI decision reversed, but his efforts were fruitless. Since then every single one of his peer-reviewed grant applications to federal, state, or private agencies has been withdrawn; and his once automatic access to prestigious academic publications has been severely curtailed.

6.6.2.- Suppressing State Dissent

One of the most recent supporters of the 'dissident movement' is South African president Thabo Mbeki. In his 'Letter to World Leaders on AIDS in Africa', which was posted to heads of state around the world on April 3<sup>rd</sup>, 2000, Mbeki wrote:

In an earlier period in human history, these (dissidents) would be heretics that would be burnt at the stake! Not long ago, in our own country, people were killed, tortured, imprisoned and prohibited from being quoted in private and public because the established authority believed that their views were dangerous and discredited. We are now being asked to do precisely the same

thing that the racist apartheid tyranny we oppose did, because, it is said, there exists a scientific view that is supported by the majority, against which dissent is prohibited. The scientists we are supposed to put into scientific quarantine include Nobel Prize Winners, members of Academies of Science and Emeritus Professors of various disciplines of medicine (SAPA, 05/05/2000)

South Africa's AIDS prevention campaigns were initiated only after the African National Congress took over from the apartheid government in 1994. Such delay has been deemed responsible for South Africa's exorbitant number of HIV-infected individuals: 8,200,000 people.<sup>199</sup> In face of such alarming statistics, President Mbeki embarked in a research effort to familiarise himself with the problem of AIDS. He is reported to have spent a great deal of time browsing the Internet for information on AIDS (SAPA, 05/05/2000). The results of Mbeki's research efforts led him to announce, a few months before the 13<sup>th</sup> International Conference on AIDS was to take place in South Africa, his intention to appoint an international advisory panel of experts to critically appraise the established medical model of AIDS. Mbeki could not have foreseen the uproar his decision would cause.

Mbeki assembled an advisory panel constituted of eleven 'dissident' and twenty-two 'orthodox' experts on AIDS. Mbeki's scheme envisioned a two-tier process where the participants would first meet to establish the terms of the debate. The actual debate, where the participants were supposed to prove or disprove at least some of the conflicting ideas, was to take place through a special closed Internet forum for the subsequent two months. After the debate had been concluded the participants would meet again in order

to finalise their results. Such meeting would take place right before the start of the 13<sup>th</sup> International AIDS Conference in the South African coastal city of Durban. Mbeki's plan, however, utterly failed. The panellists first met in the beginning of May in Pretoria, the country's capital. Mbeki's scheme proposed that dissident as well as orthodox experts congregate in multiple 'mixed' teams in order to present and discuss scientific data. The press should be invited to observe the initial debate. In reality, orthodox panellists used their majority vote to split the panel into two groups, each comprised exclusively of either dissident or orthodox experts. The majority vote also banned the participation of the media, *and* the presentation of any scientific data. In addition, the scientific 'debate', which was meant to have taken place over the Internet in the intervening two months, was a fiasco. Orthodox representatives completely ignored dissident questioning and evaluation. Moreover, the orthodox share of virtual space was left utterly blank for the two months in which the scientific debate ought to have taken place. Mbeki's organisers were reported to be furious (Rethinking AIDS, (8) 8).

The 13<sup>th</sup> International AIDS Conference opened on the 9<sup>th</sup> of July of 2000. On the 6<sup>th</sup> of July the 'Durban Declaration' was published in *Nature*, and released just before the second meeting of the advisory panel. Whilst the orthodox panel advisers had blatantly avoided any form of debate in the forum set up by the South African government, many of them comprised the list of 5,195 scientists and physicians from around the world who had signed the 'Durban Declaration'. The Durban document – 'a declaration by scientists and physicians affirming HIV is the cause of AIDS' – did not address the issues raised by

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<sup>199</sup> 20% of South Africa's 41 million inhabitants are supposed to be HIV-positive. This represents the highest number of HIV infected individuals of any nation in the world (Washington Post 10/06/00).

the dissident critique. It simply constituted a reverberation of the orthodoxy of HIV. A month later, *Nature* published the dissident response - 'The Durban Declaration Is Not Accepted By All' - where the 'clear-cut, exhaustive and unambiguous' evidence presented by the signatories of the Durban Declaration was contested [Nature 407, 286 (2000)].<sup>200</sup> Mbeki was not intimidated. His press secretary declared that if the Durban Declaration was officially presented to him it would find its place 'amongst the dustbins in the office (SAPA, 10/06/00).

The 13<sup>th</sup> International Conference on AIDS became a 'Mbeki-bashing event' (SAPA, 10/06/00). Thousands demonstrated at Durban's City Hall before the meeting began. Later, in his opening speech to the 10,000 delegates, broadcast live on South African television, Mbeki blamed malnutrition, poverty, and inequity as the causes of the great burden of disease in the African continent. Hundreds of delegates walked out on President Mbeki, as he failed to state that HIV is the cause of AIDS (Washington Post, 10/06/00). Unabated, and despite increasing international pressure and discredit, Mbeki has stuck to his position. In a controversial interview with America's *Time* magazine of September 11, 2000 Mbeki stated:

Clearly there is such a thing as acquired immune deficiency. The question you have to ask is what produces this deficiency. A whole variety of things can cause the immune system to collapse. Now it is perfectly possible that among those things is a particular virus. But the notion that immune deficiency is only acquired from a single virus cannot be sustained. Once you say immune deficiency is acquired from that virus your response will be antiviral drugs. But if you accept that

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<sup>200</sup> A number of the 13 scientific references upon which the document based its 'indisputable' evidence

there can be a variety of reasons, including poverty and the many diseases that afflict Africans, then you can have a more comprehensive treatment response

A month after his *Time* interview, President Thabo Mbeki addressed the two hundred members of his country's National Assembly. After discussing some points concerning international relations and economic matters, the President focused on the controversy his views on AIDS have caused. Mbeki said a propaganda war was being waged against him, and that institutions and individuals determined to maintain the current world economic order were leading such attempt. Mbeki stated that the United States Central Intelligence Agency (CIA) had become covertly involved in the dissemination of the notion that HIV causes AIDS, and that what passed as US aid constitutes, in reality, loans for African governments to buy anti-HIV medication. He concluded his address by demanding a positioning on the issue by the members of his Cabinet, and pleaded for support in his challenge not only to the AIDS industry, but also in his government's attempts to strike a better deal for developing nations in the international economic order (SAPA, 12/11/2000). Subsequently, dissident organisations have established 'The International Coalition to End AIDS Censorship'. Its objective is to support President Mbeki's call for an open scientific debate on the definition, causation, treatment and prevention of AIDS. 3,500 signatures have so far been gathered (virusmyth.com).<sup>201</sup>

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'did not support the points they were cited to support' (Rethinking AIDS 8 (8):3).

<sup>201</sup> In 2003 the South African government has started providing antiretroviral treatment for its population.

### 6.7.- The Medical Gaze: probing the positive body

In 1993 Kary Mullis won a Nobel Prize for inventing 'biotechnology's version of the Xerox machine' – known as 'Polymerase Chain Reaction' (PCR). PCR enables the multiplication of a minute sample of DNA into millions of copies. PCR technology was first publicised during the 11<sup>th</sup> International AIDS Conference in Vancouver in early 1996. By the end of that year, the 'viral load' test (as PCR technology is popularly known) had undoubtedly become the principal surrogate marker of disease progression.<sup>202</sup> In the Vancouver Conference the initial success of 'combination therapy' was also announced. As such, the conference marked the triumph of the virological conception of HIV aetiology and treatment. Since the mid-1980s it had been widely believed that HIV infection remained latent in the body for many years. In this 'dormant' state, however, HIV somehow depleted the infected body from its vital CD4 cells. PCR technology, postulated David Ho and his research team, demonstrated that there was no dormant period of HIV infection (Ho et al, 1995). The virulent activity of HIV could now be measured by PCR, and be identified in recently infected individuals. After PCR a number of significant changes have occurred in HIV clinical practice; the main goal of anti-HIV therapy has become the achievement of 'undetectable viral load'. Although health monitoring of the positive body continues to involve multiple pathologies, T-cell testing, which had been the primary marker of the disease for over a decade, has been upstaged by the measurement of 'viral load' as the decisive factor in treatment decision-making.<sup>203</sup> As a result of such technological developments, an important shift in the

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<sup>202</sup> The test is thought to quantify the level of HIV in plasma, relaying the activity of virus in the blood in terms of a logarithmic scale.

<sup>203</sup> The Australian National Council on AIDS and Related Diseases, for example, states that the viral load test is 'central to making decisions to start or switch antiretroviral therapy, (and able to) predict progression

conceptualisation of AIDS occurred in 1996. The syndrome AIDS would now be better conceptualised as HIV disease since the new technology had demonstrated that the positive body engaged in a continuous battle against the virus from the moment of infection.

The shift in the conceptualisation of AIDS to HIV disease was accompanied with the new treatment strategy of HAART. Previously assessed in terms of preserving immune function, antiviral treatment now came to be determined mainly in terms of viral suppression. PCR technology had revealed the high levels of viral activity in the bodies of the newly infected; as such, 'hit hard, hit early' became the new motto of biomedicine's treatment strategy. Sadly, the initial euphoria occasioned by the new 'cure' only lasted for a little while. The utility of early intervention has not been proven by clinical trials, and the efficacy of combination therapy in fighting HIV disease has often been disappointing (Positive Times, 20/03/1998).

Four years of 'hit hard, hit early' HIV treatment may be on the way out in the US, as evidence mounts of the drugs' serious side effects. AIDS experts in the US are about to complete a humiliating U-turn when the Department of Health and Human Services launches its revised HIV treatment guidelines in January. The revisions will underline the need to hold back from using powerful antiviral drugs until the immune systems of HIV patients show significant signs of decline. It reflects the view, long held by British doctors, that early use of currently available drugs may do more harm than good... British doctors were often ridiculed at conferences and in the pages of research journals for suggesting the drugs be used more cautiously, in case they proved too toxic for patients who take them for years or decades at a time...taking a combination of

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to AIDS and death independently of CD4 counts' (*Antiretroviral Therapy for HIV Infection: Principles of*



protease inhibitor and transcriptase inhibitor drugs early on in HIV disease could do patients more harm than good (*New Scientist*, 12/16/2000)

Although HAART therapy has benefited many HIV-infected patients, the benefits of the drugs cannot be evenly shared. Several recent studies have found that the new drugs work only for some patients, and that many develop severe side effects.<sup>204</sup> As we have seen, one of the main dissident arguments against the HIV/AIDS hypothesis is that traditional methods of virus detection produce no detectable virus (even persons dying of AIDS present very low levels of 'viral activity'), and that the presence of HIV is measured by indirect methods that are not specific to HIV.<sup>205</sup> The dissident critique argues that if minimal amounts of HIV were present, then traditional techniques of virus detection, rather than PCR technology should be sufficient. Kary Mullis, who won a Nobel prize for the invention of PCR technology has criticised the use of his invention to detect HIV, and has referred to quantitative PCR as 'an oxymoron'.<sup>206</sup> PCR's sensitivity will amplify whatever DNA is in the sample – whether HIV-related or not (PCR may detect HIV in those who test negative for HIV antibodies). As such, it is difficult to decide which amplified material belongs to HIV and which belongs to the contaminants, especially when HIV cannot be found in the sample without the use of PCR in the first place. For such reasons, the US's FDA does not recommend nor license PCR for diagnostic

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*Use. Standard of Care Guidelines* (10, 1997:11).

<sup>204</sup> A German study, for example, has recently reported a 44% failure rate from 198 HIV-positive patients treated with protease inhibitors, and concluded that 'the favourable results from controlled studies with antiretroviral drugs containing protease inhibitors cannot simply be translated into everyday clinical practice' (*AIDS* (15), 1997:15-17).

<sup>205</sup> These indirect measures are: detection of reverse transcriptase or the presence of a p24 protein (which, for example, is detected in 35% of patients with biliary cirrhosis) (*Lancet*, 30/05/1988).

purposes in HIV disease. Yet, as in the case of surgery for TB, the medical profession is often oblivious to issues of efficacy and validity when a new technology is favoured. Thus, although PCR is not FDA-approved for diagnostic use, and is unable to distinguish between infectious and non-infectious genetic fragments, the use of the new technique has come to dominate HIV science (Maggiore, 1996; Johnson, 1996a).

HIV is much more than a biological entity - it is a social phenomenon, a powerful marker of identity with a myriad of socio-economic consequences. As we have seen in the previous chapters of this thesis, many 'micrological' resistance strategies have been articulated to countereffect and combat the stigma of HIV and homosexuality. In the present chapter I have not attempted to provide a scientific critique of the science that surrounds HIV. What I have endeavoured to do is demonstrate how modern science, deemed to constitute 'a public space with restricted access', may protect its boundaries to the point where this 'form of knowledge that is the most open in principle has become the most closed in practice' (Hodgkinson, 1996:21). Since the inception of the first antiviral drug (AZT), debate on early intervention has existed as a discourse articulated and constrained by a multiplicity of actors and institutions: biomedicine, the pharmaceutical industry, the dissident critique, HIV-infected individuals, AIDS activism, and public health policy makers. However, only after the appropriation of PCR technology by the science of HIV/AIDS did the 'hit hard, hit early' therapeutic strategy become institutionalised as legitimate (even if contested) knowledge. As such, knowledge(s) and systems of surveillance have firmly crystallised around the positive body, which is

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<sup>206</sup> Mullis has also said: 'If there is evidence that HIV causes AIDS, there should be scientific documents that either singly or collectively demonstrate that fact, at least with a high probability. There is no such

constantly monitored in terms of its compliance to HAART treatment. The medical system, as such, has achieved an unprecedented level of incursion into the lives and the bodies of the infected. In the following chapter I shall analyse the empirical data I have collected. My objective is to examine how these configurations of power and knowledge have played out on the individuals of my sample, and the particular characteristics of the resistance strategies they might have engaged in after having received an HIV diagnosis.

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document' (Interview with Kary Mullis, *Spin* July, 1994).

## Chapter 7

### HIV-Diagnosed: Constructing Resistance and Legitimising Identities

#### 7.1.- Conducting Computer-Assisted (HAMLET) Text Analysis

The social scientific study of the ‘meaning’ of communication is articulated through a series of techniques known as ‘content’, ‘text’ or ‘thematic’ analysis. Since the first basic quantitative analyses of printed texts took place in eighteenth century Sweden (Krippendorff, 1980), the technique has significantly evolved.<sup>207</sup> The focus of the technique is the invisible dimension of language, its symbolic content. Several definitions of text analysis have been proposed (Stone et al, 1966; Berelson, 1971; Krippendorff, 1980; Shapiro and Markoff, 1997); the various approaches should be applied in accordance with the symbolic objects of communication of each particular study. As such, ‘text’ can be interpreted in a variety of ways.<sup>208</sup> The material characteristics of ‘text’ do not constitute the most relevant aspect for text analysis studies as the definition of ‘text’ depends on the nature of the research questions. However, interpretative approaches to communication material which call themselves ‘text analysis’ must observe the fundamental principle of objectivity and engage in systematic analysis.

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<sup>207</sup> Its five stages of development so far are: ‘frequency’ analysis (frequency of words/themes in a text) until the 1950s; ‘valence’ analysis (negatively and positively valued words) in the 1950s; ‘intensity analysis’ (words/themes were assigned weights to indicate the relative strength of assertions) up to the 1960s; ‘contingency’ analysis (text analysis evolved from its purely descriptive phase to investigating the associations between textual characteristics) starting from the 1960s; computer assisted analysis from the 1960s to the present (Popping, 2000).

<sup>208</sup> There are three fundamental definitions of text. The first defines text as every semiotic structure of meaning (including not only language, but plastic art, music and social action and events). The second

Objectivity implies a number of technical subterfuges to avoid bias whereas being systematic signifies the inclusion and exclusion of categories according to consistently applied rules.<sup>209</sup> In my qualitative research project the emphasis was not on statistical inference; categories were hence devised in terms of their presence or absence, not in terms of their variable scaling points on ordinal levels of measurement (George, 1959). The focus was both on ‘manifest’ (defined by the standard use of the word) and ‘latent’ (defined by all the other possible uses of the word) content of the object of study, i.e. transcripts of interviews of HIV-infected male individuals. In my research ‘text’ was viewed as a ‘linguistic’ form of expression (Popping, 2000).

## 7.2.- Code Development

### 7.2.1. Exploring Codes through Word Frequency Analysis

With the goal of expanding on the initial (potential, provisional) conceptual categories that had emerged from the NUDIST organisation and analysis of the data, the single

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definition only includes linguistic means of expression. The third definition of text refers to written language only (Lindkvist, 1981).

<sup>209</sup> Reliability is a critical component in the use of thematic analysis; it means consistency of observation and interpretation. For example, in order to determine the reliability of themes, codes should be applied to a subsample of the data by independent coders (people other than the person who has developed the codes). If desired levels of reliability and consistency of agreement of the themes in the code are not achieved then the codes should be abandoned. Consistency of observation, i.e., intrarater and interrater reliability is achieved when independent coders abstract similar information from the codes. Research design and methods, such as standardisation of the interview process; also affect the degree of consistency of observation that can be achieved. Systematic procedures of comparison between codes, and the determination of their presence or absence in the data, will also increase the reliability of codes inasmuch as they are continuously reviewed against the data and as such can be reviewed, rethought, dropped, and rewritten if necessary (Boyatzis, 1998).

words of each of the ten transcripts selected for thematic analysis were analysed by HAMLET. In the first stage of conducting thematic analysis HAMLET produced a list of the frequency of words uttered in each interview as according to the transcripts. The next step was to remove the utterances of the interviewer from each individual transcript with the objective of obtaining a more accurate lexical picture of interviewees' usage of words. Another 'frequency of words' run was then executed for each transcript, and compared to the previous run (which included the interviewers' vocabulary as well).<sup>210</sup> These lists of respondents-only utterances provided me with a complete panorama, in descending order of frequency, of all the respondents' words present in each transcript. I was therefore able to assess word-usage in each transcript, and compare word-usage between transcripts of each subset. After I had familiarised myself with each individual transcript, and in order to refine my understanding of how the two subsets understood their experience of HIV infection, a 'total' file was created for each subset. The 'total orthodox file' contained all (and only the) utterances of the five orthodox interviewees and the 'total dissident file' contained all (and only the) utterances of the five dissident respondents. Such a procedure allowed me to contrast the word-usage of each 'total file' with the general usage of words in spoken English (Leech at al, 2001), and hence determine which were the most common 'uncommon' words each subset employed in order to describe their experience of being an individual infected with HIV.

In order to illustrate the process of how I devised my categories I present in Table 1 and Table 2 below the preliminary exploratory set of codes for each subset. These exploratory

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<sup>210</sup> See appendix C for an example of a frequency of words table.

codes were devised after the most 'common-uncommon-words' were grouped together in terms of the different categories they were thought to represent. At this point in the process some NUDIST derived categories were dropped as no 'common-uncommon-words' pertaining to the NUDIST category emerged. The most important example is the 'religion' category, which I had previously hypothesised might be related to therapeutic choice. Yet, in neither one of the subsets 'Religion' appeared as relevant. In addition, new categories suggested by the HAMLET analysis were brought in. For example, in analysing the orthodox subset it was revealed that the word 'never' constituted a very frequent word in all transcripts. As such, the exploratory code 'Never' was introduced.

