UNIVERSITY OF DERBY

COMPETING REALITIES, DIVERSE NEEDS: AN INTER-DISCIPLINARY APPROACH TO RELIGIOUS ENGAGEMENT WITH HIV PREVENTION AND CARE

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Glossary

ACT UP AIDS Coalition to Unleash Power

AIDS Acquired Immune Deficiency Syndrome

AHPN African HIV Policy Network

ANERELA+ African interfaith network of religious leaders,

both lay and ordained, women and men, living

with or personally affected by HIV

ART Antiretroviral Therapy

CAFOD Catholic Fund for Overseas Development

CSW Commercial Sex Workers

DH Department of Health

EU European Union

FBO Faith Based Organisation

FGM Female Genital Mutilation

GP General Practitioner (medical)

GRID Gay Related Immunodeficiency

GUM Genito-urinary Medicine

HAART Highly Active Antiretroviral Therapy

HDA Health Development Agency

HARPAS HIV/AIDS Regional Programmes in the Arab

States

HIV Human Immunodeficiency Virus

HPA Health Protection Agency

IDU Department of Tropical Medicine and Infectious

Disease

INERELA+ International interfaith network of religious

leaders, both lay and ordained, women and men,

living with or personally affected by HIV.

LGBT Lesbian, Gay, Bisexual, Transgender people

MDT Multi-disciplinary Team

MSM Men who have Sex with Men

MTCT Mother to Child Transmission

NAM National AIDS Manual

NGO Non Government Organisation

NHS National Health Service

NRSV New Revised Standard Version Bible

NT New Testament of the Bible

OT Old Testament of the Bible (Hebrew Bible)

PCT Primary Care Trust

PSHE Personal, Social and Health Education (in

schools)

RCT Rational Choice Theory

SARS Severe Acute Respiratory Syndrome

SHA Strategic Health Authority

SIGMA or Sigma A social research group specialising in social,

behavioural and policy aspects of HIV and

sexual health. Sigma is part of the Department of

Social and Environmental Health Research in

the Faculty of Public Health and Policy at the

London School of Hygiene and Tropical

Medicine.

SOPHID Survey of prevalent HIV infections diagnosed

SRE Sex and relationships education (in schools)

TASO The AIDS Support Organisation (Uganda)

UHSPA Uganda Health and Science Press Association –

a registered Lesbian, Gay, Bisexual and

Transgender led network of groups and

individuals working to promote health rights of

vulnerable and minority groups in Uganda.

UK United Kingdom

UNAIDS United Nations Joint Programme on AIDS

UNAIDS RSTESA United Nations Joint Programme on AIDS

Regional Support Team for Eastern and

Southern Africa

UNGASS United Nations General Assembly

UNFPA United Nations Population Fund

WHO World Health Organisation

Abstract

The World Health Organisation/UNAIDS and the UK's HIV-related public health policies are premised on universal access to information, treatment and care. With a focus on wider determinants of health, such rights-based approaches and their associated commitment to consistent HIV prevention messages and effective care include also a requirement to be respectful of and sensitive to religio-cultural beliefs and practices.

There is evidence that access to HIV information and care can be restricted by the moral codes, beliefs and teachings which determine some religious responses to HIV, those, for example, which address issues of sexuality and gender, identity and belonging, authority and power. With a particular interest in a UK context of religiocultural diversity, this study asks whether existing strategic public health responses to HIV prevention and care are adequate to the multiplicity of psychosocial realities and needs of a diverse community.

The study follows comparative interpretative approaches and draws on a range of theoretical perspectives, primarily those of sociology, anthropology and psychology. It identifies the potential for dialogical compatabilities between public health practice and practical theology. Gathering and analysing data and discourse this interdisciplinary, qualitative investigation examines religion-informed responses to HIV prevention and care. With a small-scale localised study positioning the content and authority of religious belief on responses to HIV prevention and care in a UK Midlands city of high religio-cultural diversity, the primary and secondary data are 'grounded' in the experience of a local community.

In its tracing of the multiple realities of HIV in contexts of global and local religiocultural diversity, the study finds that global dimensions of HIV touch the local in unavoidable and diverse ways. Religion-defined identity and belonging are valued by people affected by HIV and the communities of which they are part, but the stigmatizing impact of HIV, often reinforced by religious beliefs and teachings, generates anxieties about the disclosure of a diagnosis, the initiation of open discussion and access to HIV information and care. Constraints on the access of sexual minorities, young people and women can raise particular concern. In situations of diverse need and contested reality quests for coherent meaning, identity and belonging confront a public health preference for consistent HIV health messages and for accessible and effective programmes of HIV information, support and care.

The study evidences diverse and often competing perspectives on HIV and highlights a need for health and social care services and religious groups to have greater awareness of the extensive complexities which the realities of diversity bring to HIV prevention policy design and service delivery. Complexity theory and practical theology inform a new and integrative model for theological, epidemiological and public health partnering through which the inadequacies in both religion-informed responses to HIV and public health HIV prevention and care policy and service delivery can be addressed.

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I am particularly grateful to all the participants for sharing with me so much sensitive and sometimes difficult to communicate information. I hope that in some way their contributions to this study will help reduce stigma, foster greater understanding and generate more effective engagement with HIV prevention and care initiatives in both public health and religious contexts.

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CHAPTER ONE

Introduction

Competing realities, diverse needs

Framing the question

The Human Immunodeficiency Virus (HIV) will be present in the blood and semen of men who have the infection and in the blood, vaginal fluids and breast milk of HIV positive women. It can be transmitted sexually and by sharing injecting equipment. It may also be passed from a mother to her child during pregnancy, childbirth or breastfeeding. With early diagnosis and regular medical attention it is manageable as a chronic condition, but there is no cure and no vaccine (National AIDS Trust 2012).

In sex, sexuality, birth, blood, dying, death and disease are located the taboos of human relationships and the framing of socio-cultural constructs (Douglas 1988). HIV cuts across all of these. It is a stigmatizing condition with anxieties, prejudices and judgements attaching to many an experience of it, a reality opened to the author in the late nineteen eighties by a remark of her daughter. An account of that moment, drafted several years later, and an introduction to the ramifications and implications it held for this study are introduced below:

'It was 1987. I was preparing for ordination in the Church of England. In response to a TV news item, our daughter said 'There's nothing in school about HIV'. At the time I had no idea what a life-changing moment this would prove to be. Her remark set me thinking. Why such silence? Why were educators and parents reluctant to speak of HIV when it was a major public health issue? How could my husband and I ensure our children were properly informed? Were there any people affected by HIV in my community or in my church?