**Table 1: Exploratory Codes for Orthodox Subset**

<b>Codes</b>	<b>Interview 2J</b>	<b>Interview 3A</b>	<b>Interview 5S</b>	<b>Interview 17 GS</b>	<b>Interview 19M</b>
<b>B/A</b>	before after	after		after before	after
<b>Gay</b>	out gay	out	out gay	out	gay out
<b>Never</b>	never	never	never	never	never
<b>Time</b>	time years	time years	time years	time year weeks months	months years
<b>Wellness</b>	well hospital health	well	well sick	well	well sick healing herbs
<b>Family</b>	mother	mother	mother father		father mother
<b>People</b>	people	people	people	people	people
<b>Belief</b>	think thought	thought	think	think thought	think
<b>AIDS</b>		HIV positive medication	HIV positive	HIV positive	HIV diagnosed
<b>Sex</b>		sex	sex	sex	sex
<b>Experience</b>		experience		experience	
<b>Relationship</b>		relationship	relationship		relationship
<b>Life</b>		died life	life		life
<b>Drugs</b>			drugs	drugs	
<b>Hardness</b>	hard	hard		problems difficult	hard



The analysis of individual dissident transcripts suggested that this subset employed many of the same categories of the orthodox subset. In addition, some new provisional categories emerged from the dissident data (these new categories are represented in Table 2 below, after the two blank rows which were introduced to highlight the distinction). For example, the code 'God' was created for this subset as the words God and spirit appeared frequently in three of the transcripts. Table 2 includes all the new (dissident) codes, and all the codes of the orthodox subset so that I could then compare the degree of presence or absence of the codes in the two different subsets.

**Table 2: Exploratory Codes for Dissident Subset**

<b>Codes</b>	<b>Interview 8HD</b>	<b>Interview 11DJ</b>	<b>Interview 15DA</b>	<b>Interview 18 DM</b>	<b>Interview 20 DE</b>
<b>B/A</b>	before after	after	before after	after	after before
<b>Gay</b>	out gay	out gay		out	out gay
<b>Never</b>	never	never	never	never	never
<b>Time</b>	time months years	time months years	Time months years	time years	time months
<b>Wellness</b>	well	well hospital doctors	doctor well sick	well	well sick treatment
<b>Family</b>					mother
	people	people		people	people
<b>Belief</b>	think thought suppose	believe thought	thought think	think thought believe	think thought
<b>AIDS</b>	HIV positive AIDS test	HIV AIDS positive KS test negative	HIV AIDS diagnosed	HIV	HIV positive cancer chemotherapy
<b>Sex</b>	sexual	sex	sex	sex	sex unsafe
<b>Experience</b>	experience			experience	
<b>Relationship</b>	relationship				relationship
<b>Life</b>	life		life died	died life death	life
<b>Drugs</b>	drugs	drugs	drugs	drugs	drugs
<b>Hardness</b>					
<b>Appended Codes</b>					
<b>Work</b>	work money	money	business		money
<b>Antibody</b>	antibody	cells CD4 viral			

	antibodies cells	load			
<b>Difference</b>	different			different	
<b>Combo</b>		combination therapy	therapy	combination	
<b>Continuum</b>			continuum		
<b>Mind</b>			mind	mind	mind
<b>God</b>	spirit		god	god spirit spiritual soul	
<b>Stress</b>	stress		stress	stress	
<b>Body</b>		body	body	body	body

(Table 2 continued from previous page)

Concept categories are operationalised by words and phrases. However, as a single word is often 'polysemous' the most-common-uncommon words identified above were subsequently examined in the specific contexts they were used.<sup>211</sup> By utilising Hamlet's 'Key Word in Context Listings' I obtained a list of all lines of text where the single 'most-common-uncommon' words appeared and as a result could identify the different meanings and contexts in which they were used. After performing a 'content analysis' of all transcripts, comparing and contrasting them, I was able to then aggregate single words and their multiple meanings into the codes.

#### 7.2.2.- Creating The Vocabulary List: word senses into the codes

After developing the codes and rereading transcripts several times in order to identify the other words used by respondents to refer to the same concept, I proceeded to create a vocabulary list. My vocabulary list included the single 'uncommon-most-common' words of each code, plus all the other words (word senses) which through the close reading of the transcripts I had decided belonged to a certain code.<sup>212</sup> For example, the word sense of the word 'drug' (used to denote both anti-HIV medication and recreational drugs) had to be amplified to include:

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<sup>211</sup> The disambiguation of a polysemous word such as 'bit' is a good example; 'bit' has different word senses such as 'the mouse bit the girl', 'it was a brace-and-bit tool', 'a 32-bit machine'. In my data it was necessary to disambiguate the word 'drugs' because it was equally applied to denote antiretroviral therapy and recreational drugs.

<sup>212</sup> Single words can not be included in different codes otherwise the categories would no longer be exclusive.

- a. when used to describe anti-HIV medication (code 'Medication') the word sense was broadened to include: combination therapy, anti-retrovirals, medication, protease inhibitors, retrovirals, 'combo', 'cocktail', and the several different specific names such drugs are commercialised as: AZT, DDI, Indinavir, etc.
- b. when used to describe recreational drugs (code 'Harddrugs') the word sense was broadened to include the whole array of recreational drugs mentioned by respondents: cocaine, ecstasy, ketamine, special K, speed, lsd, acid, marijuana, pot, splif, joint, and poppers.

The construction of a vocabulary list involves the differentiation of theoretical ideas. As such, I not only included in my vocabulary list the concepts that emerged from the HAMLET analysis of word frequencies, but also a number of theoretically-derived concepts I had explored through NUDIST. Therefore, my final vocabulary list included both *a priori* and *posteriori* coding schemes that fundamentally represented my emerging theory of how identity is reconstructed after diagnosis (Popping, 2000). Such a theory coalesced after systematic exploration of the data through HAMLET, and the previously acquired theoretical perspective I had adopted from literature review. If my codes (or categories) related single words to the relevant theoretical concepts, the vocabulary list comprised all the distinct conceptual categories that together refer to all the issues involved in the reconstruction of identity after an HIV diagnosis.

The final vocabulary list consisted of twenty codes and two-hundred-and-fifty-three word senses.<sup>213</sup> The process of developing categories had been broadly initiated with the NUDIST analysis I had conducted on the totality of the interviews I conducted. If the initial categories I used to aggregate data under general concepts had been deductively derived from literature review subsequent categories emerged from the empirical data and were thus inductively derived. The succeeding focus on ten interviews occasioned not only the revision of some of the categories generated through NUDIST but the emergence of new ones revealed by HAMLET. In this sense my research process resembled a 'stepwise' process. It started with tentative categories that were systematically revised in relation to issues of theoretical relevance by exhaustive and exclusive criteria in order to arrive at the next analytical step (Banks, 1976). The task now was to combine the categories into themes and sub-themes, i.e. broader clusters of distinct conceptions that related to the processes of restructuring identity.

7.3. Analysing Categories

7.3.1. – MultiDimensional Scaling (MDS): dissimilarity matrices and cluster analysis

Multidimensional scaling (MDS) is the name given to a number of different models that translate the information of a set of data into a low-dimensional spatial configuration, i.e. a set of points in space. Such representations facilitate the understanding of the empirical relationships found in a data set by representing complex associations between variables

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<sup>213</sup> See Appendix D for the vocabulary list.

that are contained in symmetric matrices of associations (of similarity or dissimilarity measures) (Kruskal and Wish, 1981; Coxon, 1982; Borg and Groenen, 1997). MDS translates such associations into points in space whose respective distances reproduce the numerical values of the coefficients of dissimilarity (or similarity) of the matrix. As such, the proximity and/or distance between the variables reflects the empirical relationships of the data set. In deciding upon which MDS model to use the researcher first has to consider the type of data that will be represented. The nominal (categorical) nature of my data (i.e. words assigned to codes in an unordered set of mutually exclusive categories) implied that only the order of the entries into the matrix was of relevance for the MDS solution appropriate to this type of data. In order to format the data to be suitable for HAMLET's multidimensional scaling, the data had to be configured into a co-occurrence matrix.<sup>214</sup> HAMLET's application 'Joint Frequencies' was used to calculate the co-occurrences of the words that comprise the vocabulary list. Hamlet calculates co-occurrences as the joint presence of both words within a 'context unit'<sup>215</sup>. The context unit for the present analysis was ultimately decided to be 'sentences as normally punctuated' because experimentation with the 'fixed' and 'variable' context units produced insufficient co-occurrences.

A matrix of dissimilarities between the categories was produced for both data subsets as well as a 'total' matrix for the two subsets together. The co-occurrence matrices can also be represented by HAMLET as hierarchical clustering schemes (HCS). Based on the

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<sup>214</sup> See Appendix E for the co-occurrence matrices of the data sets.  
<sup>215</sup> HAMLET allows for co-occurrence analysis to be performed within several contexts: fixed (a certain number of words); variable (delimited by special characters according to the researcher's decision); sentences (as normally punctuated); and collocations (within a span of words).

dissimilarity coefficients yielded by the matrix, HCS gathers the categories into clusters (Johnson, 1967). Hierarchical clustering constitutes a method that merges the two most similar points into a single grouping and continues to do so successively into more inclusive groupings until all variables have been accounted for. As such, HCS represented the twenty categories, referred to as 'levels of a single total hierarchical scheme', in terms of a total hierarchical scheme where each level is a special case of the next highest. As such, the higher level contained all categories whereas at the lowest level there were as many clusters as there were categories. It can be said that the solution provided by HCS methods consists of separate sets of groups or classifications that are rather unlike the spatial representational models of MDS. However, HCS methods are often used in conjunction with MDS precisely because cluster analysis provides no information on the extent of separation of the clusters, even if by forming clusters at decreasing levels of compactness HCS give considerable insight into the regions of space.<sup>216</sup> As such, the clustering scheme that was yielded by HCS analysis would later be used in conjunction with MDS to gain insight into the data sets. By constructing tables of MDS solutions with clusters drawn within, I would be able not only to determine the proximity of clusters but to home in on those with the most significant relevance (the ones formed in the initial stages of clustering).<sup>217</sup>

HCS constitutes a set of (disjoint) clusterings which are hierarchical in structure, i.e. each clustering level is a finer specification of the one below it. In the case of perfect data there is only one solution. However, if the data are imperfect, ambiguities enter into the

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<sup>216</sup> Another variety of clustering methods, so-called 'overlapping' or 'additive' clustering, are also used with MDS (Shepard and Arabie, 1977).



definition of the 'distance' between an existing cluster and the other points. Various possibilities have been suggested for defining the 'distance', and each is used in different methods of HCS.<sup>218</sup> But Johnson (1967), who developed HCS as a non-metric procedure, suggests examining such 'distances' by using the extreme values which such a 'distance' could take on the minimum ('connectedness' or 'single linkage') and the maximum ('diameter' or 'complete linkage') solutions. HAMLET, however, only enables the researcher to conduct the 'connectedness' or 'single linkage' method, which typically produces chaining (where a single cluster is repeatedly augmented by a succession of single points; see Table U). Therefore, I additionally employed the Johnson Hierarchical Clustering Program HICLUS in NewMDSX (<http://www.newmdsx.com>) software in order to be certain that my cluster analysis would not be restricted to the 'chained' perspective.

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<sup>217</sup> See section 7.4.2.

<sup>218</sup> For example, SPSS uses average and median linkage methods as 'the' solutions.

Table T: Diameter Maximum Dendogram for Orthodox and Dissident Data Sets

JOHNSON HIERARCHICAL CLUSTERING PROGRAM.

RUN NAME : Orthodox/Dissidents Data Sets

DIAMETER METHOD

	0 1 0 1 1 0 0 1 1 1 0 0 0 0 1 0 1 1 1 2
	4 4 7 3 5 6 3 7 8 6 8 5 9 2 1 1 2 0 9 0
0.34000000	. . . . . XXX . . . . .
0.31999999	. . . . . XXX XXX . . . . .
0.20999999	. . . . . XXX . . XXX XXX . . . . .
0.20999999	. . . . . XXX . . XXXXXXXX . . . . .
0.17000000	. . . . . XXXXX . . XXXXXXXX . . . . .
0.16000000	. . . . . XXXXX . . XXXXXXXX . . XXX . .
0.16000000	. . . . . XXXXX . . XXXXXXXX XXX XXX . .
0.14999999	. . . XXX . XXXXX . . XXXXXXXX XXX XXX . .
0.14000000	. . . XXX . XXXXX . . XXXXXXXXXXXX XXX . .
0.12000000	XXX . XXX . XXXXX . . XXXXXXXXXXXX XXX . .
0.11000000	XXX . XXX XXXXXXXX . . XXXXXXXXXXXX XXX . .
0.11000000	XXX . XXX XXXXXXXX . XXXXXXXXXXXXXXXX XXX . .
0.08000000	XXX . XXX XXXXXXXX . XXXXXXXXXXXXXXXXXXXX . .
0.08000000	XXX XXXXX XXXXXXXX . XXXXXXXXXXXXXXXXXXXX . .
0.06000000	XXX XXXXXXXXXXXXXXXX . XXXXXXXXXXXXXXXXXXXX . .
0.04000000	XXX XXXXXXXXXXXXXXXX XXXXXXXXXXXXXXXXXXXX . .
0.01000000	XXX XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX . .
0.00000000	XXX XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX
0.00000000	XX

**Table U: Single Linkage Dendrogram for Orthodox and Dissident Data Sets**

RUN NAME : Orthodox/Dissidents Data Sets

CONNECTEDNESS METHOD

	1 0 1 0 0 1 0 1 1 0 0 1 1 0 0 0 1 1 1 2
	6 4 4 7 6 3 8 0 5 1 3 2 7 9 5 2 1 8 9 0
0.3400000	. . . . . XXX . . .
0.3199999	. . . . . XXXXX . . .
0.3199999	. . . . . XXXXXXX . . .
0.2299999	. . . . . XXXXXXXXX . . .
0.2099999	. . . . . XXXXXXXXXXX . . .
0.2099999	. . . . . XXXXXXXXXXXXX . . .
0.2099999	. . . . . XXXXXXXXXXXXXXX . . .
0.2099999	. . . . . XXXXXXXXXXXXXXXXX . . .
0.2099999	. . . . . XXXXXXXXXXXXXXXXXX . . .
0.1900000	. . . . . XXXXXXXXXXXXXXXXXXX . . .
0.1700000	. . . . . XXXXXXXXXXXXXXXXXXXXX . . .
0.1700000	. . . . . XXXXXXXXXXXXXXXXXXXXXX . . .
0.1499999	. . . . . XXXXXXXXXXXXXXXXXXXXXXX . . .
0.1499999	. . . . . XXXXXXXXXXXXXXXXXXXXXXXX . . .
0.1200000	. XXX . XXXXXXXXXXXXXXXXXXXXXXX . . .
0.1100000	. XXX XXXXXXXXXXXXXXXXXXXXXXXX . . .
0.0999999	. XXXXXXXXXXXXXXXXXXXXXXXXX . . .
0.0900000	XXXXXXXXXXXXXXXXXXXXXXXXXXXX . . .
0.0400000	XXXXXXXXXXXXXXXXXXXXXXXXXXXXX . . .

Table T and Table U show that single linkage clustering does chain the data. In order to get a better representation of the clusterings of each subset it is necessary to look separately at each subset.

**Table X: Diameter Maximum Dendogram for Orthodox Subset**

JOHNSON HIERARCHICAL CLUSTERING PROGRAM.

RUN NAME : Orthodox Subset

DIAMETER METHOD

	0 1 0 0 1 1 1 0 0 1 0 1 1 0 0 0 1 1 1 2
	4 4 6 7 0 3 5 1 2 1 3 7 8 8 5 9 2 6 9 0
0.32999998	. . . . . XXX . . . . .
0.25999999	. . . . . XXX . . . . XXX . . . .
0.20999999	. . . . . XXX . XXX . XXX . . . .
0.20999999	. . . . . XXXXX . XXX . XXX . . . .
0.19999999	. . . . . XXX XXXXX . XXX . XXX . . . .
0.17999999	. . . . . XXX XXXXX XXXXX . XXX . . . .
0.14999999	. . . . . XXX XXXXX XXXXX . XXXXX . . . .
0.14000000	. . . . . XXX XXXXX XXXXX XXXXXXXX . . . .
0.13000000	. . XXX . XXX XXXXX XXXXX XXXXXXXX . . . .
0.12000000	. . XXX . XXX XXXXXXXXXXXX XXXXXXXX . . . .
0.09999999	. . XXX . XXX XXXXXXXXXXXX XXXXXXXX XXX .
0.09999999	. . XXX XXXXX XXXXXXXXXXXX XXXXXXXX XXX .
0.08000000	. . XXX XXXXXXXXXXXXXXXXXXXX XXXXXXXX XXX .
0.08000000	XXX XXX XXXXXXXXXXXXXXXXXXXX XXXXXXXX XXX .
0.05000000	XXX XXX XXXXXXXXXXXXXXXXXXXX XXXXXXXXXXXX .
0.05000000	XXX XXXXXXXXXXXXXXXXXXXX XXXXXXXXXXXX .
0.00000000	XXX XXXXXXXXXXXXXXXXXXXX XXXXXXXXXXXX
0.00000000	XXX XXXXXXXXXXXXXXXXXXXX XXXXXXXXXXXX
0.00000000	XX

**Table Y: Diameter Maximum Dendrogram for Dissident Subset**

JOHNSON HIERARCHICAL CLUSTERING PROGRAM.

RUN NAME : Dissident Subset

DIAMETER METHOD

	0 0 1 0 1 1 0 1 0 1 1 0 1 0 0 0 1 1 1 2
	1 8 6 4 4 3 6 7 7 5 2 3 8 2 5 9 1 0 9 0
0.38999999	. . . . . XXX . . . . .
0.34999999	. . . . . XXXXX . . . . .
0.23999999	. . . . . XXXXXXXX . . . . .
0.22999999	. . . . . XXXXXXXX XXX . . . . .
0.22999999	. . . . . XXX XXXXXXXX XXX . . . . .
0.17000000	. . . . . XXXXX XXXXXXXX XXX . . . . .
0.14999999	XXX . . . . . XXXXX XXXXXXXX XXX . . . . .
0.14000000	XXX . . . . . XXXXX XXXXXXXXXXXXX . . . . .
0.14000000	XXX . XXX . . . . . XXXXX XXXXXXXXXXXXX . . . . .
0.13000000	XXX . XXX . XXX . . XXXXX XXXXXXXXXXXXX . . . . .
0.11000000	XXX . XXX . XXX . . XXXXXXXXXXXXXXXXXXXX . . . . .
0.09000000	XXX . XXX XXXXX . . XXXXXXXXXXXXXXXXXXXX . . . . .
0.08000000	XXX . XXX XXXXX . XXXXXXXXXXXXXXXXXXXX . . . . .
0.06000000	XXX . XXX XXXXX XXXXXXXXXXXXXXXXXXXX . . . . .
0.06000000	XXXXX XXX XXXXX XXXXXXXXXXXXXXXXXXXX . . . . .
0.04000000	XXXXX XXX XXXXXXXXXXXXXXXXXXXX . . . . .
0.02000000	XXXXX XXXXXXXXXXXXXXXXXXXX . . . . .
0.00000000	XXXXX XXXXXXXXXXXXXXXXXXXX
0.00000000	XX

If we compare the 'diameter maximum' dendograms of Table X and Table Y above with the 'single linkage' dendograms of Table Z and Table W below we can see how the 'single linkage' method yielded a chained solution. Most importantly, we can infer for each subset the different significances of the categories in the process of reconstructing identity.

**Table Z: Orthodox Single Linkage Dendogram**

CONNECTEDNESS METHOD

	0	1	1	0	0	0	1	0	1	1	0	1	1	0	0	0	1	1	1	2			
	4	4	6	7	6	8	0	3	2	3	1	5	7	5	9	2	1	8	9	0			
0.32999998	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXX	.	.	
0.25999999	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXX	XXX	.	.
0.25000000	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXX	.	.	
0.22999999	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXX	.	.	
0.20999999	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXX	.	.	
0.20999999	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXX	.	.	
0.20999999	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXX	.	.	
0.19999999	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXX	.	.	
0.19000000	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXX	.	.	
0.19000000	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXXXX	.	.	
0.17000000	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXXXXX	.	.	
0.16000000	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXXXXX	.	.	
0.16000000	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXXXXX	.	.	
0.14999999	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXXXXX	.	.	
0.13000000	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXXXXX	.	.	
0.09999999	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXXXXX	.	.	
0.08000000	XXX	XXX	XX	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXXXXX	.	.	
0.07000000	XXX	XXX	XX	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXXXXX	.	.	
0.05000000	XX	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	XXXXXXXXXXXXXXXXXXXXXXX	.	.	

TableW: Dissident Single Linkage Dendogram

CONNECTEDNESS METHOD

	1 0 1 1 0 0 0 1 1 0 1 1 0 1 0 0 0 1 1 2
	6 7 3 4 4 6 8 5 7 1 0 8 3 2 9 2 5 1 9 0
0.38999999	. . . . . XXX . . .
0.35999998	. . . . . XXXXX . .
0.35999998	. . . . . XXXXXXX . .
0.25999999	. . . . . XXXXXXXXX .
0.25000000	. . . . . XXXXXXXXXXX .
0.25000000	. . . . . XXXXXXXXXXXXX .
0.23999999	. . . . . XXXXXXXXXXXXXXX .
0.22999999	. . . . . XXXXXXXXXXXXXXXX .
0.20999999	. . . . . XXXXXXXXXXXXXXXXX .
0.19999999	. . . . . XXXXXXXXXXXXXXXXXX .
0.19000000	. . . . . XXXXXXXXXXXXXXXXXX .
0.19000000	. . . . . XXXXXXXXXXXXXXXXXX .
0.17999999	. . . . . XXXXXXXXXXXXXXXXXX .
0.14000000	. . . . . XXXXXXXXXXXXXXXXXX .
0.14000000	. . . . . XXXXXXXXXXXXXXXXXX .
0.13000000	. . . . . XXXXXXXXXXXXXXXXXX .
0.12000000	. . . . . XXXXXXXXXXXXXXXXXX .
0.11000000	XX .
0.07000000	XX .

END OF METHOD

### 7.3.2.- The MDS Configurations

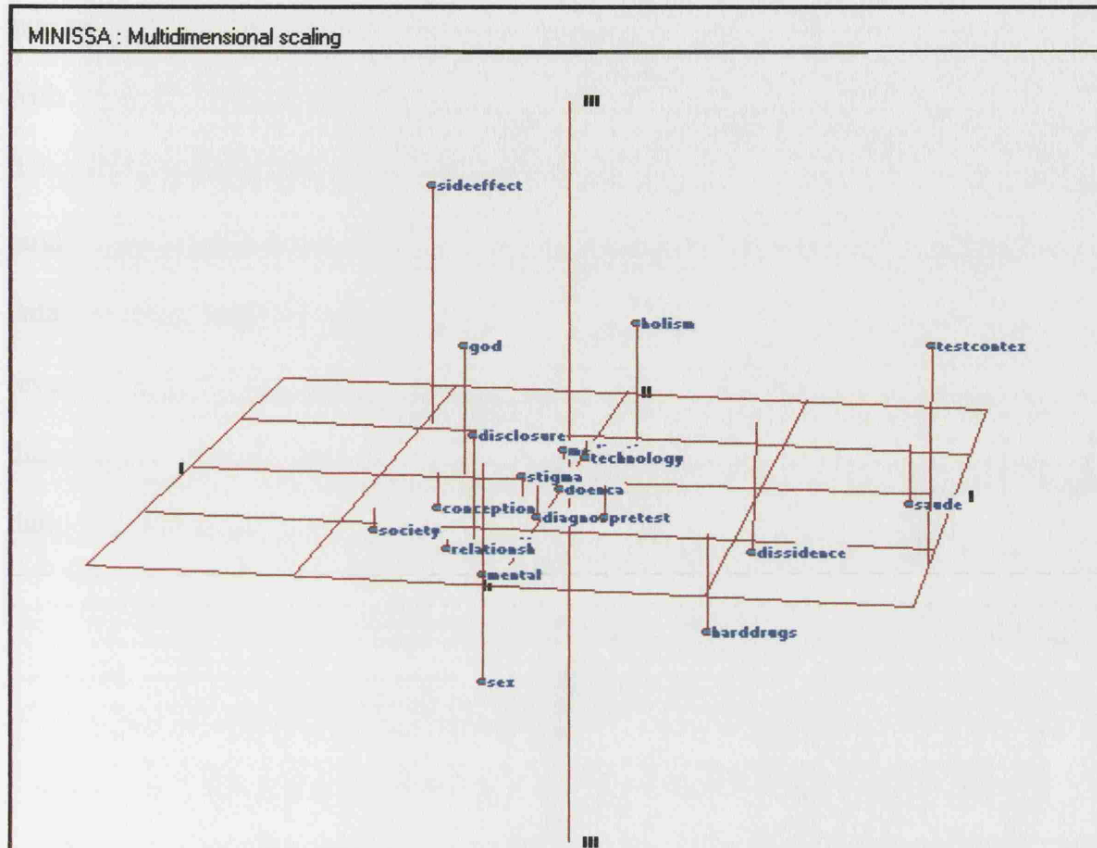
Once I had finished conducted clustering analysis, to better visualise the interaction of the devised categories I performed MDS on the data sets. As my data was represented by categorical variables, I employed the ‘Basic Non-Metric Distance Model’ of MDS whereby only the order of the entries of the co-occurrence matrix is necessary for a solution. The Basic Non-Metric Model transformed the dissimilarities between categories into two or three-dimensional representations where the distances between the categories matched the dissimilarities of the specific concepts they represent.<sup>219</sup> Initially I wanted to see how the categories would be spatially represented in terms of the entire sample (five dissident and five orthodox). The goal here was to set a possible framework for comparison with the two smaller subsets. The first table produced by the MINISSA option in HAMLET resulted in the following three dimensional solution:

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<sup>219</sup> The methods employed by HAMLET to derive similarities from co-occurrence data are the Jaccard and the Sokal coefficients. In my analysis I opted for the Jaccard coefficient because it does not include joint non co-occurrences and as such is suitable for most purposes. In addition, in non-metric MDS only the rank order of the entries in the data matrix are relevant since the method monotonically transforms the data. As such, the distances of the solution should reflect closely the rank order of the data.



Table 1: Three-Dimensional Solution for Total Data Set



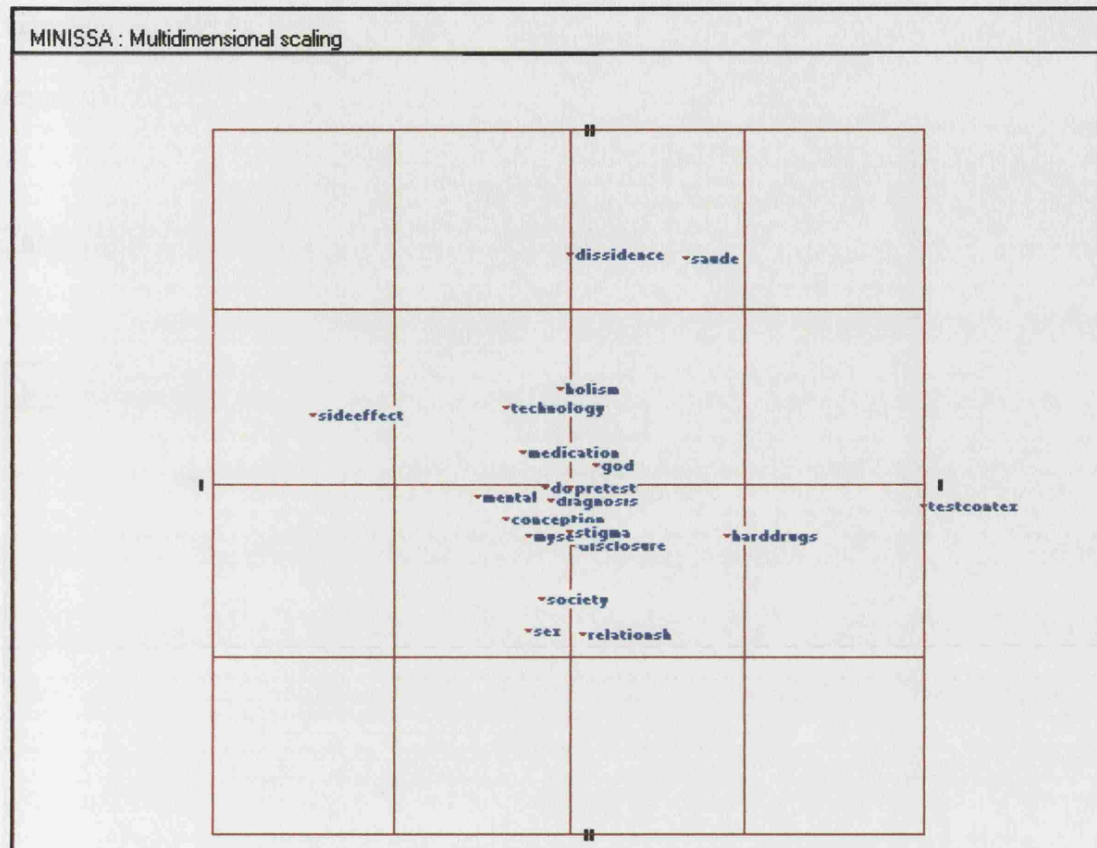
Kruskal's Stress 1 = 0.086

If we compare the Kruskal stress1 of Table 1 (0.086) with the Kruskal stress1 of Table 2 (0.14) we see that the three dimensional solution has a lower level of stress. Stress assesses the fit between the solution and the value required to preserve an ordinal relation with the data. The Kruskal stress1 of Table 1 is at an acceptable level at about 1/3 of what it would have been if the data were random (the stress 1 based on approximation to random data would be 0.22).<sup>220</sup> The lower the stress the better the fit; in case of perfect data the stress would be zero. A two-dimensional solution is expected to have a higher level of stress, i.e. to constitute a worst fit of the data in comparison to the three-dimensional solution, since the two-dimensional solution has fewer parameters to fit the data. The advantage of a two-dimensional solution is that it is much easier to visualise.

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<sup>220</sup> Average stress values based upon simulated random data sets of varying numbers of points and dimensions are given in Spence (1972), and implemented in NewMDSX. See Appendix F.

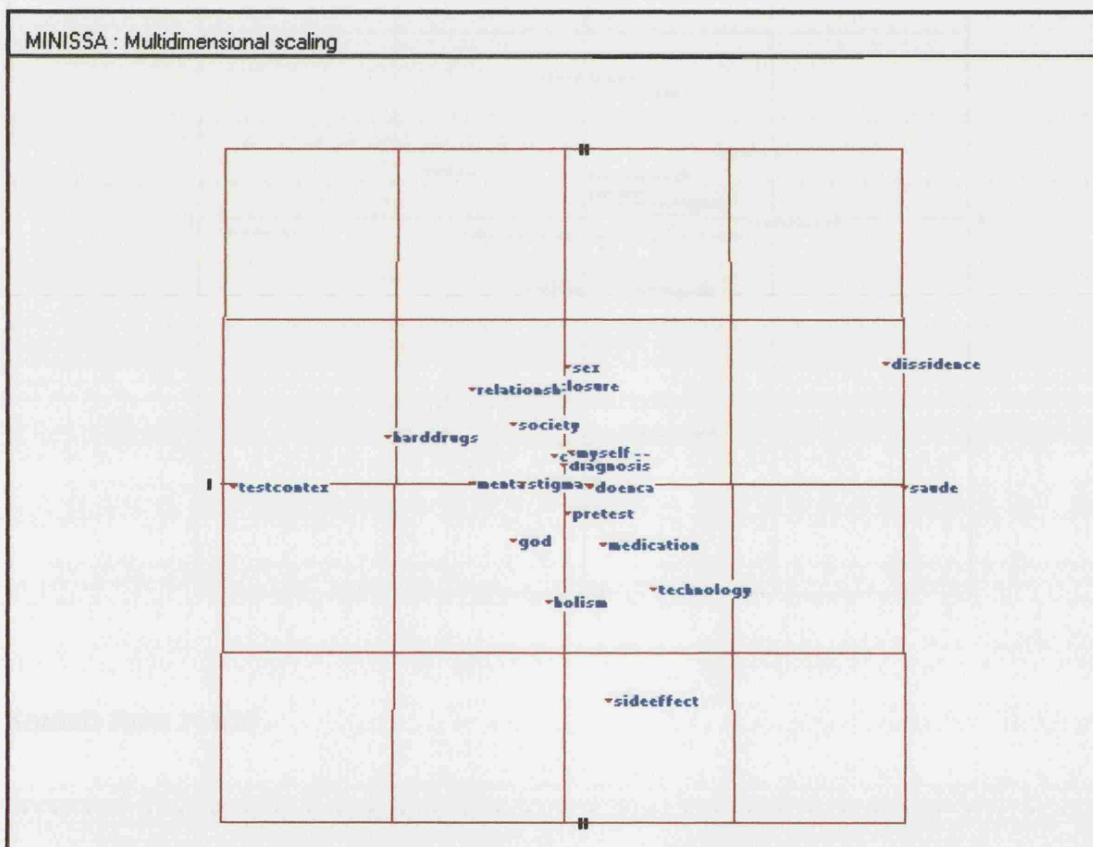
Table 2: Two-Dimensional Solution for Total Data Set



Kruskal's Stress 1 = 0.14

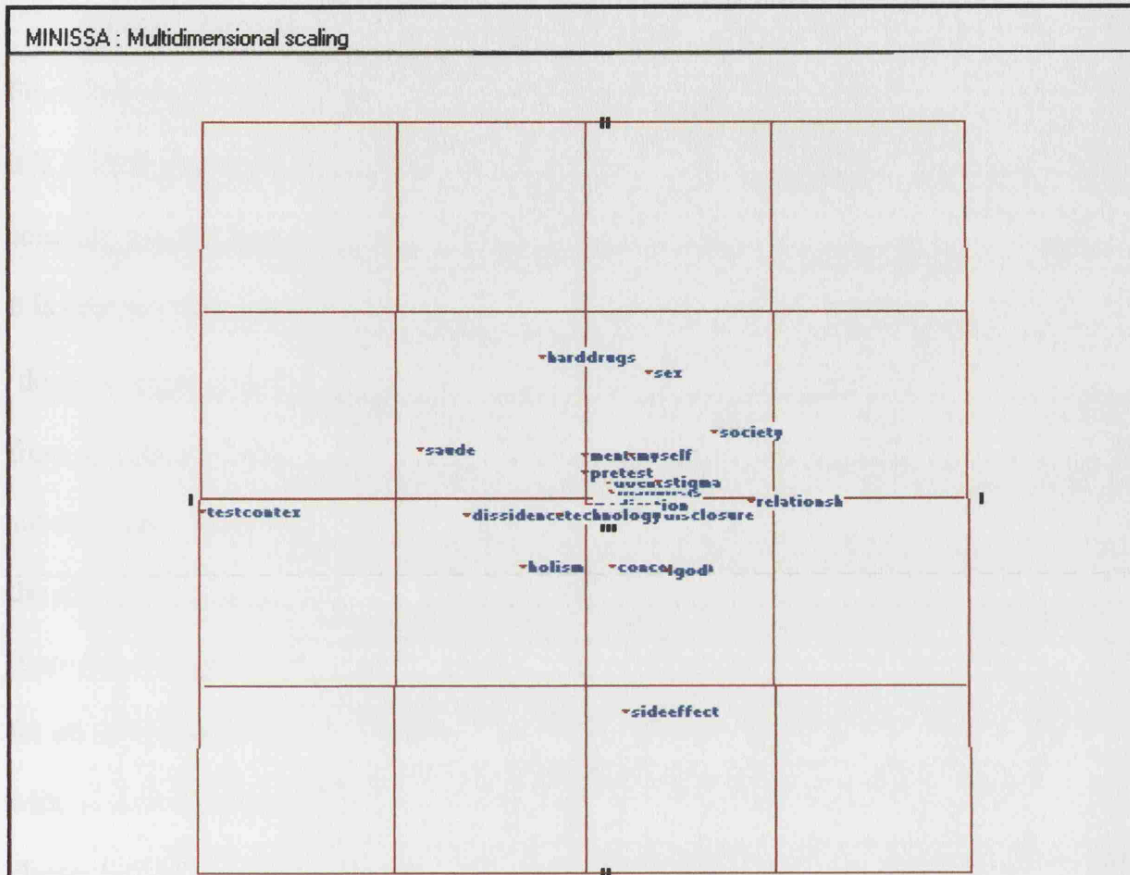
The next step consisted of conducting separate MDS for each subset. For ease of visualisation only two-dimensional solutions were used. Table 3 and Table 4 below represent the MDS solutions for the orthodox and dissident subsets:

Table 3: Two-Dimensional Solution for Orthodox Subset



Kruskal's Stress 1 = 0.12

Table 4: Two-Dimensional Solution for Dissident Subset



Kruskal's Stress 1 = 0.13

## 7.4. - Interpretation of MDS Configurations

### 7.4.1.- Zooming in on Categories: drawing clusters upon MDS solutions

From looking at Table 2 (two-dimensional MDS for total data set) of the previous section it is evident that there is a significant clustering of most categories in the centre of the solution, but that four categories are at a considerable distance from the 'central cluster'. It is also possible that the proximity of the non-central categories 'dissidence' and 'doenca' might constitute a separate cluster.<sup>221</sup> Not much else however can be inferred from comparing Table 2 with the two dimensional solutions for the orthodox (Table 4) subset. Again, there appears to be an independent cluster of 'saude' and 'dissidence', but the rest of the data generally conforms to the pattern encountered in Table 2. Table 6 (two-dimensional solution for dissidents) reveals nothing besides an apparent tendency for all categories to be clustered together. On its own MDS analysis did not provide me with as clear a picture as I needed for analysing the data, hence I proceeded to conduct a cluster analysis in conjunction with the MDS solutions so that I could spatially represent the Johnson hierarchical clustering solutions (Table X and Y). In order to analyse the clusters at the most significant levels of significance the two-dimensional solutions for each subset (table 4 and table 6) were zoomed in on so that the spatial distribution of the most important clusters could be more easily looked at. Please note that the impossibility of inserting the clusterings within the MDS solutions by computer has forced me to draw them manually, and as such very imperfectly.

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<sup>221</sup> The category 'doenca' refers words used to describe the physical ailments or the diseases associated with HIV infection. Doenca is the Portuguese word for disease.