Casting around for answers I discovered and joined a small group setting up a voluntary organisation to provide practical and social support to people in our area affected by HIV/AIDS. I learned that people from every section of our community are affected by HIV - men, women and children, white and Black and Asian, Christian, Muslim and Hindu, straight and gay; too often people who are already marginalized and further marginalized by the stigma attaching to HIV. It is important to recognise the power of the stigma, much of which is rooted in and reinforced by religious belief and teaching. It is arguably the greatest barrier to effective HIV education, prevention, care and support programmes worldwide and often a major source of anxiety for people with the virus. For instance, most of the children I know with HIV do not know

they have HIV because of the risk of inadvertent disclosure. Their parents could not be confident of a kindly response from school friends or other parents towards even a child with HIV. When a youngster is eventually given the information their first struggle may well be over whether or not it is safe to tell their best friend.

The stigma has to go. The silence has to be broken. But breaking down such dense barriers is a tall order. When troubled and anxious we can usually be confident of a sympathetic and compassionate response from our religious community. But for people affected by HIV, who may be people with the virus, their partners, relations, friends, colleagues or carers, such a response cannot be guaranteed. Ignorance, misunderstanding and prejudice can cause much pain and hurt. I have known close relatives of people with HIV, life-long church-goers, who could not bring themselves to talk to their ministers or friends at church about their situation for fear of a hurtful reaction.

An idea began to take shape. It would help if there was a community-based chaplain to offer informed pastoral and spiritual support and to raise awareness of HIV in local faith groups and communities. With funding from the Health Authority and local authority Social Services departments, in January 1994 a new community chaplaincy was created to work alongside and in collaboration with all other local HIV service providers. I was appointed Chaplain for People Affected by HIV to co-ordinate 'Faith in People with HIV'.

We were able to demonstrate immediately that this was a welcome response to real need. There was the international student with HIV who struggled to recapture her hopes and dreams for the future when her diagnosis appeared to present her with nothing but the prospect of an early death; the gay man who wanted help to find a way to tell his mother and father he was both gay and HIV positive; the priest with HIV who needed someone to talk to; the woman whose husband was diagnosed with HIV shortly after she learned she was pregnant; people with HIV experiencing harassment at work, graffiti on their house, prejudiced attitudes from health professionals. Support is available on a one-to-one or small group basis. Quiet days are held for reflection and relaxation with creative activities and complementary therapies. There is support for those coping with loss and bereavement. We mark World AIDS Day (December1st each year) with a multi-cultural gathering of remembrance and solidarity. There are invitations to preach, resources provided for clergy. services arranged and presentations made to various groups. We circulate information about HIV and local support services and raise awareness of HIV in faith communities. We keep abreast of international developments in a world with HIV and maintain links with individuals and organisations in other countries. We work to foster understanding and seek to break down the barriers of stigma, discrimination and silence which affect so many men. women and children living with HIV.

The project is widely ecumenical and is open to all whether or not they have religious belief.

Over the years I have met many people affected by HIV. Many have become friends. We have laughed together and cried together, talked and prayed together; journeyed through good times and bad, known sorrow and joy. We have struggled together with anger and disappointment and rejoiced in our triumphs.

Neither a cure nor a vaccine will be available in the foreseeable future. Treatments and medication in the richer parts of the world are helping people with HIV stay well and live longer, but in developing countries the drugs and the health care systems to deliver them are simply not affordable.

HIV exposes both the strengths and the weaknesses of our theologies, our liturgies, our pastoral practices and our teachings. HIV has become a vehicle for all the issues with which religious people are concerned – debt relief, poverty, fair trade, coping with emergencies and conflict, political and social turmoil, exclusion and marginality, gender relations, sexuality and much more. But the stigma and the silence remain. As communities with HIV, as faith communities, as health and social care institutions and as a society with HIV, we have to break the silence and learn to listen to the voices of those most affected. We have to listen to and work with one another.

Religion's engagement with HIV, and public health's engagement with religion, the author had learned, could be problematic.

The first United Nations Special Assembly convened to respond to HIV/AIDS (UNGASS 2001a) called on governments and every sector of every country and community to work together to prevent infections and support and treat those with the virus. Noting their extensive grass roots resources and worldwide networks, faith communities were to be included in any strategic and practical response (UNAIDS 2001). The UK's Department of Health consultation on HIV-related stigma and discrimination argued that 'leadership from community and faith leaders is crucial in identifying, challenging and eventually eradicating stigma and discrimination' (Department of Health 2005). Attention was being drawn to the need for strategic collaboration between faith and health in the interests of HIV prevention and care.

Some individuals and groups, however, appear unable to incorporate into their belief system those principles advocated by UNAIDS, that is, those of dialogical and interdisciplinary partnering in the furtherance of universal access to information and non-judgmental support and care. Similarly, it may be difficult if not impossible for such rights-based public health strategies for HIV prevention and care to

accommodate religio-cultural traditions which, for example, may condone if not promulgate gender inequalities and the social exclusion of sexual minorities. Arguably the one set of principles cannot be permitted to compromise the other but when HIV prevention and care services are called upon to do so on the basis of sensitivity to religious beliefs and cultural norms, needs for coherent meaning, identity and belonging confront the need for consistent HIV health messages at both personal and institutional levels. (Goffman 1963, 1984, Das 2001, Helman 2000, Weiss 2001, National AIDS Trust and SIGMA 2004, Castro and Farmer 2005, Paterson 2005).

It is this tension between UNAIDS' preferred non-discriminatory, rights-sensitive public health approaches to HIV prevention and care and religion-informed responses to HIV, particularly as they relate to contexts of local and global religio-cultural diversity, which is central to this study's investigation into religious engagement with HIV.

Asking whether the strategic public health responses to HIV prevention and care are adequate to the multiplicity of psychosocial realities and needs of religio-cultural diversity in a UK community, this study positions its interdisciplinary enquiry first and foremost in the traditions and potential of practical theology and in public health theory and practice.

Such a framework requires an initial introduction to practical theology's dialectical thrust followed by a summary of public health's significant characterisations.

Introducing practical theology

In basic terms practical theology is the process through which practitioner experience, particularly pastoral action, and reflection generate a new praxis. The theology is grounded in the interpretative activity of practice and reflection. It engages dialogically with social sciences and integrates practitioner experience, knowledge and reflection with reformed or renewed praxis. It looks predominantly to liberation theology and feminism as models, in that the changed praxis is transforming and emancipatory rather than merely interpretative and affirming of the status quo. However, a distinction between practical theology (however progressive) and

liberation theology is to be made in that some proponents of practical theology will not necessarily anticipate engagement which involves commitment to social justice, solidarity and change. Rather 'in some contexts professional reflective practice becomes an instrument of conservative, political and religious ends' (Bennett 2007: 41).

In her book *Transforming Practice*, *Pastoral Theology in an age of uncertainty*, Elaine Graham (1996) explores the relationships between practice and theology, their synthesising and their fragmenting properties and their weighting of both tradition and innovation in the hoped for progress towards greater openness and inclusivity. The objects of Graham's critiques are Christian community, Christian praxis and Christian theology, but, asking how any authenticity of truth claims can avoid the absolutist appeals of authoritarian orthodoxies, she advocates a continuing process of openness and dialogue. In a section headed 'Communities of Faith and Praxis' (Graham 1996: 199) she quotes Carol Christ:

We should not hold our views so tightly that we cannot appreciate the perspectival truths embodied in the lives and works of others. We should think of our 'truth claims' as the product of embodied *thinking* not as eternally or universally valid *thought*.

(Christ 1988: 15)

Although Graham argues for continuing openness and dialogue and goes on to posit the value of 'encounters with alterity' (Graham 1996: 200) and difference in articulating truth claims and generating social change and community values, she limits her critique and recommendations to the theological appropriations and practice of Christian communities. Implicit in Graham's emphasis on the formative nature of praxis to one faith community, the Christian, lies an argument for the transformative nurturing influence of praxis among a diversity of communities: communities of faith, secular institutions, professionals and lay. It is this potential for a practical theological approach to partnership between religion and public health, the one engaging closely with the 'alterity' of the other and vice versa, in the interests of HIV prevention and care that this study seeks to investigate. However, it is important to identify at the outset that there is paradox at the heart of this engagement, a paradox identified also

by Graham (1996: 206). That dialogue, that 'conversation' as Graham terms it, with otherness which offers mutuality, friendship and a wider appreciation and discerning of realities also risks a retreat to a closely bounded 'fixity' characterised by separation and exclusion. Encounters with the diseased other, such as the one with HIV, may elicit precisely such a response.

Practical theologians value relationship, mutuality and engagement with the marginalised 'other' in discerning those theological, moral and social truths which are open to acknowledging the ambiguities and confusions which religious texts and doctrine can represent. Practical theologians charge praxis with expressing and making truths real. Doing so amid the complexities of a globalised locality and its inherent encounters with and responses to diversity and difference, including wider religious diversity and difference, positions this study's theological enterprise in the practical camp and as the investigation progresses a practical theological development appropriate to pluralist contexts of public health and HIV prevention and care will be proposed. Before proceeding, though, some consideration follows of the strategic challenges public health policy makers face in responding to modernity's needs.

Introducing public health theory and practice

Recent years have seen a shift in the direction of both UK public health policy and global approaches to and influences on public health. Historically in the UK, the design and delivery of policy and practice have been dominated by disease-focused definitions problematised and responded to by medical professionals with government/health sector-led interventions. Globalisation's complexification, individualisation's stress on personal choice, market-led influences and an interest in wider determinants of health such as social exclusion and economic inequalities have contributed to calls for the greater involvement and participation of communities, individuals and other sectors and agencies in policy making and service delivery (Griffiths and Hunter 2007: 1-10, Wanless 2007: 11-18, Baggott 2000).

... the lesson appears to be that public health campaigns must be as inclusive as possible and incorporate an awareness of the broader social, economic and environmental context of health if they are to maximise their impact on policy.

(Baggott 2000: 253)

With the global health crises of SARS (severe acute respiratory syndrome), avian flu and Ebola, and a growing realisation that nations could not avoid the impact of global developments and events, public health in general and prevention in particular assumed a higher profile. With this came a greater emphasis on multidisciplinarity, partnership working, calls for strategic co-operation at country and global levels and an integration of values and ideals such as those of solidarity and sustainability as suggested by McKee. Indeed, McKee goes further and posits such values at the centre of global co-operation.

Without global co-operation based on the values of public health – solidarity and sustainability – prospects for collective action to confront increasing numbers of shared threats to health will become even more elusive'.

(McKee 2007: 75)

But greater networking, integration, interdisciplinarity and a concern for social exclusion and inequalities suggest a transparent, social democratic, human rightsbased approach to public health. This cannot be guaranteed. Clearly for some health events and emergencies rights-restricting controls and compliances may be anticipated and justified at grass roots, governmental and public health levels. The SARS outbreak in 2002 and 2003, for example, was contained by mass quarantine measures (McClean 2007:218). There are those contexts, however, where breaches of liberties and a reinforcing of social exclusions, inequalites and controls occur without democratic or scientific sanction. In responses to physical and mental disabilities, to sexual health and to HIV, for example, misinformation, misunderstanding, fear of contagion and infection, religio-cultural moral conceptualisations, political and financial interests can impact basic freedoms and rights. Treatment and care can be refused for fear of disease transmission, discriminatory and unnecessary surveillence and restrictions on movement, isolation and imprisonment can be imposed. Ensuring rights-based approaches to public health particularly, in this study's context, those relating to HIV prevention and care and given global articulation and promotion by UNAIDS, remains a global challenge.

Towards shared praxis

This introduction to public health theory, policy and practice is identifying similarities between the impact of local, national and international diversities on public health responses to HIV and the impact of those diversities on religion-informed responses to HIV. Similarities in language and similarities in practice are present. A language of relationship and dialogue, of conversation, interdisciplinarity, equalities and social justice, of person and community, of professional and lay, of access and agency, paradox and transformation is spoken by HIV prevention and care policy makers and by practical theologians and by those involved in interreligious and community relations. Best practice requires each to seek out the hidden and the silent, the excluded and the disempowered. They have to contend with increasing diversity and complexity and the challenges of responding to a multiplicity of perspectives. But too often, despite their respective rootedness in pastoral care and concern, in a world with HIV they remain strangers to one another.

Ultimately, this study argues for a closer dialogue between public health, religion and HIV in the interests of prevention efficacy and access to care. With a focus on dimensions of religion-informed responses to HIV it draws on the resources of sociological, anthropological and social psychological discourse to claim a theoretical platform for complexity theory's trans-disciplinary significance. In so doing the study sets out the central conceptualisations informing HIV's relationships with key global realities of diversity and inequalities and their challenges to local needs for belonging and identity, authority and power. Drawing on the experience of a culturally and religiously diverse UK city the investigation goes on to develop the practical theological interest in dialogue as 'integrative theology' and proposes a new model of engagement through which public health policy for HIV prevention and care can be known and delivered as held-in-common belief and practice.

Throughout the study, unless an alternative meaning is made explicit in the text, 'HIV prevention and care' will refer to public health policy and practice governed by principles of universal, non-judgemental access to information, treatment and care and an appreciation of the wider determinants of health.