Table A: MDS Solution and Johnson Dendrogram for Orthodox Subset

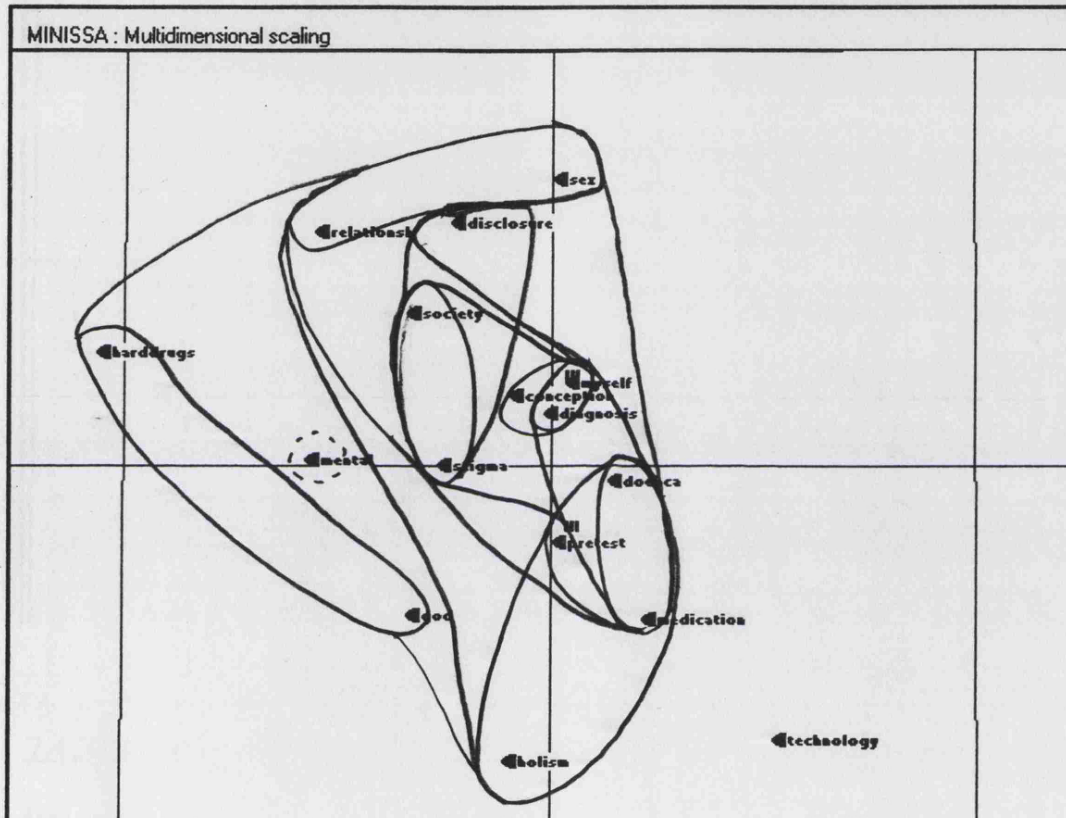
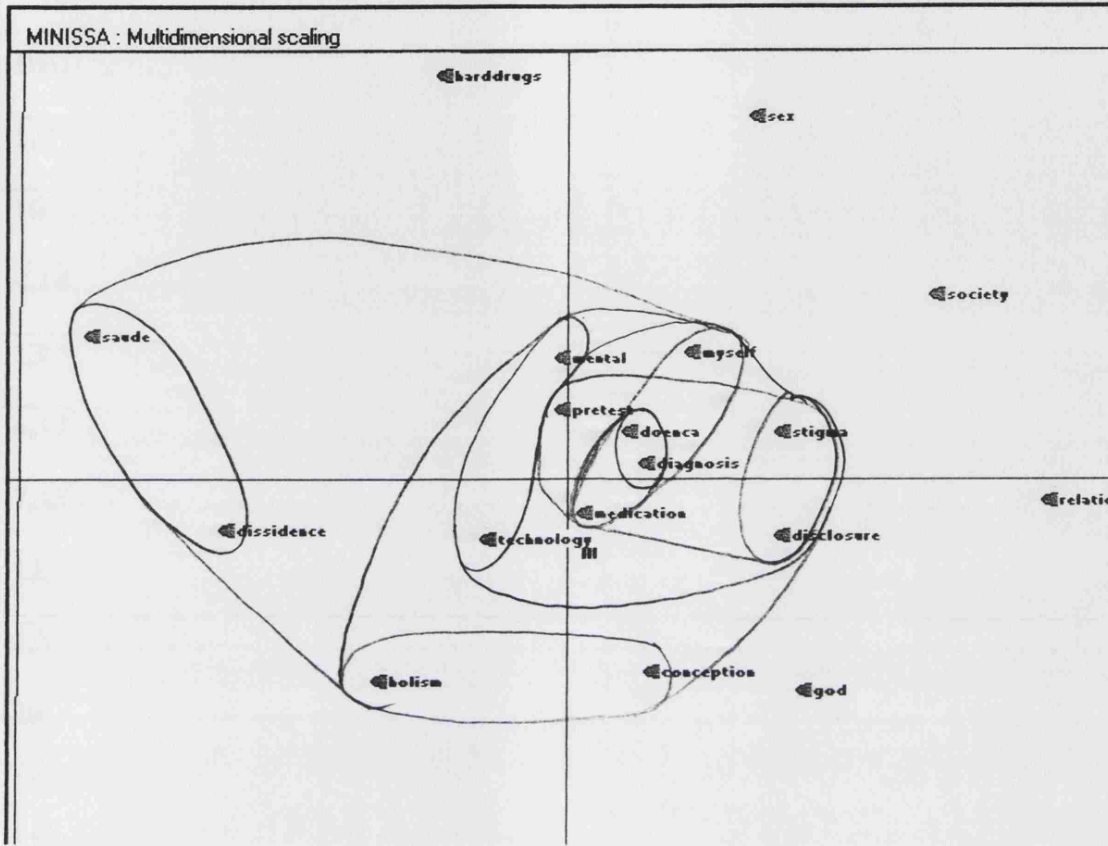


Table B: MDS Solution and Johnson Dendrogram for Dissident Subset:



7.4.2.- Different Clustering Patterns: grasping the differences and/or similarities between data sets

In the Intersection Table below dissident and orthodox clusters are compared at the median level of clustering, i.e. halfway through their HCS tables as outlined on Table X and Table Y (diameter maximum dendrogram for orthodox and dissident subsets respectively). This table represents the intersection of the clusters of the orthodox subset with the clusters of the dissident subsets (Coxon, 1999).





The intersection matrix above tells us the dissident and orthodox individuals perfectly coincide on cluster 4/14 (eq); and that they partially coincide on two other subsets (ss), 3/18 and 5/9. Note that in subset 3/18 dissidents form part of a bigger cluster ‘dominated’ by the orthodox whereas the opposite is true for subset 5/9. For example, for the subset 3/18 (disclosure/stigma) dissidents associate only category 12 ‘Pretest’ whilst the orthodox individuals have a wider group of associations with the disclosure/stigma subset that does not include ‘Pretest’, but does include categories 1,2,11, and 17, respectively ‘Conceptions’, ‘Diagnosis’, ‘Myself’, and ‘Society’. This constitutes important information about the data inasmuch as it tells us how the different groups of individuals interpret their HIV diagnosis. Before I proceed to look at their fundamental differences in section 7.5.3., let me first separately describe how these individuals reconstruct their distinct identities in order to ‘mend’ their shattered ‘cocoon’.

7.5.- Thematic Analysis: describing the meaning of clusters

The description of the particular processes of orthodox and dissident individuals is based on quotes from my data, which have been organised from the most to the least significant levels of meaning (descending order from the first clusters). In the following sections (7.5.2. and 7.5.3.) all quotes will be extracted for the ten interviews that comprise the ‘thematic’ subsets.<sup>222</sup> The quotes will be related to transcripts by numbers: the five orthodox interviews will be numbered from one (1) to five (5), and the dissident interviews from six (6) to ten (10). The different organisation and sequencing of clustering is different in the two subsets. As such, the analysis of orthodox individuals

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<sup>222</sup> The quotes have been somewhat edited to remove the repetitions, hesitations, and errors of spoken language, and to preserve anonymity.

was based on their specific clustering processes as illustrated in Table X.<sup>223</sup> For the dissident individuals the analysis followed the information illustrated by Table Y.<sup>224</sup>

7.5.1.- Orthodox Positivity: a legitimising identity

HIV diagnosis constitutes a ‘fateful moment’ that launches the individual into a process of reconstructing his ‘shattered’ identity in an attempt to restructure a sense of self which will enable him to continue to participate in social life (Giddens, 1991). Castells (1997) argues that in contemporary, or ‘network’, society most social actors organise meaning around a primary identity. There are three forms of identity building: legitimising identity, resistance identity, and project identity.<sup>225</sup> Whereas ‘project identity’ characterises the strategies of identity building of the gay movement, or feminism, where actors moved beyond resistance to seek transformation of the fabrics of social structure,

<sup>223</sup>

Table 1.- Table MDSO revealed the following sequencing of clustering for *orthodox* individuals:

Sequencing	Orthodox Clustering
A	A- Diagnosis/Myself
A+B	B- Doenca/Medication
A+B+C	C- Society/Stigma
A+B+C+D	D- Conceptions
A+B+C+D+E	E- Relationship/Sex
A+B+C+D+E+F	F- Disclosure/Pretest
A+B+C+D+E+F+G	G- Holism
A+B+C+D+E+F+G+I	I- God/Harddrugs

<sup>224</sup>

Table 2.- Table MDSO revealed the following sequencing of clustering for *dissident* individuals:

Sequencing	Dissident Clustering
A	A- Diagnosis/Doenca
A+B	B- Medication
A+B+C	C- Myself
A+B+C+D	D- Mental/Technology
A+B+C+D+E	E- Disclosure/Stigma
A+B+C+D+E+F	F- Pretest
A+B+C+D+E+F+G	G-Conceptions
A+B+C+D+E+F+G+I	I- Dissidence/Saude

the types of identities which are forged from an HIV diagnosis constitute ‘legitimising’ and ‘resistance’ projects. A ‘legitimising’ identity is ‘introduced by the dominant institutions of society to extend and rationalise their domination *vis à vis* social actors’ (Castells, 1997:47). The achieved identity of the orthodox individual can be seen as a ‘legitimising’ cognitive construct achieved through the dialectic between the infected person and the surrounding social structure (Castells, 1997).<sup>226</sup> The genesis of such identity takes place at the moment of diagnosis. Once a diagnosis is given it is immediately juxtaposed to previously acquired notions of a selfhood spoiled by deviant sexuality:

I wonder in a way in a kind of a group consciousness thing of being gay if a lot of us do not wish this upon ourselves because we as individuals and me as an individual was always told by society that I was sick and that I was diseased and that what HIV gave me gave people and now I have a physical manifestation of my sickness and I am diseased and I think that on a level me as an individual and my upbringing and my personal problems with esteem and self-worth and within the gay community I live in it has somehow promoted HIV because it gives us the stigma that we so long have been labelled with and maybe in some way desired but it is strange initially with my diagnosis I was so devastated a lot of changes in the last two years and I have a very different image of myself now and so my

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<sup>225</sup> Network society is the term Castells (1997) applies to characterise what Giddens (1991) calls late-modernity, and what Bauman (1997) refers to as post-modern society.

<sup>226</sup>The social structure refers to political institutions, the AIDS service industry, the welfare system, religious institutions, biomedicine, and alternative medical models. The discursive fields that surround HIV/AIDS are produced by such institutions as well as by the AIDS movement, religion, academic

image about being gay now and being positive is that I am have a disease but that although I have no idea how I became infected I feel that if I was not infected now and I was the person I am today I think I would less likely put myself in any situation which could potentially be of risk because I do not need to see myself as sick or diseased or inferior or I do not need to and in a way now being gay and being negative you are not part of the ghetto almost it is starting to be like you are kind outside of the ghetto you know what I mean a lot of people who the weirdest way is another way of identifying ourselves and isolating ourselves you know what I mean so many times I heard in clinics when someone comes in who is not physically attractive or desirable people say I do not think that person is positive how could they be who would sleep with them? (#3)

I mean when I tested positive I all the feelings of low self esteem and self hatred they all came back and I thought if I was not gay I would not be positive that I would not have had the diagnosis but in many in some ways being diagnosed was I mean I was devastated (#5)

I think there was always this punishment thing when it was like you know God will not love me because I am gay and I used to pray as a child when I was a teenager even I used to pray to be straight I used to pray on my hands and knees that when I woke up in the morning I would never have these feelings again and I hated myself because of my sexuality and that was what religion was for me it was

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research, the media, networks of 'positive' friendships, the dissident movement, and by networks of so-called long-term survivors.

sort of punishment and fear of being burned in hell you know I think when I was diagnosed there was a lot of self-blame and I blamed myself for being gay and I thought if I was not gay I would not be HIV then that turned into some really horrible thoughts about myself and the sexual abuse that happened when I was very young and then got caught up with those very old feelings that I am only gay because of the sexual abuse and if I had not been abused therefore I would not be gay therefore I would not be positive and it was all unhealthy and I think I am dissociated now I it is like I forgive myself for having become infected in whichever way I did I looked after myself the best way I could it has happened I will live with (#4)

The previously tainted gay self now has to cope with the reality of the added burden of HIV infection. His previous association with 'gay' as identity, and as such the medicalisation of the problem of AIDS that the institutions of gay culture reproduce from mainstream society, occasions the individual to look for help within and through the gay-associated institutions of the AIDS service industry such as HIV clinics and support centres. These institutions diffuse and articulate standard biomedical recommendations for HIV infection that currently are as follows:

With regard to specific recommendations, treatment should be offered to all patients with the acute HIV syndrome, to those within 6 months of HIV seroconversion, and all patients with symptoms ascribed to HIV-infection.<sup>227</sup>

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<sup>227</sup> Current British HIV Association (BHIVA) guidelines recommend that anyone with a CD4 count between 350 and 500 cells, and with a viral load above 30,000 copies, should consider HAART treatment or be monitored at least once every three months. Anyone with a CD4 count less than 350 cells with any

The acceptance of the 'diagnostic invitation' (Kenen, 1996) marks the consolidation of the 'legitimising' identity, and inscribes the body of the infected individual with the official label of PWA, i.e. Person (living) with AIDS (PWA).<sup>228</sup> The implications of the biomedical inscription produce significant shifts in the subjectivity of these individuals inasmuch as the laboratory measurements that define HIV disease (the 'counts') come to constitute the principal metonymic signifiers around which the PWA understands his health. Dominant discursive practices often subjugate any resistance the individual might offer to the biomedical control of his body. In addition, these 'counts', where institutions and the interior of positive bodies intersect, exert a fundamental role in the cognitive processes of the PWA by institutionally legitimising the individual into the sick role.<sup>229</sup>

I have chosen to take medication initially probably out of fear because I had I bought this fast progressor diagnosis so I started medication on that when I started I had 350 CD4s and my viral load was about 140,000 so yeah I could see that clinically I was OK but then I had gone from 2 months before from 12,000 viral load and CD4 of 490 so it could have been just a blip it could have been I was a bit run down a bit anxious whatever and maybe I should have waited you know but I was I made my decision out of fear I did not want to die now I have a totally

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detectable viral load should be offered HAART therapy. (*Crusaid's Information Exchange* fact sheet on HAART guidelines).

<sup>228</sup> The seeds of the legitimising PWA identity dates back to 1983 when the first autonomous 'People Living With AIDS' movement was established in the United States to resist the then prevalent label 'AIDS Victim'. The movement was initially a self-help type of organisation that quickly grew into a coalition of local groups (Patton, 1990).

<sup>229</sup> A 'deviant' sick role (where the patient never recovers) since antiretroviral medication often fails to achieve its desired goals (Turner, 1995).

different view because I think if I am starting on no viral load and CD4 count of 600 and my medication stops working I still have plenty of years to be asymptomatic unless the viral load rebounds which I know it often does if you stop the medication so I do not know (#2)

I have been doing them now for 3 years there was a time they reminded me I had HIV but now they have just become part of my life they are quite dominating in terms of they are something that you just have to do and it is something that you can not forget to do and there have been occasions it is not so much that I did not want to do it I am just bored of doing it now it becomes like God do I really have to do that? I do my combination twice a day I have had to do them three times a day in the past... when I start I have always sort of planned when I start a new combination initially it was when I started the first lot I set myself six months you can do this on the dot you will not forget now when I start a new combination for the first three months I do it religiously so it then becomes habit but you know it is sort of if I have gone to work and I have not taken my pills with me and I go out for a drink after work I have to come back home it is that sort of thing (#4)

I knew that test was going to be positive because you do not get PCP unless you have HIV I went back to talk to the doctor I was thinking how long have I got she said do not worry there is combination therapy and people are living full lives it is not a question as it would have been 18 months ago you will be OK so I seemed to like her she asked me if I had any issues around taking drugs 'this is our gold



standard therapy DDI DDR AZT do you want to go on it?' some people have a big thing about making their mind up about that I had a CD4 count of about 20 and a viral load of 164,000 I was not going to dwell on whether they were too toxic for my body or my immune system.... I am very actively involved with my treatment with my combination and the choices that I have I take very much an active role I read a lot about the new developments NAM (National AIDS manual) is on my bedside table in the drawer I mean because I do not want to frighten people off but I have always I take responsibility for my actions and my conduct in life and I think one of the reasons I survived the last few months is because I was determined to get well not to let the virus storm through my immune system so I am taking a very powerful triple combination and I am very compliant besides I believe in the psychological dimension of health and I have taken a very active role in that too mainly through my hydrotherapy which has enabled me to reach a level of relaxation I had not known before and in this way I help my body can cope with the toxicity of the drugs as well (# 1)

The health of the positive body thus becomes the responsibility of the PWA who procures to actively restructure his immune system through compliantly adhering to HAART regimes. As such, regularised control and reflexive monitoring produce a structuration of the positive body within a dynamic that mediates the relationship between a reconstituted 'positive' agency and the social structure. The aim of the PWA is to cast the interiority of the body in accordance with biomedical parameters of good health. Hence the Cartesian framework of a medical strategy that subjugates the lived body to technologically

produced representations of its health comes to view. The harsh consequences of HIV infection and treatment are understood as a contingent reality that might have been avoided had the individual not put himself at risk. As such, in order to 'mend the protective cocoon' the positive self has to engage in a process of (re)interpretation that at best seeks personal absolution at worst a justification for the previously HIV-negative but positively-tainted gay self in the acquisition of infection:

Because of the way I felt about myself I met the guy shortly after moving to London and you know was also incredibly fucked up in those days very lost did not have any sort of self worth blah-blah-blah and was seeking out abusive relationships very much so I sought out this perfect abusive relationship and gave this man lots of power turned I take full responsibility of my ability to turn this man into an abusive man and he was an IV drug user he was perfect he was a dealer we used to drive around in stolen cars and things like that he was just perfect for me to and at one point I ended up sort of I got into injecting for a while and you know I just something clicked then it was like I was trying to destroy myself and I think that was the time I did put myself at risk for I was very young and you know years of therapy and later I can understand that but at the time I was very wrapped up in seeking out abusive relationships and creating a self-destructive environment for myself so that scared me after that I really started to sort of work on myself and try and respect myself more and I think that has been a continuous process of 10 or 12 years but I think starting to respect myself and part of that was not to put myself at risk for HIV (#2)

I went and got tested and it came back positive so then I told him and he got his results and it was positive as well so I am fairly clear that is where it came from I was hugely angry with him but since then I have come to accept 50% of the responsibility I do not feel angry anymore I also think if it had not been him it probably would have been somebody else I do not think I would have not been able to maintain safe sex indefinitely I mean probably just knowing the places that I like going to and sort of the lifestyle that I lead I probably would have ended up having sex with somebody who had HIV at some point (#4)

In the process of reinterpretation engaged in by the PWA the positive agency, unlike the one previous to HIV infection, should not allow for the stigma of HIV (or gay) to continue causing damage. As such, the PWA almost always engages in health-producing behaviour with the objective of helping the positive body not to psychosomatically manifest the psychological stresses involved in carrying the stigma of HIV. Another goal is to countereffect side effects involved in HAART therapy. As a result, many PWAs employ complementary and alternative therapies to 'relax' and 'support' their threatened bodies. The appropriation of the AIDS crisis has pushed aside the implementation of purely CAM strategies for dealing with HIV infection. However, one of my respondents had been dealing with his long-term diagnosis exclusively on a CAM basis. His 'alternative' belief system seemed to have a significant impact on maintaining the plausibility of a therapeutic strategy (mostly) discredited by combination therapy, and illustrates a moment of 'resistance' in the constitution of the legitimising identity.