Background

As reported at pages one to three above, from 1988 until January 2005 the author was working in the context of HIV support within the voluntary sector and faith communities in the Midlands region of the UK. As an Anglican priest, the Bishop of Leicester's Chaplain for People Affected by HIV, she established a community-based project responding supportively to the pastoral and religious needs and concerns of people in the area affected by HIV. The organisation also seeks to raise awareness of HIV in faith communities and other community and professional groups and works to break down barriers of stigma and discrimination. Leicester is a community of high religio-cultural diversity. There are an estimated 240 faith groups across fourteen different faiths, mainly Christian, Hindu, Muslim and Sikh with smaller populations of Buddhists and Jews (Leicester City Council 2008: 6). The reluctance of many faith groups to engage with issues associated with HIV, particularly those of sexuality and gender, has been notable.

Although an integral part of local HIV and sexual health service provision and working routinely in multi-disciplinary partnerships with other agencies and organisations, to some extent the project always assumed a marginality, not only in respect of the faith communities, but also in respect of the health and social care agencies. This marginality and institutional boundary-crossing in the worlds of 'faith' and 'health' has made visible a number of issues and facilitated access to a range of networks which an exclusively 'in-house' experience would rarely provide. For Ballard and Pritchard (1996) such dialogical frontier-riding is a defining characteristic of practical theology.

... creative insights come precisely at those places where disciplines overlap or challenge one another. There is, therefore, no need to be ashamed to be living at the boundaries, in however lowly a way. Maybe the practical theologian has to endure the risk of marginalisation, ridicule and error but he or she can also be at the place of the new possibility, discovery and prophecy.

(Ballard and Pritchard 1996: 107)

And, from a public health context, in a paper contrasting the relationships between social movement organisations and district health authorities in two neighbouring low

prevalence cities and their impact on formal organisational structures, policy process and service provision, the capacity to create innovative alliances across a number of sectoral and organisational boundaries was counted a significant factor in establishing a more stable and locally autonomous response to HIV/AIDS (Petchey et al 1998). This notion of 'innovative alliances', amid experiences of marginality, characterises the author's community chaplaincy project and is woven throughout the fabric of this study.

In 1997 the author completed a dissertation in part fulfillment of the requirements for the degree of Master of Theology (MTh) in Applied Theology (University of Oxford). Through a variety of theoretical perspectives the MTh/Post Graduate Diploma course aimed to develop critical and theological reflection in institutional and other contexts by continuously and rigorously relating experience and theory, learning and practice to contemporary interaction with religious tradition. Those theoretical perspectives included dimensions of psychology (eg religious experience, development of faith, concept of self, moral development), theology (eg racism, feminism, ministry in a plural world), sociology (eg religion, change, function, reality, culture/sub-culture), organisational (leadership, conflict, power and authority) and liturgical studies (eg rites and rituals, coping, expiation). Having identified HIV's potential for exposing conflict between engaging with social and religious taboos and ensuring universal access to information, treatment and care, the work examined the role of religion in the implementation of Public Health Medicine's strategic responses to HIV with special reference to an area of central England between 1991 and 1995. Issues of power and authority and the place of symbolism and imagery featured throughout, most significantly in constructions of meaning and the appropriations of beliefs.

Over several more years as a practitioner in HIV prevention and support the author noted changes in HIV's impact at local and global levels due mainly, it seemed, to

- the availability of improved and improving treatments and
- the increased attention on heterosexually transmitted HIV in high prevalence regions.

Assumptions were being made about the efficacy of advances in treatment:

- that HIV was no longer life threatening and
- that it could be safely regarded as a chronic, manageable condition.

And strategic shifts in emphasis targeted prevention resources at those deemed to belong to higher-risk minority groups:

- heterosexual African men and women,
- gay men,
- injecting drug users.

Any existing tendencies within the general population to ignore HIV were strengthened. HIV was usually someone else's problem.

During the early years of the new century, more African migrants, often asylum seekers fleeing political persecution and violence, from high prevalence regions of sub-Saharan Africa began to settle in the UK. Religious beliefs and identity, particularly those relating to the more strictly conforming appropriations of Christianity and Islam, were significant bearers and shapers of belonging and meaning for many newcomers seeking to establish a home and relationships in a strange environment. There were many new diagnoses of HIV. Paradoxically, at one and the same time, HIV and its taboos were driven both under cover and into view.

Reproduced below are the notes prepared for a presentation by the author in 2004 to the then members of the Multi-disciplinary Team for HIV and Sexual Health in Leicester. They set out some examples of the extensive and complex global, local and personal experiences and issues with which many asylum seekers and refugees were contending. The presentation was delivered in an attempt to both contextualize the experience of many people with HIV and also to draw attention to some of the additional demographic complexities which Leicester and its health and social care providers were facing in their efforts to respond effectively to the HIV prevention and care needs of its communities.

Some thoughts on issues facing agencies providing HIV services to asylum seekers and refugees

GLOBAL ISSUES

Impact of globalisation

- breakdown of traditional political structures
- inequities in access to markets
- economic disadvantage, unemployment, poverty
- weakened (transitional) social and economic infrastructures eg education, health and social care, transport
- greater cultural diversity
- breakdown of social cohesion leading to increase in community tensions and conflict
- changed expectations and aspirations
- economic, material and political benefits to some exacerbating social divisions eg international travel, elite education, access to trading partners

Demographic change

- pressures on family and community networks
- changing identities and roles gender, children, grandparents, extended family
- social mobility
- economic mobility
- pressures to migrate
- homelessness, statelessness, in-country displacement

Psycho-social impact

- cumulative loss leaving family members including children, death of family, friends, loss of country, stability, security, identity, status etc
- human rights abuses eg violence, unlawful imprisonment
- HIV diagnosis
- destitution (or fear of)
- isolation, unfamiliarity with system, language, culture etc
- lack of control and power
- coping with trauma

and much more.

Responding to need

In order to make any sense of the needs of people affected by HIV in Leicester it is important to take account of the international as well as the local contexts which affect users and providers alike.

Extraordinary and massive changes in our understanding of ourselves and our society are occurring in this country and around the world. There are great epistemological shifts taking place. How individuals and societies think of and understand themselves is changing in significant ways. Cultural

and religious frameworks which have served a people well for generations are found wanting, inadequate to the task of shaping a community's relationships and polities.

HIV exposes and compounds the tensions and the difficulties in the starkest possible way. Those of us who work in this context are working with extremes of vulnerability and strength, our own and our service users, which for most of the time lie hidden. We encounter on a daily basis the soft underbelly of global change and its accompanying insecurities. There are no answers. There is no map. Nothing 'works' except raw human compassion – and no-one has enough.