As soon as I was diagnosed I started I spoke to this naturopath I knew in Australia from when I was diagnosed with EBV she said start with echinacea and mushrooms she knew all this she was brilliant and when I came over to England I did many I started looking at herbs and now I am at a point I diagnose myself if something comes up I know what to follow if I have diarrhoea I know what to take I have just had shingles so you learn you learn...a lot of my belief system is about the earth and the environment my belief in a god is more like an energy that helps the world grow I believe in energies as such in acupuncture I guess yet again we go back to my childhood I was very sick as I child I had asthma I had bad I remember talking to therapists about my childhood ailments as a young child you know I was pumped with drugs to the point that I can not remember I think that was in my unconscious when I was growing up I still did western medicine but I guess really it was my mother's influence I have always been kind of a greeny as well an environmentalist I recycle a lot of stuff and I am a vegetarian I am pleased I am pleased I live that kind of lifestyle I am proud of it for a while I just did all kinds of treatments I did not know exactly what I was doing I was experimenting I think or maybe I was just afraid (#5)

Despite the alleged 'gentleness' of CAM, the enactment of his 'alternative' protocol is not only very structured but also very constraining, in fact it would appear more constraining than HAART's requirements.<sup>230</sup> The surveillance of the positive body is

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<sup>230</sup> Depending on the particular 'combination' of antiretroviral drugs the timing and frequency of taking the pills has to be strictly respected. Some drugs interact with certain kinds of foods so they can only be taken after a certain number of hours some foods have been consumed.

analogised in this individual's CAM strategy, and the biomedical conceptualisation that HIV is a powerful virus that needs to be suppressed is reproduced He continued:

What I do basically now once a week I do acupuncture and occasionally I will do Chinese herbs because I just started on this trial Todoxin it is called so I am cutting back on well I am not doing Chinese herbs because the Todoxin is too much it is 12 times a day every 2 hours I do supplements and if I get sick I look at what is happening and I use a lot of herbs western herbs I try to think of myself as being well but at the back of my mind there is always the issue that I have HIV I say if I did not have this bloody virus I would be one of the healthiest people I know I go to the gym three times a week well I try I am vegetarian I do supplements I recently cut out wheat so and I try to look after myself the best I can and when I need emotional support I will turn to one of my therapists I have considered using the drugs of course especially now with combination therapy but I will try the alternative first if it works it is much better it is a more comprehensive gentler approach without all the side effects and the toxicity of the combination drugs...there is three of us really we run seminars lectures about nutrition colonic irrigation NLP spiritual healing they have all come and given lectures about HIV we used to be at the Information Exchange now we have a room well a space at the IDT so we can use that once a month but unfortunately the turn up is so poor we had a shiatsu seminar and only 2 people showed up especially now that combination therapy is here (#5)

The 'circuit of culture' has produced a multitude of social metaphors surrounding HIV/AIDS (Woodward, 1997), which by impinging upon the AIDS body the 'apocalyptic metaphor', have magnified the stigmatising burden of HIV diagnosis (Palmer, 1997). As such, the social stigma that accompanies the illness, and the psychosocial consequences of the diagnosis, may be as debilitating as any physical manifestation of immunodeficiency syndrome. The stigma attached to HIV is such that disclosure of HIV status is an equally problematic issue whether one is disclosing it in the context of a gay friendship, to a member of the family, or to a sexual partner:

Of course I did not take my shirt off while I was there and I was very concerned I mean I already looked haggard now I did not want any physical evidence of the virus you know the stigma the rejection could be so frightening even among friends as I have experienced (#1)

My aim in a very broad sense is to do something to help gay men and also I think that the whole thing about positive people is that they are so in the closet and I mean I explained to a friend about HIV and the issue came up and I mentioned I am positive and he got really annoyed with me and he was like how dare you tell me I am sick of people telling me they are positive he was weird and I said to him do you not realise when we were young we were in the closet because we were too scared to come out and HIV has put people back in the closet again but it is not a gay closet anymore it is an HIV closet you know it is almost ok to be gay but it is not at all ok to be positive and that is sad it just adds another stigma to being gay it just adds another way for people to hurt each other and to be hurt (#3)

I was in Florence Italy and this guy cruised me and he was like cruising me all night going from bar to bar I ended up having sex with him we went back to the hotel my hotel we had sex and then he came in my mouth and he was like my God you could get positive and I was like I am positive and he freaked out he was like how dare you have sex with me you could have infected me and I was just like fuck you at no stage I have put you under any risk fuck you get out of my hotel I am not dealing with your bullshit and you trying to stigmatise me and make me into some kind of I do not know some social pariah I will not allow it... these experiences can be very stressful (#5)

My mother I am seeing her in a month she lives in Switzerland she is in France right now and she phoned me and told me that she bumped into a friend of hers there who told her I was positive that I was dying and she was on the phone and she was crying she was saying tell me you have not got AIDS and I just used the language to get away with saying to her honestly I do not have AIDS but everyone else in my life I am out to about my status but my mother it is this whole thing I have a problem with her manipulating and controlling my life so the reason she does not know is because of my relationship with her as a child and not my relationship with her as gay positive man but I will tell her when I see her I will explain that yes I am positive but that is it is not a death sentence that the drugs are very promising she does not know all that (#3)

Subject-position and representation are inseparable moments in the process of identity construction. As such, these 'positive' subjectivities are significantly blemished by notions of culpability, shame, and isolation. Illness narratives are often not descriptions of the past but of systematic ongoing efforts to reconstruct a self that includes both the experience of illness and ways to counteract it (Frank, 1997). The constant references to self-absolution that appear in the PWA narrative suggest that the self is actively engaged in a recontextualisation of infection without which his continued existence as a social being may be significantly problematised:

It has got something to do with shame you know the idea of getting sick and dying of AIDS in front of my family and the people I had known all my life that was not a good picture you know what I mean? (#5)

I spent a lot of time at the beginning first of all punishing myself for allowing myself to get into those situations and then be angry at them and then just thinking why am I doing this I have to forgive myself I have to forgive whoever infected me what is the point of spending the rest of my life bitter and twisted you know it has happened how it got there it was bad luck you know I have to get on with it in someway (#1)

I had a lot you know very affected by HIV over the years and just overwhelmed by it at that point I remember I started using I had taken an anti-depressive because I was just so overwhelmed and I do not really it is not something that I



like using it I think it changes you somehow it was Prozac I started with and you know I was living in this false world for a while part of me was hugely grieving from these things and the other part was yes everything is lovely and I was partying like mad and I do not blame myself in anyway but I still feel that somewhere it was all this depression and actually lack of hope and you know feeling very suicidal at times and so when I did get infected even though you know I can forgive myself because I did everything I possibly could to protect myself (#2)

Sometimes it amazes me I am going through a big change and the people who are around me are very different well they are not very different I do not have a lot of people around me now I have lost a lot of friends and I am quite surprised that people I have known a long time that I am diagnosed that I am living with this disease they do not seem to understand I feel a huge gap between us this sort of isolation imposed isolation but I suppose I only have myself to blame (#4)

The PWA experiences the materiality of his physical body through constructs, associations, and images that relate it to the technologically produced vision of an interiority rendered problematic by medical discourse. As such, through a reflexive engagement with the discourses of medicine the PWA acts upon his body to bring it close to technologically produced standards of normalcy. It could be argued that in this capacity, especially when biological imbalances are the direct result of the powerful allopathic palliative being used to prevent a disease that might not yet have manifested, the PWA represents a 'disembodied consciousness' (Turner, 1996). However, the

disembodied consciousness is not always successful in subjugating its materiality onto the symbolic level of meaning:

The reason I changed was the second set of drugs I went on to contained ritonavir and it started to cause me gastric problems it made me produce too much stomach acid which burned the lining of my stomach and I was sick as a dog really and St Mary's was going to take 8 weeks to have an endoscopy and Barthes could do it in a week so I went there.... The earlier part of this year was very difficult because what happened when I was on the combo that contains zidovudine and zalcitabine it was working from the point of view of keeping my virus undetectable and my CD4 high but starting sort of January I lost 2 stone of weight subcutaneous fat was just falling off of me not muscle wastage but a sort of strange case of lipodystrophy it did not get put anywhere because I lost that weight the toxicity of the drugs suddenly kicked in so I started throwing up once a day which did not help put the weight back on (#4)

I know the drugs are quite toxic and they can be very detrimental to some of your organs my liver function is quite bad at the moment and I have diarrhoea and you know I have a little bit of lipodystrophy on my legs but the virus the drugs are helping to slow down the replication of the virus my viral load is about 40,000 from 75,000 and my CD4s are better so they are working (#3)

Recreational drugs are widely used in urban gay communities across the western world (Lewis and Ross, 1995), as they are among subcultures in crisis (Hanna, 1979). The five

orthodox individuals of my subset were current drug users.<sup>231</sup> As such, drugs are employed in the ritualistic articulation of sex and drugs as a mechanism to cope with the tripartite stigma of being gay, being infected, and possibly terminally ill:

I never stopped having sex you know like some people do after their diagnosis if when I go to a clinic for a VD check up and they say how many people have you had sex in the last 6 months and it has always been difficult for me to work out because there will be weekends when I will go up to the heath it will be a huge number you know six in a night and I do that through a weekend when I will go to Trade I love having sex on drugs it is absolutely the best and I will do loads of drugs and have lots of sex and then I will not have any for a couple of months so it is very erratic... love having sex on drugs it is a big release (#4)

The speed and the coke and the acid it did my head in and I became quite mental I became quite paranoid I became psychotic I was incredibly paranoid you know I lost touch with reality for a while and I had to go back to Wales for 3 months to sort of come down and when I came back uh created a few mistakes again I had a great time on drugs when I was in Wales but now sex and drugs are completely different when I was you know 21 it was an escape then I was doing loads of acid and things like that (#2)

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<sup>231</sup> Except for #5 who used cannabis only (but had been a user of harder drugs such as cocaine and ecstasy) all other individuals were current occasional users of cannabis, cocaine and ecstasy.

I have had a Trade spiritual experience spiritual emotional experiences at Trade but I think it is because of the drugs not because of Trade because I have had those experiences elsewhere that is my experience drugs are like a spiritual psychological emotional tool... it was a very spiritual experience you know when I came out of it I knew I was not Jesus but thinking well there is something in here about spirituality but also about the insights you gain about your own life if you know what I mean (#4)

Spirituality is another theme through which life with HIV is contextualised in an attempt to reconstruct a mended self. However, such spirituality is embedded within the level of the psyche and of the physical healing of the body, not as a disembodied Dionysian entity floating above the mind/body complex. As such, the legitimising identity of the PWA may think of itself as spiritual but in reality it is very much firmly grounded on the positivistic, dualistic paradigm that has framed and institutionalised the construction of knowledge and power relations of the modern era.

I did psychotherapy that started on the spiritual aspect because I think psychotherapy has a lot to do with the spiritual and that started in must be six years now a very close of friend died and that was kind of the beginning ok looking at my life really (#2)

Looking into the abyss I think a genuine sense of spirituality is beginning to grow in me since my diagnosis...my mind is being set free of all the shit I used to carry around (#3)

Like healing and spirituality I guess I always had a link to nature I have always been kind of an environmentalist so I think it had to come sooner or later anyway but HIV has brought more about spirituality and healing and self-worth and all those kinds of issues into my life (#5)

### 7.5.2.- Positively Dissident: a resistance identity

Narratives about HIV/AIDS represent instances where the PWA attempts to locate his own 'authentic' voice (Frank, 1996). When successful such endeavours are heard by the speaker as authentic reconstructions at the level of self, body and 'other' (HIV). As such, in a broadly Foucauldian perspective, where the lived body is seen as a product of discourse, the discourse of medicine is opposed by the discourse of the patient. This voice validates the experiences of the patient who consents to the 'colonisation' of the body by the disempowering discourses of medicine (Radley, 1997). Hence, a degree of appropriation of the sense of loss of the autonomy of the body is enabled by the possibility to speak for oneself and not be spoken through (Frank, 1996). Illness narratives are deemed to be relevant in the reconstruction of the (lived) body not only because of what they say, but also because as 'exemplar' displays they provide templates for the alternative ways of being that can be assembled in the face of serious illness (Frank, 1996). As such, the discourse of the PWA demonstrates that life with HIV is a 'liminal' process that constantly altercates 'between and betwixt' disease and health (Turner, 1967). However, the role of the 'exemplary' narrative depends on whether the told story constitutes a successful account of how the patient deals with the physical reality of the virus or whether all that is offered is a 'chaotic' narrative (Frank, 1995). The successful narrative of the PWA may disrupt the dominant discourse of medicine and as such momentarily shift the balance of power relations. Yet, discourse is not sufficient in itself to explain the corporeality of the physical body neither in health nor in sickness. In the quote below a PWA describes his 'style of coping' as an embodied action (represented in speech) enacted in order to deal with the limitations imposed upon the 'colonised' body

(Frank, 1995). As such, the significance of such action as a resisting practice that aims at freeing agency from the constraints of a demanding 'regime' of therapeutic drugs lies in its embodied nature, which permits material effects that go beyond symbolic reinterpretations of the experience of the disease and focus on what the body can do.

If I have been good for the week before I do not mind missing one dose a week it is probably not a good idea but I just think well I am human if I missed one during the previous week then there is no way I will miss another I can remember when I was on the ritonavir/siquinavir combo I had to take it at eight in the morning but was supposed to take it with food and I was at Trade and there was no way that I would put food down my throat so I did not take the pills also I try and move things so that if I am going to Trade at the weekend now it is what twice a day so if I was to go to Trade now I would move it a couple of days before hand so that rather than taking it at what 8 in the morning and 8 at night I would take it at midnight and midday so that Trade could happen without too many problems but it is not a good idea because the drugs need to follow their own rhythm but to be compliant all the time it is impossible if I am to keep on living a relatively normal life (#4)

Identity construction is fundamentally related to the signifying practices and symbolic systems that characterise the cultural environment, which shape and contain, as much as they allow, the internalisation of meanings that ultimately produces varying subject-positions. The body of the PWA does not constitute a totally 'passive' entity completely

'colonised' by dominant discourses, even if its legitimising nature means that the PWA derives meaning from institutionalised sources. On the other hand, the 'resistance' identity embodied by dissidents is a cognitive construct achieved by a more dynamic agency unwilling to relinquish the individual freedom and self-determination perceived to be enabled by its independence from the colonisation of medical discourse.

Because the interiority of subjects is historically contingent, and consequently can not be given any analytical priority, does not mean that subjects never exercise any power.

Hence, dissidents occupy 'positions/conditions devalued and/or stigmatised by the logic of domination (and are) thus building trenches of resistance and survival on the basis of principles different from, or opposed to, those permeating the institutions of society'

(Castells, 1997:56). The material effects of the ontological position occupied by

dissidents constitute them into very distinct *species* of (positive) homosexuals indeed.

Still, at the moment of infection all my respondents subscribed to mainstream notions surrounding HIV. As such, the 'fateful moment' caused emotional responses similar to

those of the PWA. However, unlike the PWA for whom a diagnosis is immediately

collapsed to previous notions of a tainted selfhood, for the dissident-to-be individual the

diagnosis set him into a process of questioning biomedical practice. It could be

hypothesised that the gay component of identity was less significant for dissidents than it

appears to be for the PWA so they did not immediately turn to the institutions of gay

subculture. Another possibility is that such individuals possessed a countercultural streak

before the diagnosis.



What made me sick was the HIV fear believing initially in the HIV causes AIDS model my ill health whatever ill health I have had has been caused by the stress of the HIV model (#7)

Surprisingly I could sleep the night of the diagnosis I actually had this incredible sleep I probably was exhausted from emotions or something like that and then fortunately for the next few months I kept going through this business of having you know these sleeps I did not have nightmares or anything like this I would wake up in the morning but then the recollection of the diagnosis hit me and I would have this sort of depression not monstrous I was still going to work I mean the day of the HIV I went back down into work I pushed myself and sort of worked like hell but I guess looking back I was pretty depressed for almost a year (#8)

The same individual later talks about his attitude towards biomedical solutions to the problem of AIDS in relation to his previous self:

I guess I have always been a free thinker and I have done things on my own my whole life and you know I was saying how there is a neurotic inside of me and how I always enjoyed preferred being on my own but being an AIDS dissident is very difficult you have to just basically do it on your own there are no doctors to support you I mean no institutions like the NHS to help you with treatments and it is basically a lonely road and I do not know it would be nice to be able to you know have a friend or someone to support you on the way I mean Continuum is

the only support I have I was actually talking to (deleted) about that about he also I mean he is very involved in all this and the pressures of being a dissident there are so many levels of pressure you know from not being able to talk to your friends or even your doctor and that and being constantly bombarded with all the HIV information like have you seen these new advertisements on the tube it is ridiculous that in itself creates a huge psychological burden (#8)

Dissident positions contradict the logic of biomedicine that measures health in terms of technological representations of the body's inner reality by privileging the sensory experience of the lived body. As such, dissidents challenge the Cartesian dualism of biomedicine where the body is subordinated to the mind.

I was on the three combination medication for about 6 months after I left the hospital after I got out of hospital I it was difficult for me because I did not know whether after a while I decided to stop the medication I thought sod this I must have been living with this virus for at least 11 years and I have always been the perfect picture of health so why do I have to start polluting my body and my mind with these drugs and their toxicity so I stopped them I refused to become a victim of the rigamorous of having to take the pills if I had looked upon this as a death sentence and I have seen too many go down with that a few months after their positive test results very often because they have taken it as a death sentence the whole world collapses for them their psyche started to dysfunction I know some who did not know what to do anymore I just kept on living as if nothing had

happened just kept on with leading a normal life I really believe that that is the only way to secure a normal life span if you do have this virus the mind body spirit connection is very important when I was on the combo I got so many side effects especially this horrible neuropathy on my feet and I am convinced it was due to the AZT I and the siquinavir made me vomit a lot you know this book by Hilda Clark she was working for the government and she was sick of being told by the government what to say all the time apparently you can not get this book anymore I was just told but my best friends the couple I mentioned just got this through a pharmacy she also says that the whole HIV=AIDS is a total lie that it has not been proven at all she is very much along the same lines of Continuum (#9)

It was a few months after I decided to stop the combination and it was incredible in April I had a blood test and I went to see him after the test and he asked me what is it with you I have never seen you like this and he said I feel terrific I have never felt so good before and do not tell me shit from your computer I know that the results must have improved drastically the viral load was down to 430 which was below the level of undetectability now is 250 and the CD4 count was 167 still not out of PCP danger and then I told my doctor that I had stopped with the combination and that is why my counts were so much better I mean of course I am sure that because my frame of mind had improved so much because I was not polluting myself with all that toxic my frame of mind had much to do with it but I actually think that stopping the drugs has it has initiated an upward trend in all my counts (#10)

Dissidents are concerned with what the body 'can do' whereas the PWA is concerned with what the body 'means'. As such, dissidents enable the body to operate beyond the colonisation of representational practices and to move beyond institutionalised ascriptions of the 'normal'. Medical discourse has established the notion of an inherent normality of the human body. Once the capacity to see beyond and through the epidermis became an established professional practice, the 'statistical man' took over the 'biologically unique man' (Illich, 1976). This new system of knowledge converged onto bipolar definitions of what constituted the normal and the pathological body. As a result, normative configurations of power/knowledge privileged biophysical proximity to observed ranges of parameters rather than the lived experienced of functioning bodies, which might nevertheless deviate from the established norm. The ever-increasing capacity of medical technology to probe the depths of the body is both an effect and a result of such discursive practices. The extent and the nature of the deviance shapes the degree to which a 'phantom normalcy' may be achieved by the abnormal individual, and the 'phantom acceptance' the abnormal being may be granted by 'normal' society (Goffman, 1968).

In resisting the ascription of a PWA identity the dissident individuals faces a series of challenges. Such resistance is articulated through marginalised discourses and stigmatised by the institutionalised HIV/AIDS model. The distinct alternative discourses that surround the biological, social, and moral dimensions of HIV/AIDS may be differently appropriated by each particular individual; yet, the psychosocial pressures involved in maintaining the plausibility of such a belief system is equally shared.

I do like to have a hot bath but these are relaxation techniques I do think that relaxation techniques are very important I would just make the point though that within these issues I work in a way that is kind of described by other people as dissident I suppose and I think that dissidence is a chronic dis-ease in itself I think that there are particular stresses involved in trying to maintain an energy contrary to the prevailing orthodoxy that you can not go into a tube station and see one of those big ads for HIV testing without realising that you are alienated it is a constant experience of alienation as opposed to the experience of the HIV community and I think that are particular risks and stresses with that that would not matter if you are diagnosed or not (#6)

I was trying to get DLA I guess I caused a lot of trouble because I was a dissident I remember saying I used to go to Body Positive in Earl's Court and back then all I was saying was that not everybody with HIV gets AIDS and people were saying you are wrong everybody with HIV gets AIDS how dare you say that but nowadays it is not controversial to say that because everybody knows I hope everybody knows now that not everybody with HIV gets AIDS it is not controversial anymore but back then it was because it was challenging people's beliefs I sort of drifted out of AIDS because it is like I spent 3 or 4 years I mean I got the editor of Positive Nation the editor the editor of Pink Paper some people from the medical research council so I got people who believed in HIV who believed in combination therapy to come and have dinner and I paid for it is quite

an expensive restaurant in the West End it is not that expensive but it was because I was paying for it all but I wanted to get them around the table to talk you know friendly but scientifically with each other to discuss I did that it was interesting because the guy who was editor of Positive Nation he was a nice guy alright he believed HIV existed just got them to sit down they were not bad people because some of the dissidents thought that the people working at Positive Nation were evil nasty people and they were not this guy was gay he was on combination therapy himself so he would not be taking something he thought was going to kill him so I reckoned we should respect what this guy believes but we should still communicate perhaps we can find some middle ground and respect for the different view points so I was very interested in doing that I was very interested in getting debate going like I wanted the gay press to debate the cause of AIDS to look at all the different hypothesis that were and people to understand that there is some controversy about what are the causes of AIDS (#7)

Resistance identities are mainly constituted via the 'reverse' discursive practices of the dissident critique, and as such demand to be acknowledged by employing the same (scientific) categories that are used to disqualify it (Foucault, 1981). However, committing to a belief system that is discredited by the institutional apparatus of mainstream society can constitute an unstable process:

I see this doctor at Ealing hospital because he is he is known as being more tolerant and not pushing the drugs on you so I see him regularly and he does all

the tests and the CD4 counts and viral load and all that is on the file but I do not want to know because you go up and down sweating and worrying but since I have been reading Continuum and realising the waywardness of these things anyway how can you match them up...I went along to Dr (deleted) in January that was about nine months after the diagnosis in 1992 and I was struck quite nicely with him he was not so busy those days I suppose so we had a nice long chat and he asked me you do not mind if we take some blood tests and I said no as long as I do not get the CD4 results because I just did not want to obsess I do not give a fuck I am asymptomatic at the moment but I can not stand the idea that he is looking out for ways and means for actually sort of suggesting to me that it might be a good time to start on combination therapy ...you know I am a Continuum reader and in many ways I see myself as a dissident because I refuse to take combination therapy and I pretty much do my own thing in terms of health and nutrition and I tell him (the doctor) that he should be reading it and he is aware that he gets mentioned in it occasionally this kind of thing but you know his empire is growing and I get the feeling that if I wanted sort of some quick treatment or something if I all of a sudden sort of decided I want an appointment like I can do now you know being a patient of (deleted).... the thing is that sometimes I question my own sanity I everybody believes in HIV that HIV causes AIDS and to hold on to dissident views and to stay strong in my conviction is not so easy and what I was saying that the isolation is enormous and that there is no way to isolate me from all the AIDS facts and statistics and blood counts and all

these things and all I am doing is taking infusions and some supplements so I get paranoid sometimes (#8)

I mean I ask myself should I should I be worried about counts and all those measurements I mean when they are so detrimental to my state of mind and if they make no such difference but I still have not been able to break the habit I it is like a security blanket my spirit is not that strong yet but that is my goal (#9)

Other dissidents deal with the uncertainty of their belief system by constructing narratives with high levels of incorporation of the 'reverse' discursive practices that constitute the basis of the dissident critique. They may resist the colonisation of science, but embedded within a scientific society that repudiates their cosmology, dissidents maintain their fragile belief system through the use of the same scientific discourse they attempt to escape:

I do not believe that the viral load is actually measuring HIV infectious particles I do not believe that but I believe the viral load is measuring a pathogenic state which is a non specific pathogenic state I am speaking with some doctors from St George's and they told me if you have TB TB is interesting because 50 percent of all the AIDS cases in the world are actually TB cases if you have TB or PCP it makes your viral load go sky high but also bacterial infections viral infections there are loads of things which affect your viral load that can make it go up so



when you treat the conditions they go back down so I think it is measuring a high pathogenic state it could be high cellular turn over but I do not believe it is measuring HIV so I had a very high viral load which is strange because my CD4 count actually doubled with a high viral load which you would not expect and then some people said your CD4 just doubled that is just more CD4 cells for the virus to eat so before the viral load test came up it was a good thing if your CD4 came up but there is no proof that HIV kills CD4 cells so but the hypothesis is that you have a high viral load and that the virus is running around eating the T-cells and through an indirect invisible mechanism that is yet to be identified the CDC states that HIV kills CD4 counts through a yet to be identified invisible mechanism I mean the Pasteur institute has shown that bystander cells not infected cells are the cells that are actually dying and the infected cells are not there has also been some research which was published in science which actually measured you can calculate the age of the cell by measuring the telomeres because each time the cell goes through mitosis each time the cell divides the telomeres become shorter so you can calculate the age of the cell and these scientists calculated the age of cells in AIDS patients and said this does not make any sense because all the cells were old cells and that really could not be the case I sort of believe HIV does not kill T-cells there is no evidence for that (#7)

For the dissident disclosing his ideological stance, not his status, constitutes the main social problem. The stigma of resisting such a subjugated social location occasions

several problematic situations that are resolved by the representation of mainstream society and its values as the 'other'.

The risk involved is not so great as they want us to believe you know suppressing your sexuality that way it is very dangerous for the body and the soul are connected and sexuality is an expression of spirit and it should not be it is not about sexual acts dangerous acts it is about human connection and if someone is not on my level of understanding then sod them (#9)

The whole thing I just really strange I do not think about it anymore I just it is as if I had no HIV I do not even feel strange about not doing the combination it is like I am not on the same boat with all these HIV positive guys who are doing the drugs but to be honest I find it very difficult to explain to people what my beliefs are I mean the language of Continuum is too complicated but to just say HIV does not exist or something like that people just look at you like yeah right (#10)

Despite the significant social costs involved in the articulation of a dissident identity, dissidence is interpreted by the individual the most important technology of the 'dissident' self. The maintenance of the boundaries between 'us' and the mainstream 'other' with its detrimental colonising surveillance practices is understood as constitutive of mental and physical health.

I had a doctor friend and he said you know you do not want to be part of an experiment I was feeling pretty grim you know because I just felt so powerless I mean the only option at that time was AZT and there was nothing else I just felt like if the only medication they were offering was like poison gas I had a friend well not really a friend but somebody I used to see every once in a while here in London he was a lovely guy and he was diagnosed a year before I was and he went straight into AZT and it was scary I mean the guy just completely deteriorated in one year and he was dead in two and I just you could see that it was the drugs he was taking because he was perfectly fine and then they started pumping him with AZT and that was when the doses were very high and he looked terrible I could there was a sense in my guts that it was the drugs so but the fact is that I am that I have been diagnosed with HIV but I have never been sick with an AIDS illness with an opportunistic infection so why would I take those terrible combination drugs when I am perfectly healthy you know even before I was diagnosed I mean from the start of the epidemic or the health crisis as we should say really because there is no epidemic I just had it deep down inside of me you know that whatever they are offering is the killer people who take the drugs are the people that are more likely to be dying I mean I was optimistically about the doctor who told me people are lasting 8 to 10 years this kind of thing and I was supposed to say wow that is a real relief off my shoulder when they gave me the CD4 I it was about 500 and I was scared really scared because I thought well I do not have much more time but now after becoming a Continuum reader and being you know knowing that these counts can go up and down if you

have the flu or been vaccinated now I just do not care I still do not want to know them because I would go crazy with worry but deep down I do not really care anymore I feel healthy my body is strong so why should I not think of myself as healthy? (#8)

I think one of the ways to keep my health is to focus my mind on being well staying well living clean eating the right foods organic foods getting rid of toxins and fighting on a mental and emotional level I mean it works for me I have not been sick or been to a doctor in over five years (#6)

I think I got better because I wanted to because I found the will to live you know and I started to take more responsibility for myself considering drugs considering food considering supplementation considering you know getting enough sleep and so on I take care of myself and because before cancer or whatever I did not I was not conscious about my body what my body is and what it can do how it sort of heals itself if the conditions are right beyond the physical now I know there is another level I know it is all about how you treat yourself and also about your own being happy being happy in being happy you start projecting yourself into the future and if you start projecting yourself into the future there is a whole new I do not know approach to life you realise you will need your body for longer and in order to use your body for longer you have to do something you know you have to treat your body nicely so that it continues doing what it is meant to do for longer but I think that quitting combination was also key in my healing I was drugged up

I mean not recreational drugs but combination therapy TB medication as well as all the toxic stuff from the chemo still in my body and there I was thinking the combo was going to save me it is such bullshit and I was developing I had lipodistrophy and you know I had not even noticed but it was shocking later I realised I did have it or at least the beginning of it and that is such a terrible thing you see all these guys now they are on combination therapy and they begin to have that terrible look it is like the AIDS look you can see it from a mile and I know this sounds so shallow but that was one of the main to me that would have been one of the worst things to walk around looking like a freak but thank God that I am so grateful to God or whatever that I quit because since then my CD4s have tripled and my viral load is down to nothing (#10)

### 7.5.3. Legitimising and Resisting: homing in on the fundamentals through clustering

In the previous two sections I conducted a type of step-by-step cumulative analysis of the social processes that constitute the formation of a new type of subjectivity based on the clustering information I gathered through HAMLET. Yet, I have not yet explored in what specific ways they are fundamentally different. The 'Intersection Table' of section 7.4.2. was very useful in helping me understand the principal nodes (clusters) of differences between the dissident and the orthodox individuals.

The two subsets only perfectly coincide in one cluster (4/14), or 'Dissidence' and 'Saude'.<sup>232</sup> This cluster signifies the most relevant point at which the two coincide; yet this does not necessarily mean an agreeable coincidence. By looking at 'Table A: MDS Solution and Johnson Dendogram for Orthodox Subset' one can not locate the points dissidence and 'saude' because they constitute the most distant points in the matrix (see Tables 2 and 4). The interpretation of these different clustering patterns seems to suggest that their distance in the context of orthodox experience translates the rejection that the dissident cosmology by orthodox individuals:

The first that that I time that I came across that was in Vancouver but I think it is bull you know science is a developing entity and new developments come along so what is true today may not be true in a year's time but that is for everything but then when they say a fact is not a fact I am just like sorry but I go for this but if it offers you some sort of mental health or offers you some sort of solace then that is fine and that can obviously have an effect on you as a person but it has no effect on your stress levels and your cd4s but to endorse things that end up limiting someone's life expectancy through ignorance or whatever I just do not have time for I think Continuum is dangerous because people can be easily influenced (#4)

The distance of the code 'saude', on the other hand, can only be explained by the poor health experienced by orthodox individuals. The same cluster (saude/dissidence), in the context of dissident discourse, occupies the last clustering position in the sequencing of

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<sup>232</sup> Saude, the Portuguese word for 'health', was the name given to the code that contained words and word senses related to good health and well being.

clustering stages evidenced by the information provided by the Table Johnson (see footnote 231). This fact seems to suggest that dissident narratives of health, as we have seen, interpret good health as a direct consequence of the dissident location, and its positive implications in terms of rejection of the biomedical solution for HIV.

The second cluster subset where dissident and orthodox individuals overlap is within issues of disclosure and stigma (3;18). Again, the partial coincidence is a discordant one. As I have shown in the previous section, for the dissident the issue of disclosure is problematic in terms of the subjugated position of their resistance identity whereas for the PWA it is the stigma of HIV that constitutes the problem. The next instance of partially coinciding clusters is represented by codes 5 and 9, or 'doenca' and medication.<sup>233</sup>

Some of some of the last 6 months being sick from drug reactions have really stressed me out not from antiretrovirals it was not side effects but from prophylactics mainly the septrin because I took every prophylactics I took I would come out you know after 10 days violent rashes that would stay with me for 2 weeks afterwards and so on and so on and then I would take another one and the same thing would happen and there was just I got so stressed about a friend of mine caught a bacterial infection on his arm and I kind of could have caught it off him so then I had to take another kind of antibiotic which I was seemed to be so reactive to and I just did not want to take any more drugs to be sick for longer I was sick of being sick but that has only been in the last 6 months I guess because

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<sup>233</sup> 'Doenca', to remind the reader, is the Portuguese word for 'disease' and was used to name the code that contained all the words and word senses that represented issues of disease.

I guess I had gained a lot of knowledge about what is available what can honestly be achieved and expected from drug therapy no but then sometimes when you are not feeling so good you can get depressed there is times when things happen when people say things that you you are not feeling so good so you get a vulnerability there so HIV per se does not the first time I got I suppose I felt that bad about it is in terms of being sick and looking haggard if I keep on being reactive to all of these drugs then how long am I going to be sick for then what is going to happen if there is going to be no more drug choices and you know I had all this time in my hands because I was so sick and I got very anxious and depressed about the whole situation (#4)

The quote above illustrates the often experienced reality of iatrogenic disease in the context of HAART and/or related biomedical guidelines (of prophylactic drugs to prevent opportunistic infections). However, the PWA conceptualises health in terms of the body's counts, not in terms of the lived body. The definition concerns the meaning of the body, not what it can do. The opposite relation is enacted by the dissident individual for whom the iatrogenic potential of HAART is seen not only as causative of disease, but as an inefficient and toxic compound that is going after the wrong culprit in the aetiology of the diseases known as AIDS. As such, the coincidence of the cluster 'doenca'/medication represents the diametrically opposite views of the two subgroups in terms of health and illness paradigms.



## 7.6.-Beneath Representations

The main objective of this research project was to understand the impact a ‘fateful moment’ can have on the fragile basis through which our ontological security is maintained in the world, the self. Initially I framed the research questions in terms of the kinds of coping strategies infected individuals devised. At that point in the process of conducting research my framework was grounded on the specific social processes and discourses which had been (mainly) articulated at the beginning of the health crisis. For at least the first half of the 1980s, when AIDS ‘victims’ were ostracised by most political and medical institutions, many turned to what was then widely known as ‘alternative’ medical systems. Until the medicalisation of the AIDS problem coalesced around the development of antiretroviral drugs, the New Age and the holistic health movement played an important role in the coping strategies of many AIDS ‘victims’. The evolution of ‘alternative’ medicine to the potentially integrative framework of CAM (complementary and alternative medicine) is to a great extent attributed to the initial significance of alternative medicine in the AIDS crisis (chapter six). Therefore, I was interested in finding out if religious or spiritual cosmologies had any relevance in the choice between allopathic treatment and ‘complementary and alternative medicine’ treatments. I also articulated the question of the restructure of the self in terms of whether individuals agreed that HIV was a ‘blessing in disguise’. The theme of HIV as a catalyst for positive psychological and spiritual transformation had been widely articulated in the beginning of the AIDS crisis by so-called ‘alternative’ or spiritual healers who understood the development of the syndrome as a symptom of the inner workings of the

damaged gay self. These discourses attempted to shift power relations by repositioning the AIDS body not as an 'apocalyptic' metaphor (Palmer, 1997) but as an exemplary instrument whose healing could catalyse the much needed process of transformation on a global level. At last the Age of Aquarius would rise.

The discovery of the 'dissident' category illustrates how the resisting discursive practices around AIDS have changed since the 1980s. The resistance project that 'alternative' conceptions of healing had represented has been entirely subsumed by the repositioning of a redefined CAM in a complementary role to biomedicine. By the late 1990s the most significant resistance project was articulated through the 'reverse discourse' practices of the dissident critique and the social movement it had spawned. In the sixty seven interviews I conducted only one revealed the association between therapeutic choice and a 'New Age', 'greeny' worldview (interview # 5 of section 7.5.1.). In addition, in my sample 'HIV as a blessing in disguise' turned out to be a totally discredited notion; only two of the sixty seven respondents agreed with the statement 'HIV is the best thing that has happened to me' (I quote here from two NUDIST interviews):

Yes definitely I am lucky to be HIV HIV made me open to life without  
HIV I would have wasted my life when I discovered I was HIV I  
discovered my mortality and I discovered how important was every  
relationship... I would have been a dug dealer I do not know some really  
grim life (# 17)

My life would have taken a completely different direction if I had not been HIV I have changed a lot and I am afraid I would have I would still be the prat that I was if I had not been if my life had not been so fundamentally changed the day of my test (#11)

Narratives that proposed HIV as a blessing (Hay, 1984) reflected strategies of coping rather than actual experience. The realities of life post-HIV do not reflect an improved social existence; however the 'framing' of the experience of illness in a positive light is frequently employed in a cognitive effort to symbolically mend the 'protective cocoon'. The mending of the shattered cocoon of the AIDS body is not confined to the individual level; it is a desire articulated on the (sub)cultural level. The 'gay circuit' phenomenon described in chapter four emerged in the 1980s as a response to biomedical definitions of the gay body as the sick body. The fact that the 'circuit' is mainly (but not exclusive) an American phenomenon might explain the low number of individuals of my sample who had ever attended these events (only four had ever attended and only one could have been described as a 'circuit queen'). As such, the effects of the 'circuit' in resisting biomedical definitions of the body played no role in the reconstruction of the identities of my sample. As we saw in chapter five, Queer Spiritual Discourse (QSD) constitutes another resistance project which attempts to dissociate the homosexual body from notions of intrinsic deviance. The elitist nature of QSD, a historical and theological body of ideas, which have been produced by gay and lesbian scholars and intellectuals, may explain the fact that none of my sixty-seven respondents were aware of it. As such, QSD constitutes a resistance project with very little effect on the material lives of its constituency. To sum

it up, the initial framework of my research project would have yielded very little relevant information on the processes of restructuring of the positive self.