Figure 1. Notes from presentation by author to MDT HIV/Sexual Health, Leicester. (Margaret Morris 2004)

The city's widening religio-cultural diversity both masked and exposed interfaces between differing realities. Expressions of those clashes between inclusivist public health approaches to HIV (essential to ensuring universal access to information, treatment and care), and responses shaped by boundaried appropriations of religiocultural teachings and identities (essential to individuals searching for stability and security), began to emerge with a new force. The stigma attaching to HIV appeared to thrive. And stigma's children, blame and shame, silence and denial, were too often rooted in and authorized by religious teachings and beliefs. Few people were prepared to be open about their HIV diagnosis in their religious group. Anxieties about disclosure and confidentiality affected well-being and placed limits on access to support. Issues of late diagnosis and any potential for providing community-based testing sites claimed attention. Women were blamed for infecting partners and children. There were leaders who declared no 'good' Christian or Muslim would have HIV. Reports began to surface of claims that prayer would heal a person of HIV and that GP-prescribed medication should not be taken. Such mixed if not conflicting messages were not conducive to good health promotion (Speller, 2009a).

In the interests of good service provision and reduced HIV incidence the author sought to assess more deeply the implications of religio-cultural diversity for the adequacies of both public-health-defined and religion-defined responses to HIV prevention and care. She was persuaded that the increased complexities of diverse religion-informed realities in global and local conceptualizations of Leicester's experiences of and responses to HIV merited further study.

Most studies concerning religion in responses to HIV have focused on those regions of high prevalence for HIV, mainly sub-Saharan Africa. And although Chinouya's work with African communities in the UK (Chinouya and O'Keefe 2005, 2008a, 2008b) has progressed the interest in the impact of religious beliefs and teachings on individual and community responses to and experiences of HIV, little attention has been paid to multi-faith contexts of local UK prevention and care policies and service delivery.

This investigation into religious engagement with HIV prevention and care begins by tracing HIV's emergence on the epidemiological stage and its early positioning in socio-political and religio-cultural consciousness and discourse.

HIV - Epidemiological contexts and contestations

An emerging phenomenon

In the early 1980s world attention was drawn to gay men presenting with an unusual and previously unknown disease syndrome (Altman1982, 1983; Health Protection Agency 2011a, Avert 2011). It became known as GRID, Gay-Related Immune Deficiency. In due course similar cases of immune suppression were noted in other population groups, most significantly among young women and men in Uganda, Tanzania and Zaire (Serwadda, Mugerwa et al 1985). By 1983 the cause, a virus, was identified by Dr Robert Gallo of the National Cancer Institute in the States and Dr Luc Montagnier of the Pasteur Institute in France. Although a process not without its contestations, eventually the virus was named HIV, the Human Immunodeficiency Virus (Barré-Sinoussi et al 1983, Marx 1985, AVERT 2011). A blood test was developed, the term GRID dropped and a specific HIV-associated range of opportunistic infections and potentially life-limiting illnesses became known as AIDS (Acquired Immune Deficiency Syndrome). HIV is present in body fluids and the main routes of transmission are

- penetrative sex without a condom with a person with HIV,
- sharing HIV-infected needles, syringes or other injecting equipment in clinical or recreational settings,

- using unscreened and untreated blood and organs for donation,
- from a mother with HIV to her child during pregnancy, childbirth or breastfeeding.

There are treatments, some of which assist prevention, but there is no cure and the development of a vaccine continues to present a significant challenge (World Health Organisation 2011b, World Health Organisation Initiative for Vaccine Research).

It may be many years after acquiring the infection before ill health alerts an affected individual to consult a doctor and test for HIV. Those who are unaware of their infection may transmit the virus unwittingly to others. With the medical advances of recent years and where access to well-resourced care and effective treatments are consistently available, infection with HIV can be experienced and managed as a chronic condition with little or no impact on normal life expectancy. In resource-poor environments, particularly those of sub Saharan Africa, and in spite of great strides in developing HIV health and social care provision through, for example, The Global Fund for AIDS, Tuberculosis and Malaria (Global Fund 2011) and the Gates Foundation (Gates 2011), medication, testing and information remains neither regularly available nor universally accessible with the risk of infection and death potentially greater.

The earlier the diagnosis, the more effective the treatments. Therefore, with reduced deaths and increasing number of people living HIV, a renewed emphasis on prevention and testing characterises many public health responses to HIV, including those of the UK (Health Protection Agency 2011c). Thirty years of local, regional and global engagement with HIV have charted a journey of contestation and complexity. Those tensions attaching to Gallo's and Montagnier's identification and naming of the virus, only alluded to in the first paragraph but addressed more fully below, can be seen in hindsight as a signpost to continuing conflicts between biomedical, socioeconomic, commercial and political interests and between preferences for uni-, multi- or inter- sectoral and -disciplinary strategies and approaches to HIV prevention and care (Mann et al 1992, Ellison et al 2003). This introductory chapter continues by contextualising a particular area of dispute and noting its impact on engagement with HIV.

Disputed relationship between HIV and AIDS

The causal relationship between HIV and AIDS has been strongly disputed in some quarters, notably by Dr Peter Duesberg, a virologist at the University of California, Berkeley, who between 1987 and 1992 published papers arguing that HIV is harmless and does not cause AIDS (Duesberg 1987, 1988, 1991, 1992). This position, of course, was refuted by Gallo and Montagnier (Blattner et al 1988), but Duesberg went on to contend that AIDS was the result of nutritionally compromised immune systems, or certain kinds of drug use (particularly the recreational 'poppers' often associated with gay lifestyle) and the taking of AZT (otherwise known as Zidovudine or Retrovir), an early treatment for HIV-related immunodeficiency. [Eileen Stillwaggon also proposed the malnutrition/vulnerability to HIV argument, not as a participant in the causality dispute, but in the context of advocating a multi-dimensional approach to prevention and care (Stillwaggon 2002)].

The disputes and the confusions and uncertainties they generated have been blamed for the slow response of some governments to their in-country HIV epidemic. The South African post-apartheid silence of President Nelson Mandela was regretted, but the denials of President Thabo Mbeki were subjected to particularly severe criticism and public protest when it was seen that Duesberg's influence impacted the government's strategic decision making. HIV as a cause of AIDS was discounted and the promotion of natural and traditional African remedies favoured over the provision of allopathic anti-retroviral treatments which could have helped reduce sexual and mother to child transmission at a time when prevalence in the country and the region was escalating.

Following Duesberg's 'poor nutrition' argument, Mbeki claimed that HIV in South Africa was due to poverty. Poverty's impact on the global epidemiological HIV map is clear in that malnutrition can increase vulnerabilities to infectious disease, and can restrict access to treatments, information and the means to control or change behaviours (Stillwaggon 2002). For example, economic pressures and inequalities may restrict personal agency including sexual decision-making and place individuals at greater risk. Indeed, early strategic responses to HIV, in acknowledging the additional vulnerabilities to HIV infection which people in low-income countries faced in responding effectively to the epidemic, led to the setting up of the Global

AIDS Fund. Unlike Stillwaggon, Mbeki linked his assertions about poverty with Duesberg-like denials about the significance of HIV. The government's consequent refusal to support the provision of antiretrovirals attracted world wide condemnation at a time when, from the data available, the number of people living and dying with HIV was higher in South Africa than anywhere in the world.