The emergence of a new unit of analysis in the midst of my field work changed the focus and the direction of my research. The category 'dissidence' suggested that resistance in the contemporary arena of power relations of HIV/AIDS could no longer be articulated from outside the discursive practices that 'own' it. As such, resisting the stigma of AIDS in the technologically-advanced context of contemporary Anglo-American society is an effort enacted from within the discourse of science. Magical New Age connotations around the 'healing' of AIDS can not be sustained in societies where the guardian of moral boundaries is no longer the religious functionary but the medical professional. The articulation of a resistance identity constitutes an attempt to resist the medicalisation and the control of the positive body. Yet, the dominant discourse of biomedicine is also the starting point for such a strategy of opposition to medicalisation, and its effects on processes of embodiment. Discourse, medical discourse in this case, is both an 'instrument' and an 'effect' of power (Foucault, 1973). The 'productive' aspect of biomedical power produces the resistance identities, which oppose the legitimising identity of the PWA. Power in this sense is relational, a strategy which is invested in and transmitted through all social groups. As such, dissidents attempt to resist not the malevolent imposition of ascribed biomedical definition by the new 'clergy' but a 'series of loosely linked assemblages' that reproduce medical dominance (Lupton, 1997).

Many HIV-infected individuals appear to normalise a pathological relationship to their bodies in order to conform to technologically produced signifiers of health. The fundamental issue in the articulation of the PWA identity is the relinquishing of agency that the adoption of a legitimising perspective necessarily implies. When the pathological state of the positive body is reinterpreted as necessary for a simulacrum of health that includes serious iatrogenic dis-ease, the gay body fails to resist the institutional inscriptions which have been labelling it as deviant since the early modern era (chapter three). The adoption of such a 'passive' positioning by the PWA implies the relinquishing of his agency in the production of his own corporeal meanings. Thus the PWA is ultimately implicated in his own subjugation by the discursive practices that endeavour to constrain the positive body that is his self.

Dissidents engage in processes and practices that destabilise the subjectification of the body as the object of control of the institutional gaze. The dissident chooses to interpret health from an embodied, experiential, lived perspective. As such, the resistance identity represented by the dissident position asks what can my body 'do', not what does my body 'mean'. This form of resistance identity should not be understood as a deluded positioning incapable of accepting the truth of AIDS. A more productive way to understand what such a resisting possibility may mean is to consider AIDS dissent from the 'questioning' logic of contemporary (post-modern) society where 'meta-narratives' no longer sustain plausibility structures. In their recalcitrance dissident individuals affirm the effects of representation upon our materiality, and the consequences they impinge upon our organic beings. However, by embodying the subject position of AIDS dissident

these individuals defend the processual nature of our materiality, a contingent and continuously evolving 'event'. Dissidence uncovers the fact that in the naturalisation of the binary positive/negative much is socially constructed and highly political. More fundamentally, the embodied experience of dissidence raises the important question of the 'possibility of a free consciousness that could precede, and be revealed beneath, representations' (Bray and Colebrook, 1988:57).

## **Appendix A: Interview Guide**

Start by informing interviewee that the interview data is strictly confidential, that he/she may refuse to answer any question, and that in case excerpts of interviews were to be published any biographical information would be changed in order to assure that confidentiality is maintained. Get interview consent then proceed to cover content areas to be explored in each interview.

**What is your name?**

**Where were you born?**

**When were you born?**

**What is your educational level?**

**Are you employed?**

**What is your current job/occupation?**

**Where did you grow up?**

**How long have you lived in London?**

**Why did you come to live in London (in case not from London)?**

**Do you define yourself as:**

- 1. Homosexual**
- 2. Heterosexual**
- 3. bisexual**
- 4. gay**
- 5. lesbian**
- 6. queer**
- 7. other**

**Are you 'out' as (all the above except hetero)? Develop (work/social/family context)**

**Do you participate in the so-called gay community in any way? Develop (how, where, types of activities, reasons)**

**Do you volunteer your time/money to gay-related charities?**

**Are you:**



- a. single
- b. married
- c. divorced
- d. separated
- e. widowed

**If partnered/in relationship/ married for how long?**

**Have you (ever) been involved in (a) (any other) relationship you consider significant?**

**Develop (quantity, duration, context)**

**How do you feel about your sexuality? Develop (development in time; role of external factors: school, religion, society, family; role of internal factors: own feelings and experience)**

**Have you ever been bullied/discriminated because of your sexuality?**

**When did you realise you were attracted to the same sex? Can you recall that experience?**

**Explore whether thinks gay is born not acquired (do you think you were born gay?)**

**When did you have your first sexual experience? Develop (who, where, how, feelings)**

**Have you ever had sexual relationships with men/women (depending on gender and sexual orientation)?**

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**When did you first test positive for HIV?**

**Had you been tested for HIV before? Develop (reasons, context, frequency)**

**Can we talk about the time you received your diagnosis? Develop (context of test, revelation of diagnosis, experience with medical personnel, feelings, reaction)**

**Did you tell people about your diagnosis? Develop (when, how, who, reactions, own feelings)**

**Do you know how you got infected? Develop (source, time frame from diagnosis, context, feelings, suspicion of seropositivity, symptoms)**

**Are you 'out' about your status? Develop (work, social, time, family, sexual, context, emotions)**

Is there anyone you have a significant relationship with who does not know about your status? If so, why? Develop (reasons, feelings)

Have you been discriminated because of your status? Develop (context, reaction)

If in relationship ask:

1. Are you in a monogamous relationship? Develop (definition of monogamy, sexual 'contract', safe sexual practices)
2. Do you have safe sex with your partner? What is your partner's 'status'?
3. Do you have safe sex with your casual partners? Develop (known status of casual contacts, mutual consent, disclosure)

If not in relationship ask:

1. Do you have safe sex with your partners? Develop (known status of casual contacts, mutual consent, disclosure, context, reasons)

What do you consider to be safe sex?

Did you practice safe sex before you were diagnosed? Develop (frequency, practices)

**Has your sex life changed in any way since you have been diagnosed? Develop (libido, context of sexual encounters, frequency, practices, feelings, temporal developments)**

**What is the role of sex in your life? Develop (meanings, feelings, function, context)**

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**How is your health at the moment? Develop (health history, conception of good health).**

**Have you ever/do you have any HIV-related disease? Develop (what, when, context, hospitalisation, feelings). Have you ever/do you have any visible signs of HIV infection? Develop (feelings, reactions, sexuality, concealment)**

**Did you receive (specific) treatment for such diseases? Develop (where, how, what, whom, hospitalisation)**

**Do you know your 'counts'?**

**If yes: what are they? Explore significance**

**If not: why not? Explore significance**

**Do you see an HIV specialist? Develop (who, where, history, trust issues, frequency of monitoring, relationship with doctor)**

**Have you ever/are you currently taking any kind of antiretroviral therapy? Develop (history of medication taking, conceptualisations, feelings, experience of well being, side effects, types of medication, social and medical context)**

**Why did you first decide to take the treatment? Develop (decisive factors: role of disease, symptoms, counts, doctor, self-conviction, information, role of AIDS-service industry, network of positive friendships)**

**Has your health changed since going onto the medication? Develop (counts, symptoms, well-being)**

**Where do you get your HIV medication?**

**Can you describe how anti-retrovirals fight HIV infection?**

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**Have you ever/are you currently using any kind of complementary therapies in order to deal with HIV infection? Develop (history of cp use, conceptualisations, feelings, experience of well being, side effects, types of therapies, social and medical context)**

**Do you see any other kind of medical/health practitioner? Develop (who, why, how)**

**What made you decide to use cp in order to cope with HIV infection?**

**Has your health changed since starting to use complementary medicine? Develop (counts, symptoms, well being)**

**Where do you receive your cp?**

**Can you describe how cp therapies fight HIV infection?**

**Are there any other activities you follow in order to maintain/improve health?**

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**Have you ever/do you take recreational drugs? Develop (types, reasons, context, feelings)**

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**Do you receive HIV-related income support? Develop (type, history, time)**

**Have you ever/ do you attend HIV support groups? Develop (which, frequency, motives, role)**

**Have you ever/ do you receive any kind of support (financial, emotional, psychological) from HIV charities or associations? Develop (which, frequency, motives, role)**

**Do you volunteer your time/money to HIV-related charities?**

**Have you ever/ are you involved in any kind of HIV/AIDS activism? Develop (which, frequency, motives, role)**

**Does HIV affect your psychological well being? Develop**

**Does HIV affect your daily life? How?**

**Does HIV affect your vision of your self? Your future plans?**

**Do you think of yourself as a sick person? Develop (reasons, conceptions, and contradictions)**

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**(this was added after the new category of dissidence)**

**Can you explain HIV/AIDS in medical terms?**

**Do you think HIV infection leads to AIDS?**

**How do you think AIDS develops? (check for co-factors, lifestyle, nutrition, stress, other)**

**Have you ever heard the notion that HIV does not cause AIDS?**

**Have you ever heard that some scientists question whether HIV exists?**

**(Develop reactions and opinions on such views, information sources, information's impact)**

**If someone is a 'dissident' then:**

**Where did you first learn about these 'dissident' theories? Develop source, context, reaction, impact.**

**What impact did they have in the way you deal with your diagnosis? Develop positive and negative aspects**

**What impact did they have in your sexual/social/professional life? Investigate the process of dissident-identity acquisition**



**Do you come from a religious background? Develop (which, whose, role)**

**Have you heard of Queer Theology? Develop**

**Do you consider yourself a religious/spiritual person? Which rel/spirit? Develop (belief system, role, effects)**

**Do you belong to any kind of church/religious or spiritual group? Develop (type, activities, frequency, objective, meanings, adherence)**

**Have you ever had any kind of religious/spiritual experience? Develop (when, how, what kind, impact, context)**

**Does your religion/spirituality have any role in how you deal with HIV? Develop (healing, techniques, perceived benefits, actual benefits, reason, meanings). Here distinguish from complementary therapies not necessarily associated with transcendental/spiritual cosmologies).**

**Has HIV had any impact on your religion/ spirituality?**

**Would you say HIV/IDS has changed you? How? (develop)**

**Would you agree with the statement: 'HIV is the best thing that has happened to me'?**

## **Appendix B: Transcript (GS, 04/1998, File 37)**

(The last five thousand words of this transcript had to be removed from the thesis due to limitations on the number of total words of the thesis)

**Preliminaries said; permission granted.**

**C: Can you tell me where you are from and how long you have been living in London?**

**G: I was born in London in 1964 so that makes me 35 and lived here in Harrow I was born in Harrington but lived in Harrow until I was 8 then my parents moved to Oxford and I lived there until I went away to boarding school at the age of 13 until 18 near the south coast then I studied chemistry at school I wanted to become a doctor decided at the last minute I did not want to be a doctor I wanted to be an actor big change so then after school spent a year in Oxford at a college of further education doing English A level and theatre studies A level in a year then spend a year cooking at a pizza parlour and then spent three years at drama school in Gilford and then spent the next few years touring around the country working I spent quite a few years working as an actor and doing temp jobs and my last acting job was in 1989 uh it was a tour of Great Expectations in the middle and the far East which was around 4 months and came back into this country at xmas of 1989 with four thousand pounds in the bank did not want to work as an actor because I had lost contact with friends and those sorts of things I just wanted to settle down for a while so I started doing some volunteer work for Crusaid and then after a while I needed some money so I got a short term contract with somebody who was doing some HV training for the health service in the summer of 1990 and he said during it was**

supposed to be six weeks I was just doing some administration and he said why do you not come along and see what I do it was in front of some 20 midwives and it was just doing basic training what AIDS stands for how it is transmitted and that sort of thing and halfway through the morning he said so Henry what do you think and with the communication I got as an actor and the knowledge that I picked up working for Crusaid I have the skills and the knowledge to do some basic HIV training which he realised so he started to employ me as a trainer so that is more or less what I have been doing ever since using the skills I got as an actor I get paid a lot more and it is there is a real I can see real benefits rather than just entertain.

C: Can you tell me a little bit about when you realised you were gay?

G: Looking back I can sort of see I enjoyed watching Tarzan movies on a Saturday night that would have been when I was about 4 or 5 and I had no real concept of what it was the real thing I realised was around the age of 11 or 12 that was when I was able to not necessarily put words to it but in terms of labels but I could put words into the desire you know who I fancied you know I like him rather than her and it was actually when I was 12 uh my mother had a first of a series bouts of mania mental breakdown type of thing and she had one she had just had a hysterectomy it was the summer of 1976 and she had I was supposed to be at home because it was a holiday and my father was due to come up to London to do a lecture or something like that and he could not leave me at home the next day because my mom could not cope with me so what he did was he brought me to London and dropped me outside the science museum with 25 quid in my pocket at the

age of 12 and said go look around at that and I will pick you up at 4 in the afternoon at least that is my memory of it and I did not go to the science museum I went to Soho and that is where I had my first sexual experience it was with a man who must have been much older than me he must have been oh old 24 in a straight cinema booth in Soho.

C: So you realised from a very early age then?

G: Oh yes.

C: Do you think you were born gay?

G: I am sure I was.

C: How did you feel when you went back to meet your dad?

G: I knew it was something that I should not talk about my parents had made it very clear my brother is 5 years older than me and in conversations with my brother which I had been part of it which was you are not supposed to have sex with women until you are married nothing had been talked about sex with boys I did not feel guilty I was very excited and wanted to do it again.

C: Did you continue to have sex?

**G:** The next time I had sex was about a year later it was the first time I had penetrative sex in boarding school only happened when I was 18 and only three times with a guy my age.

**C:** What about sex with girls?

**G:** No I never thought about it I was I it just never crossed my mind I was only aware of men and it did not seem wrong to me so there was not a dilemma of having to choose really.

**C:** Did you tell anybody?

**G:** I came out in boarding school when I was 16 and it went around the school pretty quickly as those sort of things do and then fairly shortly the teachers knew originally one of my best friends said you can not be gay being gay is standing on a street corner and picking somebody up and I just said yes I think the language I may well still have been using was I like men or I am a homosexual I am I do not know when I started using gay.

**C:** How did they react?

**G:** Well it meant that I was never to have sex with anybody else at boarding school because the moment I identified myself uh nobody else would even consider because it

would label them but I managed to maintain the respect of other people I ended up being the head of house of 80 boys I was a prefect.

C: What about your parents?

G: I told my dad when I was 18 just before my A levels around the same time I told him I did not want to be a doctor I wanted to be an actor he sort of accepted it he is a doctor and I can remember his words being I do not think you are because I have not seen any of the symptoms I never asked him what the symptoms were but he just thought I was under the pressure of the exams and sort of making a change from doctor to actor teenage type of problems he has now pretty much accepted it we do not talk about it much about it but you know it is just one of those sorts of things my mother he suggested not telling my mother because of her mental state most of the time she is fine but her bouts of mania are set off by family emotional difficulties and so we decided not to tell her but she found those magazines I had been hiding for 9 years so she found them when I was 21 threw them all out and called me home and confronted me with it and I said yes at the time she told me she was concerned about me being 50 and a lonely old queen since then she has expressed worries about religion and how it sort of she she believes in she is a member of the C of E she has got very strong Christian beliefs and she can not quite marry the Christian upbringing that I had with being homosexual she thinks it is a sin but we get on we get on.

C: Is your dad religious as well?

G: No he is not he is a complete atheist a real scientist.

C: What about yourself are you religious?

G: I think I am fairly spiritual but I have had real problems with the times that I have tried to when I was a teenager I explored being a church member when I was in school I was in the church choir that sort of thing but I did try and be part of the church in terms of you know being a Christian and accepting Christ when I was 16 that was my quandary it was not so much about my sexuality but I had real problem when I came out I think that was the one area where I had real problems over the other members of the school church not treating me in what I thought was a Christian way so I had problems with organised religion but even then I saw that the churches teachings about homosexuality being a sin and therefore members of the church judging somebody else for doing something like that as somehow surely that is not what Christ and Christ teachings are about they are about accepting everybody and I find religions where people are not accepted because of things that they do or because of what they are kind of tricky.

C: Did you really want to belong to the church?

G: I think I was I think I was looking for some kind of identity because there were not many other people around me I did not feel as if I were a member of anything I felt very different because I was very clear about my sexuality and it was being expressed in a way

that was not normal for a teenage boy so I wanted to be a member of something and when I was rejected from that I went OK let us find the resources within me so I became very independent very early.

C: How were you rejected?

G: I remember some of my friends when I was 16 telling me being a homosexual is a sin and me trying to have conversations with them about the philosophy of Christianity you know it was never very being told by a group of people who you want to be a member of that you are committing a sin was difficult and I felt as if well it is their lack not mine and I did not feel as if what I was doing was a sin so it was their problem.

C: Have you ever heard of Queer Theology?

G: No.

C: Are you familiar with the work of John Boswell?

G: No who is he?

C: He is a gay historian what about HIV when did you find out?



G: I found out in 1992 uh the way it came about obviously I had a clear understanding of what HIV was because I had been working with it for a couple of years and I had been having tests every 6 months or so since about 1986 I was going out with this guy a New Zealander called Ian and we had been going out for about 3 months we both said that I mean I had had and he had said that he had just before we started going out with each other that he had a negative test tests that had come back negative it was in the summer of 1991 we came back from a club on a Sunday afternoon and we had sex and I had stopped checking to see if he was wearing a condom or not and it was not until after he had finished fucking me that I realised he was not wearing one and so even though everything I knew well I sort of rationalised it well it has happened once then therefore we had been OK practicing safer sex OK we might be having sex outside of the relationship we both were uh but we discussed how the sex outside of the relationship was safe how we both had negative tests just before we started going out with each other therefore the risk was pretty small so we continued to have unsafe sex with each other it was during a hectic.

C: Were you having safe sex outside the relationship?

G: I was and pretty much I mean not in the 1970s but as soon as I was aware of AIDS I was having safe sex always we negotiated that between the two of us how we would not have unsafe sex outside the relationship and decided not to have unsafe sex outside during a fairly hectic time in terms of we would go to Trade at weekends and sex parties after that and they were a couple of occasions one where I almost caught him about to be fucked by somebody without a condom and I just put the condom on the guy and and the

next time was in November when I was having sex in one corner and I heard somebody say to him not without a condom and I thought hang on so the next day I confronted him probably not a good idea because we were both coming down the next day I confronted him and said do you remember he did not remember because he was so off his face and I said to him does it worry you and he said no well it worries me because I thought well if he can not remember he is telling me he is having safe sex but he might not remember the times he is having unsafe sex so I finished the relationship because I was so angry I was so angry he had no regard for me.

C: How long was this relationship?

G: 9 months. 3 months later end of January I went and got tested and it came back positive so then I told him and he got his results and it was positive as well so I am fairly clear that is where it came from I was hugely angry with him but since then I have come to accept 50% of the responsibility. I do not feel angry anymore I also think if it had not been him it probably would have been somebody else.

C: Why do you say that?

G: I do not think I would have not been able to maintain safe sex indefinitely I mean probably just knowing the places that I like going to and sort of the lifestyle that I lead I probably would have ended up having sex with somebody who had HIV at some point.

C: Can you tell me about your lifestyle?

G: There was a period I do not do it so much anymore now I may do it every 6 weeks but I used to do it every weekend you know getting off my head and getting laid basically I did that constantly for 2 years and I still like doing it I also like the leather scene so it was likely to happen.