How far Mbeki's with Duesberg's appropriations of the 'HIV does not cause AIDS' hypothesis undermined biomedical evidence-based initiatives and strengthened those religious practitioners and traditional healers claiming witchcraft or evil doing as causes, and appealing to gods, spirits or ancestors for cures cannot be known, but such beliefs hold significant sway in South African and other contexts world wide (Kalichman and Simbayi 2004, Kalipeni, Craddock et al Eds 2004, Rödlach 2006, Wanyama et al 2007, Thornton 2008, Finnocchario-Kessler et al 2011). These several aspects of the South African experience evidence yet further the complex, often hidden, global and local diversities influencing responses to HIV prevention and care (Barnett and Whiteside 2002, Allen and Heald 2004, Campbell, Foulis et al 2005, Allen 2006, Dodds 2006, Whiteside 2006, Thornton 2008, Esack and Chiddy 2009).

An epidemiological map

Global HIV

After thirty years HIV remains a seemingly intractable public health concern. The estimated number of people living with HIV in South Africa at the end of 2009 was close to six million and the prevalence rate for those between the ages of fifteen and forty-nine years was 18.3 per cent (UNAIDS 2011).

Global estimates of HIV infection at end of 2009			
Total	33.3m	28.6m (2001)	
Adults with HIV	30.8m	-	
Women	15.9m	-	
Children under 15 years	2.5m	-	
New infections	2.6m	3.1m (2001)	
Deaths due to AIDS during 2009	1.8m	1.8m (2001)	

Table 1. Global estimates of HIV infections at end of 2009 (UNAIDS 2010a Report on the Global AIDS Epidemic)

Regional estimates of HIV infection at end of 2009			
Asia and Pacific	4.9m	4.4m (2001)	
Eastern Europe and Central Asia	1.4m	0.7m (2001)	
North America, Western and Central Europe	2.3m	1.8m (2001)	
Latin America	1.4m	1.1m (2001)	
Middle East and North Africa	0.46m	0.18m (2001)	
Sub Saharan Africa	22.5m	20.3m (2001)	

Table 2. Regional estimates of HIV infections at end of 2009 (UNAIDS 2010a Report on the Global AIDS Epidemic)

But HIV is more than a biomedical phenomenon. It catches individuals and groups in a still too often barely acknowledged web of legal, cultural, socio-political and economic as well as metaphysical, symbolic, linguistic and metaphorical responses (Mann 1992, Treichler 1999, Sontag 1989). The need to relate public health programmes for HIV to inequalities and differing realities and tie them to protections of human rights was highlighted by Jonathan Mann, the first Director of the World Health Organisation's Global Programme on AIDS, and others in the early years of the epidemic (Mann 1992: 537 ff). According to Mann HIV/AIDS made it clear that human rights' violations, discriminatory and prejudicial practices and attitudes and 'restrictive and coercive public health measures' were counterproductive (Mann 1992: 540).

In a draft resolution annexed to the Political Declaration on HIV/AIDS, 'Intensifying our Efforts to Eliminate HIV/AIDS' in 2011, The United Nations General Assembly set out a multi-dimensional summary of the commitments needed to prevent HIV transmission and provide treatments and care for those affected. The summary noted that HIV remains an 'unprecedented human catastrophe inflicting immense suffering on countries, communities and families throughout the world' (UNGASS 2011a: 2). More than 30 million people have died with AIDS; more than 16 million children have been orphaned (that is one or both parents have died with AIDS) and there are over 7,000 new infections each day. The highest rates of prevalence and impacts of infection are felt most strongly in the populations of low- and middle-income countries particularly those in sub-Saharan Africa. But there is some progress to report:

- 25 per cent reduction in the rate of new infections in over 30 countries;
- reductions in mother-to-child transmission;
- antiretroviral treatment to over 6 million people;
- reduction of AIDS-related deaths by more than 20 per cent in the past five years. (UNGASS 2011a).

However, there remain areas of continuing concern:

- inadequate funding,
- gender inequality (women and girls remain those most affected by the global epidemic),
- poverty,
- limitations on access to HIV information and services and to condoms,
- poor response to infection patterns including injecting drug use, mother-tochild transmission and the needs of people with disabilities,
- limited availability of affordable, effective medicines,
- gaps in commitments to human rights and evidence-based programmes.

Multi-sectoral approaches and the eradication of stigma and discrimination are stressed as necessary dimensions to local, national and international strategies. The Political Declaration is the first which has included specific reference to men who have sex with men (Political Declaration on HIV/AIDS: 5 [29] UNGASS 2011a).

Aligning UNGASS's intensified efforts to eliminate HIV/AIDS with the United Nations' plans to eradicate extreme poverty through its agreed commitment in 2000 to the Millennium Development Goals (Political Declaration on HIV/AIDS: 2 [6] UNGASS 2011a and Millennium Development Goals 2000), a new commitment to 'halt and begin to reverse' the spread of HIV by 2015, was agreed (UNGASS, 2011a: 7 [51]). The creation and delivery of effective health messages and services in contexts of economic, political, ideological, religio-cultural and behavioural diversity, not to say conflict, will continue to make heavy demands on international, national and local resources. The complex interfaces between HIV and public health both expose and obscure those demands in a unique way.

The rest of this chapter explores such phenomena in the context of the United Kingdom's experience of HIV and asserts stigma's place in defining and representing key tensions in efforts to reverse infection rates: the tensions between responding to HIV in health terms, in moral terms or in combinations of both.

United Kingdom HIV

The first infections in the UK, as in America, were identified in gay men during the early 1980s. Gay men were also among the first to respond supportively to people affected by HIV, driving the development of various projects. Terry Higgins was one of the first in the UK to die with AIDS. The Terrence Higgins Trust in London, set up shortly after his death and in his memory (1982) became the model for a number of voluntary agencies around the country. There were also self-help groups, principally Body Positive (Body Positive North West for example) and Positively Women (now Positively UK). There was housing and HIV-specific respite and hospice care at London Lighthouse (later closed and merged with the Terrence Higgins Trust). There were help lines and other reliable sources of information, the National AIDS Manual for example, resources for funerals and memorials (the AIDS Memorial Quilt) and political activism (Act Up).