C: So you are no longer angry?

G: No but uh I think I had issues around my parents or particularly my mother or my upbringing because my mother had this unstable mental health which I never worked through because I did not understand what was going on and in a way the HIV was the thing that brought us back and since then we sorted things out.

C: Let us go back to the day you got your results?

G: I went to the hospital with a friend who was also very good friends with Ian and I went and saw the same health advisor that had given me the pre-test counsel and she just said you are HIV antibody positive and she said do you want a whiskey and I went sorry and she got out of the bottom of the filing cabinet she got a bottle of whisky and at that stage I did not drink so I said no thank you and I could see she wanted to do something she asked me if I wanted a cup of tea but all I wanted her to do was to sit down and talk some of this through with me so i said yes I would like a cup of tea so she left to make

this cup of tea for what seemed ages and I can not remember what we talked about but she took me through the things and then we called my friend in and he was more in shock that i was but i do remember that I did not want to get into the tube to go home I wanted space around me I did not want to be crowded I was in shock for a while I can not remember how long I just kept going functioning from day to day I just kept on working.

C: You were an HIV educator by then what did you think the diagnosis meant?

G: Even though I knew and I had been telling people for the last 18 months that it would take 9 to 10 years on average until they would die I still thought oh it is going to be tomorrow I remember I thought and I discussed this with people who work within the industry and then found out they were positive several people have said to me and I had this thought this myself two months and then I will be dead then you get to those two months and you think six months and then you get to those 6 months and you think oh sod it I suppose it took me about 2 years to really sort most of it out I mean occasionally there are things that jump over my shoulder.

C: Like what?

G: It is usually about something else I can remember though suddenly getting a CD4 count of 190 so it is below the 200 mark so thinking oh I have AIDS or having to start treatment.

C: So let us talk about that one are you on treatment?

G: Yes I have been on treatment now since for 3 years I got my positive result in 1992 but it must it seems like I have been on treatment forever it must have been early 1995 when I got that result of about 210 190 what I had always I had worked out pretty quickly because of what I knew that there was not a lot of treatment around but what was around was effective and would work at around 200.

C: Are you talking about AZT?

G: Yes so I had said to myself right when my CD4 counts gets to about 250 200 that is when I will consider starting therapy or AZT because that is what it was and I got my result and my doctor had this list of things that I could take which was AZT or I could go on a trial and I thought well I had thought I should go on a trial because that is the only way I will get anything more than AZT and it was there was a trial around at the time called the Quatro trial there was a combination of AZT DDC 3TC and one the no nucleoside protease inhibitors called Loverite and the idea was either you either took AZT and 3TC or you took all 4 or you took 1 drug for 8 weeks and then another for 8 weeks and then another for 8 weeks on rotation and I liked the idea of taking all 4 drugs together uh and I thought OK I will do this but the problem was.

C: Why the appeal of 4 drugs together?

G: Because I always thought just in my head more will be better than one it just seemed more logical to me it is not very scientific or it was not at that stage but just seemed to make sense and just at the time they were proving that 2 drugs was better than one so I thought well if they are proving that then surely 4 drugs will be better than 2 but they had not quite crossed all the its and dotted and the is for the trial they said you have to wait to start this but it will not be long so I continued going every 2 to 3 weeks to have my CD4 count and it continued to drop particularly rapidly.

C: Were you otherwise well?

G: Yes I was otherwise well I was a bit tired but there was no physical stuff there was a tiredness and a lethargy and I could feel that there was something going on but there was no physical manifestation.

C: Had you had any diseases?

G: I had some skins problems but no diseases as such I never have uh and it got to April and then said OK we will be able to start in 4 weeks time I went and saw the doctor who was going to do the trial and had my blood taken and my CD4 count came back as 120 and I thought this is very low it was getting lower and lower and lower and went on to therapy and it went back up to 300 350 but that is when I became not ill but the side effects kicked in and I was sleeping 16 hours a day for the first 4 weeks and then after a 4 week period of feeling so unwell but I knew I was adjusting to the drugs I started to feel

better this was around September and I went back to work that worked very nicely for about 2 years and then my CD4 just started to drop again and I managed to get a hold of all my viral load results because they had been doing this as part of the trial and my viral load was about 9,000 10,000 and I thought uh not good so I said to them look I need to change then I changed to a combination containing 2 protease inhibitors and 2 new nucleoside reverse transcriptase inhibitors so it was a completely different set of drugs.

C: So this was your decision?

G: Yes I said to them look I think I need to change and they went yes we think so too but it was precipitated by me by this time I was pretty involved in training about treatments and there was little I did not know I mean when I had started I am one of those people who is incredibly curious about their own health so I needed to learn it about for myself but also I was already starting to train nurses in how the virus replicates what drugs are being used the latest research so it was both from a personal point of view and from a work point of view that I needed to know this information and as more and more research came along there was little that I did not know and I am pretty much a control freak when it comes to me so yes it has always been my decision I often ask for a suggestion and the doctors will tell me what they think.

C: Which hospital do you go to?

## Appendix C: Word Frequency Table (Dissident Subset)

Note that the words at the top of this table mostly conform to common usage frequent words (with a few exceptions such as HIV). Words and word senses used for the construction of the categories in the vocabulary list (Appendix D) come mostly from the second and third page of the list. For reasons of space only the two top pages of the word frequency lists are reproduced here (the Hamlet produced tables were however much bigger as outlined in section 2.2.3.4.3.)

HAMLET - Computer-assisted Text Analysis - 27/09/2003 20:30:13

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Words listed in descending order of frequency

from the file : C:\Documents and Settings\Claudio\Mis  
documentos\interviewsR\dissidcomb.txt

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3008	I 1336	the
1326	and 1037	to
1005	was 937	a
905	that 826	of
824	it 811	not
742	is 591	you
563	in 509	but
466	my 447	know
394	had 383	have



324	so	322	do
318	because	299	they
296	he	288	with
283	me	255	this
234	all	234	think
221	for	218	are
218	did	209	there
206	be	195	like
192	very	184	then
180	am	180	just
180	on	174	what
168	mean	167	if
165	about	164	we
163	really	159	HIV
149	would	140	or
137	people	132	at
129	an	126	as
124	when	124	who
119	time	117	were
114	been	113	E
112	uh	111	can
111	from	111	thing
109	out	105	she

101	get	101	said
100	thought	99	no
96	lot	88	sort
86	one	86	up
85	could	85	went
83	him	83	years
81	now	80	got
80	kind	79	positive
79	well	77	never
77	sex	77	want
76	AIDS	76	go
75	A	75	going
75	has	75	things
74	life	73	some
72	much	72	myself
71	drugs	70	these
70	Yes	69	gay
68	J	68	used
67	which	64	being
63	H	62	other
61	back	61	started
61	way	60	into
59	M	59	more

59	them	56	after
56	by	56	No
55	only	55	something
54	your	53	actually
53	say	51	first
51	how	51	quite
51	will	50	before
49	also	49	see
49	still	49	through
48	anything	48	months
48	whole	47	always
47	test	46	even
45	believe	45	came
45	should	44	having
42	God	41	bit
41	told	41	work
40	mind	40	why
39	any	39	combination
39	take	39	too
39	year	38	doing
38	good	38	right
37	feel	37	many
37	treatment	36	again

36	met	36	mother
36	sick	36	taking
35	does	35	their
34	doctor	34	friend
34	little	33	don't
33	guy	33	money
33	own	33	person
32	course	32	days
32	his	32	made
32	wanted	31	down
31	her	30	different
30	few	30	found
30	health	30	make
30	might	30	therapy
30	those	30	two
29	come	29	died
29	London	29	off
28	cells	28	knew
28	last	27	anymore
27	Australia	27	doctors
27	everything	27	friends
27	guess	27	man
27	maybe	27	most

27	relationship	27	saying
27	since	27	stuff
27	than	26	everybody
26	getting	26	probably
26	start	26	yes
25	body	25	couple
25	death	25	hospital
25	until	25	whatever
25	where	24	felt
24	here	24	left
24	over	24	point
24	problem	23	ago
23	better	23	Continuum
23	find	23	three
23	understand	23	viral
23			

## **Appendix D: Vocabulary List**

The 'wild card' characters # added to some of the words of the vocabulary list has the following effect: when comparing words in the text with the vocabulary list, individual letters corresponding to the position of the character # will be ignored. This provides a way of treating words as equivalent which differ only in their suffixes.

### **Conceptions :-**

active

attack

bombard#

choice

difficult#

fight#

hard

option

poison #

powerful

strong#

toxic#

### **Diagnosis :-**

antibody#

blot

convert #

elisa

HIV

infect#

positiv#

sero

status

virus

western

Disclosure :-

tell#

told

Dissidence :-

continuum

dissident#

duesberg

oxid#

peter

Doenca :-

aids

arc  
cancer  
candidiasis  
chemotherapy  
cmv  
condition  
cryptosporidium  
giardia  
hepatitis  
herpes  
ill#  
infection  
kaposi  
karposi  
ks  
lymph#  
opportunistic  
pcp  
pneumonia  
salmonella  
sarcoma  
shingles  
sick



std

swollen

sympt#

God :-

energy

healing

soul

spirit#

Harddrugs :-

acid

addict#

alcohol

canabis

cannabis

cocaine

coke

crystal

crystalmeth

ecstasy

grass

joint

**k**

**ketamine**

**poppers**

**puff**

**smoke**

**specialK**

**speed**

**spliff**

**Holism :-**

**acupuncture**

**alternative**

**antioxidants**

**aromatherapy**

**chinese**

**complementary**

**cp**

**diet**

**food**

**heal**

**herbs**

**homeopathy**

**hydrotherap#**

massage

meditat#

natural

naturopath

nutrition

organic

oxidants

supplements

tablets

visualis#

#### Medication :-

antibiotics

antiretroviral

antiviral

azt

clinic

cocktail

combination

combo

ddd

ddi

ddr

doctor  
hospital  
indinavir  
inhibitors  
physician  
prophylactics  
protease  
retrovirals  
septrin  
specialist

**Mental :-**

anxi#  
breakdown  
crisis  
depress#  
devast#  
paranoi#  
pressure  
prozac  
psych#  
stress  
suicid#

vulnerab#

worr#

Myself :-

gay

homosexual#

I

Pretest :-

before

negative

Relationship :-

boyfriend

buddy

lover

partner

Saude :-

asymptomatic

healthy

Sex :-

condoms

cum

fuck

raw

rubber

safe#

sexuality

shag

unprotected

unsafe

Sideeffects :-

diarrhoea

fatigue

letharg#

lipo#

nausea

neuropathy

tire#

vomit

Society :-

brother

**dad**

**family**

**father**

**friends**

**mom**

**mother**

**mum**

**parents**

**sister**

**Stigma :-**

**afraid**

**ashamed**

**blame**

**contamina#**

**fault**

**filthy**

**forgive**

**frighten#**

**grief**

**guilt**

**responsib#**

**shame**

tears

Technology :-

blood

cd4

cell#

count#

level#

load

measure

serum

tcell#

viral

Testcontext :-

counsel#



## Appendix E: Co-occurrence Matrices

COMMENT INPUT DATA SIMILARITIES (CO-OCCURRENCES) FOR BOTH DISSIDENT AND ORTHODOX SUBSETS

```

0.21
0.12 0.17
0.08 0.09 0.05
0.16 0.32 0.17 0.08
0.13 0.15 0.14 0.03 0.14
0.06 0.09 0.06 0.04 0.10 0.09
0.13 0.12 0.06 0.08 0.15 0.11 0.06
0.15 0.26 0.16 0.06 0.32 0.11 0.08 0.17
0.16 0.15 0.09 0.07 0.17 0.10 0.09 0.08 0.15
0.18 0.34 0.13 0.05 0.26 0.14 0.07 0.11 0.21 0.14
0.16 0.21 0.13 0.06 0.21 0.12 0.10 0.13 0.17 0.12 0.14
0.15 0.12 0.13 0.02 0.11 0.08 0.08 0.04 0.06 0.09 0.13 0.11
0.02 0.05 0.04 0.12 0.07 0.04 0.03 0.04 0.08 0.03 0.03 0.04 0.02
0.12 0.17 0.10 0.03 0.13 0.06 0.09 0.03 0.07 0.09 0.19 0.15 0.15 0.04
0.05 0.04 0.06 0.02 0.06 0.09 0.01 0.09 0.09 0.05 0.04 0.04 0.04 0.00 0.03
0.15 0.14 0.17 0.01 0.19 0.11 0.06 0.08 0.10 0.15 0.20 0.09 0.13 0.02 0.11 0.02
0.14 0.23 0.21 0.04 0.21 0.14 0.11 0.12 0.15 0.14 0.16 0.17 0.13 0.04 0.13 0.06 0.21
0.10 0.18 0.11 0.10 0.18 0.12 0.06 0.12 0.21 0.16 0.11 0.15 0.04 0.07 0.06 0.09 0.05 0.09
0.02 0.03 0.02 0.00 0.02 0.01 0.04 0.04 0.01 0.02 0.02 0.03 0.04 0.03 0.00 0.00 0.02 0.02 0.01

```

COMMENT INPUT DATA SIMILARITIES (CO-OCCURRENCES) FOR DISSIDENT SUBSET

```

0.21
0.11 0.21
0.12 0.13 0.07
0.13 0.39 0.21 0.10
0.13 0.17 0.18 0.04 0.14
0.03 0.08 0.06 0.06 0.11 0.06
0.15 0.13 0.07 0.12 0.16 0.09 0.09
0.16 0.35 0.25 0.09 0.36 0.12 0.07 0.18
0.17 0.18 0.11 0.10 0.22 0.10 0.09 0.09 0.21
0.15 0.36 0.14 0.09 0.30 0.16 0.07 0.11 0.24 0.16
0.15 0.25 0.17 0.08 0.23 0.12 0.12 0.11 0.19 0.16 0.16
0.12 0.13 0.13 0.03 0.11 0.09 0.05 0.03 0.07 0.07 0.12 0.11
0.03 0.06 0.08 0.14 0.09 0.05 0.06 0.07 0.11 0.05 0.04 0.07 0.04
0.08 0.19 0.11 0.05 0.16 0.04 0.08 0.03 0.11 0.08 0.16 0.14 0.09 0.06
0.06 0.04 0.11 0.03 0.06 0.10 0.03 0.08 0.08 0.05 0.02 0.04 0.05 0.00 0.00
0.11 0.13 0.16 0.02 0.18 0.13 0.06 0.04 0.13 0.14 0.20 0.08 0.10 0.03 0.10 0.01
0.14 0.24 0.23 0.07 0.22 0.13 0.12 0.10 0.20 0.14 0.15 0.22 0.13 0.05 0.14 0.06 0.20
0.12 0.26 0.16 0.14 0.22 0.16 0.08 0.19 0.24 0.23 0.14 0.20 0.05 0.09 0.09 0.08 0.06 0.12
0.00 0.01 0.00 0.00 0.01 0.00 0.00 0.03 0.01 0.00 0.01 0.02 0.00 0.07 0.00 0.00 0.00 0.00 0.00

```

COMMENT INPUT DATA SIMILARITIES (CO-OCCURRENCES) FOR ORTHODOX SUBSET

```

0.21
0.13 0.13
0.04 0.04 0.02
0.19 0.25 0.12 0.04
0.14 0.14 0.09 0.02 0.14
0.08 0.10 0.05 0.00 0.10 0.13
0.12 0.10 0.05 0.02 0.14 0.14 0.03
0.15 0.18 0.09 0.01 0.26 0.10 0.08 0.16
0.15 0.12 0.08 0.02 0.11 0.11 0.08 0.07 0.09
0.21 0.33 0.12 0.02 0.22 0.12 0.06 0.10 0.19 0.12
0.16 0.17 0.09 0.02 0.19 0.12 0.08 0.15 0.15 0.07 0.13
0.17 0.11 0.14 0.00 0.11 0.07 0.10 0.04 0.05 0.12 0.15 0.11
0.01 0.03 0.00 0.08 0.05 0.02 0.00 0.02 0.05 0.00 0.02 0.02 0.00
0.15 0.16 0.09 0.01 0.09 0.08 0.10 0.03 0.04 0.10 0.21 0.17 0.20 0.03
0.05 0.04 0.02 0.00 0.07 0.08 0.00 0.10 0.10 0.04 0.05 0.05 0.03 0.00 0.05
0.18 0.16 0.18 0.00 0.20 0.08 0.07 0.11 0.07 0.17 0.20 0.10 0.16 0.01 0.11 0.02
0.14 0.23 0.19 0.00 0.19 0.15 0.10 0.14 0.10 0.14 0.16 0.13 0.13 0.03 0.13 0.06 0.21
0.08 0.10 0.06 0.03 0.13 0.06 0.04 0.05 0.16 0.08 0.08 0.09 0.04 0.03 0.04 0.10 0.04 0.06
0.04 0.04 0.04 0.00 0.02 0.02 0.07 0.04 0.01 0.04 0.02 0.04 0.07 0.00 0.00 0.00 0.04 0.03 0.03

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## Appendix F: Minissa Tables

MINISSAN VERSION 3.20 MINISSAN VERSION 3.20 MINISSAN VERSION 3.20

MINISSAN VERSION 3.20 MINISSAN

SOLUTION IN 3 DIMENSIONS:

\* \* \* \* \*

STRESS DHAT = 0.085256

STRESS1 BASED ON APPROXIMATION TO RANDOM DATA (SPENCE, MBR 1979

V14) = 0.222623

FINAL CONFIGURATION

1	0.5905	-0.1681	0.1394
2	0.1183	0.0421	0.1528
3	0.3535	0.3485	-0.3046
4	-0.8289	-1.0870	0.6082
5	0.0410	-0.0411	0.0736
6	0.4979	-0.2138	-0.5095
7	-0.5739	0.8662	0.4188
8	-0.2532	-0.4364	-0.6217
9	0.0139	-0.3875	-0.0295
10	0.4027	-0.3349	0.5439
11	0.3882	0.0892	0.2701
12	-0.1716	0.1211	0.1467

13 0.5600 0.9091 0.0121  
14 -1.5089 -0.6605 0.2439  
15 0.3219 0.5629 0.7276  
16 0.5840 -0.9806 -1.1276  
17 0.8234 0.4257 0.1369  
18 0.2102 0.2846 -0.1202  
19 -0.1198 -0.6593 0.1070  
20 -1.4490 1.3198 -0.8680

MEAN 0.0000 0.0000 -0.0000

SIGMA 0.6337 0.6159 0.4681

SOLUTION IN 2 DIMENSIONS:

\*\*\*\*\*

STRESS DHAT = 0.127965

STRESS1 BASED ON APPROXIMATION TO RANDOM DATA (SPENCE, MBR 1979

V14) = 0.255066

FINAL CONFIGURATION

1 0.3494 0.1060  
2 0.0472 0.1086  
3 0.4739 0.4350  
4 -0.4317 -1.4043

5	0.0432	0.0301
6	0.7775	0.1069
7	-0.8680	0.5730
8	0.0054	-0.6734
9	0.1964	-0.2793
10	0.4571	-0.1148
11	0.2220	0.3169
12	-0.1735	0.0544
13	0.1006	1.0308
14	-1.0627	-1.3734
15	-0.1486	0.8884
16	1.5432	-0.7597
17	0.4579	0.7722
18	0.0540	0.3729
19	0.2502	-0.5742
20	-2.2933	0.3839

MEAN -0.0000 0.0000

SIGMA 0.7516 0.6596

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