Condom use and safer sex were promoted. Before needle exchange programmes became widely available injecting drug users were at risk through shared injecting equipment. Edinburgh became 'the AIDS capital of Europe' (McCarthy and Welsby 2003) but since the early introduction of a harm reduction approach and the rolling out of needle exchange programmes, the 'injecting' route of transmission in the UK has been relatively low. People with haemophilia were another at-risk population in the early years of the epidemic until 1985/6 when stringent controls on ensuring infection-free blood supplies were put in place (National Blood Service). Heterosexual transmission was low.

A government-generated nation-wide awareness campaign, 'Don't Die of Ignorance', was conducted in the mid-eighties. With ring-fenced funding, early policy responses followed existing strategies for sexually transmitted infection prevention, that is, diagnosis and treatment based primarily in GUM clinics. But the need for increased social care including statutory, independent and voluntary provision was soon

acknowledged. Heightened anxiety due to continuing uncertainty about transmission routes and risks of contagion led to the isolation of people living with HIV in both social and clinical contexts. Stigma was an early and widespread socio-psychological response, but HIV/AIDS became a social cause for which many celebrities committed themselves to fund-raising events and projects. Red ribbons, the lapel-adorning symbol of support, became visible on TV presenters, members of Parliament, actors and pop stars. Elton John, for example, founded the Elton John AIDS Foundation in 1992. Based in New York and London the foundation has raised millions of dollars for HIV prevention and care projects, harm reduction and the elimination of stigma in Africa, Asia and Europe (Elton John AIDS Foundation). Diana, Princess of Wales, filmed visiting and shaking hands with a man with HIV in a London hospital in 1987 (NAT 2011a), was deemed to have had the greatest impact on an early widening of public interest and concern.

Although the total annual increase in diagnoses has fallen in recent years, largely due to a decrease in the number of men and women infected heterosexually in another country, mainly in sub-Saharan Africa, the number of people living with HIV in the UK continues to rise. Over the years new infections among men who have sex with men have remained high (42 per cent of individuals diagnosed in 2009, Health Protection Agency 2010a). A 2011 report of the House of Lords Select Committee on HIV and AIDS in the United Kingdom (HIV and AIDS: no vaccine, no cure 2011 at www.parliament.uk) anticipated that the total number of people living with HIV by 2012 would exceed one hundred thousand. Figures for 2009 are listed below at Table 3.

HIV in the United Kingdom at end of 2009		
People living with HIV	86,500	
Individuals with HIV seen for HIV-related care	65,000	
Newly diagnosed	6,630	

Table 3. HIV in the UK end of 2009 (Health Protection Agency. HIV in the United Kingdom: 2010 Report [2010a])

The report refers also to the diversity of urban and metropolitan populations where infection levels are highest and to the need for faith leaders to be involved in

prevention and awareness work. Announcing the report's publication in a BBC interview, the committee's chair, Lord Fowler, who led the 1980s 'Don't Die of Ignorance' campaign, described the efforts to prevent HIV in the UK as 'woefully inadequate' (BBC 31 August 2011).

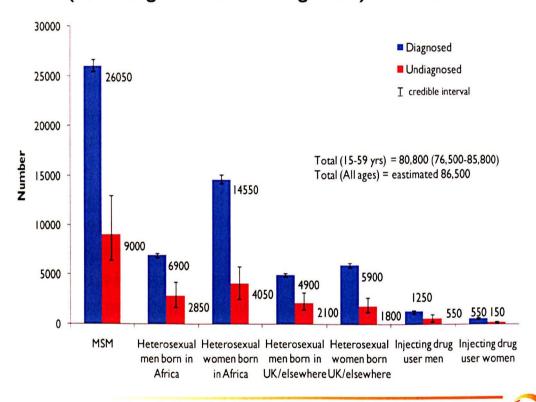
The Health Protection Agency makes available a set of slides illustrating in graph form a range of prevalence and incidence statistics. The following, pertaining to the 2010 Report (Health Protection Agency 2010b, HIV in the United Kingdom 2010 Slideset, 1, 2, 3), have been selected as most informative for the purposes of the present study. The first (Table 4) shows the estimated total of individuals living with HIV in the UK as at 2009. In the slides 'MSM' refers to the transmission group 'Men who have Sex with Men'. They may or may not identify as homosexual, gay or bisexual. The next two slides show trends in HIV and AIDS diagnoses and deaths in the UK between 2000 and 2009 (HIV in the United Kingdom: 2010 Report; Health Protection Agency 2010). The second slide (Table 5) gives the total numbers of UK diagnoses and deaths and the third (Table 6) gives trends by prevention groups.

With a nationwide strategy published in 2001, the UK's principles and practices underpinning strategic public health responses to HIV chime with those advocated by UNGASS¹ (UNGASS 2001a). Although not without dissenters, those, for example, urging anti-smoking, anti-obesity, anti-drug and alcohol use as well as sexual health interventions based on prohibitions on behaviours and restrictions on freedoms and human rights (Baggott 2000: 256, Davies 2010: 73-75), universal access to information, treatment and care are familiar anticipations within UK health services. Moral assessments of an individual's behaviours and lifestyles are to be avoided by practitioners and providers in the interests of access to community-wide service provision, health promotion and the reduction of barriers to good public health (Department of Health 2001, 2003). Although significant to the good governance of

¹ The UK National Strategy for Sexual Health and HIV (Department of Health, 2001) was to be reviewed in 2010. At October 2011 the UK was without a national strategy (National AIDS Trust, 2011b).

Table 4. Estimated number of adults (15-59 years) living with HIV (both diagnosed and undiagnosed in the UK: 2009). Health Protection Agency 2010b, HIV in the United Kingdom 2010 Slideset, 1.

Estimated number of adults (15-59 years) living with HIV (both diagnosed and undiagnosed) in the UK: 2009

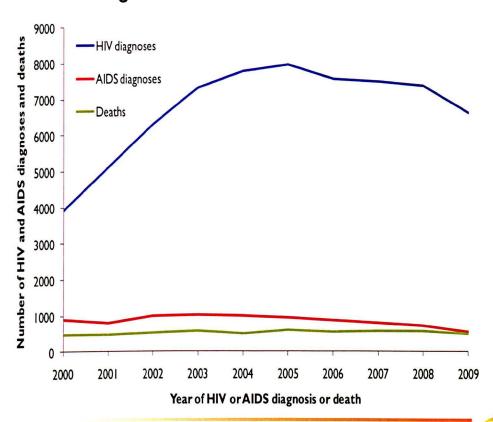


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Table 5. New HIV and AIDS diagnoses in the UK and deaths among HIV infected individuals: 2000-2009. Health Protection Agency 2010b, HIV in the United Kingdom 2010 Slideset, 2.

New HIV and AIDS diagnoses in the UK, and deaths among HIV infected individuals: 2000 - 2009

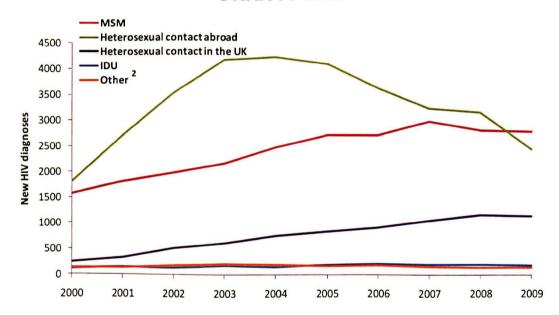


HIV and AIDS New Diagnoses and Deaths

HIV and STI Department - Centre for Infections

Table 6. Number of new HIV diagnoses by prevention group, UK: 2000-2009. Health Protection Agency 2010b, HIV in the United Kingdom 2010 Slideset, 3.

Number of new HIV diagnoses¹ by prevention group, UK: 2000-2009



¹ Data are adjusted for missing route of infection

HIV and AIDS New Diagnoses and Deaths

HIV and STI Department - Centre for Infections



² Includes Mother to child transmission and blood product recipient

all evidence-based public health strategic design and delivery (Beaglehole et al 1993: 140; Speller 2009a, Fahy 2009) these principles can encounter particular resistance in the contexts of sexual and reproductive health where attitudes and practices are informed by those beliefs, whether or not conceptualized, defined or endorsed in religion-informed terms, which permit no license beyond strictly prescribed heterosexual marriage. Where such beliefs hold sway those behaviours and relationships which do not conform will attract particular opprobrium. It is then that messages of exclusion and taboo are generated (Douglas, 1988) and the best public health policy and practice become aware they are dealing with stigma's impact on community health (Speller, 2009b). Stigma's presence in this study, in its conduct and development, now begins to assume a more definitive role. It is a role which will be discussed in greater detail and depth as the work proceeds.

Prevention and care strategies

Conceptual tensions

UK policy for HIV is premised, then, on universal non-judgemental access to information, treatment and care. There is a requirement also to be respectful of and sensitive to religio-cultural beliefs and practices (Department of Health 2001, 2003). Cultural, including religious, sensitivity conflicts with rights-based approaches when some religious responses to HIV and people affected by it appear to promulgate discrimination and inequality and reinforce stigma particularly where beliefs and teachings about sexuality and gender are concerned (World Council of Churches 1997, Esack et al 2004, Quraishi 2005, Agadjanian 2005, Anderson, Elam et al 2008, Kostick et al 2011). And, although not solely religion-related though, arguably, often ideologically generated, it is the case that, since those early diagnoses among gay men and groups in Africa, HIV prevention and care initiatives built on public health principles of universal and open access have had to contend with issues of prejudice, discrimination, silence and denial created by an early association of HIV with what some hold to be promiscuous and immoral behaviour. Blame and shame surfaced as early features of popular HIV discourse around the world, fuelling a now familiar and seemingly intractable HIV-related stigma.

The more negative and judgmental the response, the greater the stigma attaching to HIV and people affected by it (World Council of Churches 1997, Department of

Health 2001, 2002, 2005; National AIDS Trust/SIGMA 2004). And the greater the stigma the greater the risk of undermining strategic Public Health HIV prevention, education and support programmes. Stigma's impact on people affected by HIV and on local service delivery cannot be ignored (Das 2001, Weiss and Ramakrishna 2001, UNAIDS 2005, Collins et al 2008, Mbonu et al 2009, Aga et al 2009). But stigma and the religio-cultural and social norms which generate it and make it present serve also as that which defines 'right' community and 'right' relationship. The outsider-ness which stigma confers regulates and preserves individual and group identity (Douglas 1988, Goffman 1963, Weiss and Ramakrishna 2001). For many, it becomes an essential device in diverse communities where confusions of identity and different behaviours can threaten cohesion and well-being. Historically, religions have played a visible part in establishing and maintaining traditional boundaries. For many communities and individuals religious identity is the primary defining characteristic.

In England there is some evidence, though limited for religion, that the more ethnically and religiously diverse communities are those with highest prevalence for HIV (Census 2001 [2003] Local Authorities KS07 Religion, Census 2001 [2006] Focus on Ethnicity and Identity, Experimental Population Estimates by Ethnicity 2009 [2011], Health Protection Agency [2010c] Diagnosed HIV Prevalence in Local Authorities in England), suggesting that the boundary-setting significance of the specification and preservation of individual and community identities may raise stigma-related barriers to HIV prevention and care if diagnoses customarily are late, and late diagnosis is a matter of concern. Of course the figures can be interpreted in different ways. A higher than UK national average, that is, higher than 1.7 diagnoses per 1,000 population, can indeed indicate demographic factors such as 'a high proportion of men who have sex with men, people from ethnic minorities and immigrants from countries with high prevalence of HIV' (Health Protection Agency [HPA] 2011b). It will also point to high numbers accessing care from their local NHS services. A low prevalence value may indicate that there is 'a high rate of HIV but residents may be unaware of their infection and/or may not be seeking care' (Health Protection Agency 2011b). Strategically, the prevalence of diagnosed infection is taken as an indicator of undiagnosed HIV infection (Health Protection Agency 2011c) and is to drive the increased provision of testing sites.

Stigma, discrimination and judgmental attitudes can deter individuals from being tested for HIV, from seeking information, care and support, from disclosing their HIV status to sexual partners and also put at risk adherence to drugs regimens (Department of Health 2005). Clearly, moral codes, beliefs and teaching influence personal and collective responses to HIV in that belief systems and world views can both reinforce and reduce the stigma attaching to HIV and people affected by it. But, despite wide dissemination of HIV information and campaigning at international, national and local levels over many years and the adoption by some religious organisations of nonjudgemental and anti-discriminatory policies and statements (World Council of Churches/UNGASS 2001, African Religious Leaders' Assembly 2002, Interfaith AIDS Conference Bangkok 2003, Cairo Declaration 2004), most recently those issued by religious leaders at a prayer breakfast in New York hosted by UNAIDS and a UNFPA sponsored 'Summit of High Level Religious Leaders' in the Netherlands (UNFPA 2010, UNGASS 2011b), there remain significant barriers to effective prevention and care strategies. So much so that, thirty years since AIDS was first named, HIV remains a significant global challenge to public health.

Strategic conflicts

As noted above, few countries (thirty three worldwide, twenty two of which are in sub Saharan Africa according to the UNAIDS 2010 report) have achieved reduced prevalence (more difficult when increased numbers of people are living longer with HIV due to greater availability of antiretroviral medications), making Uganda's efforts particularly noteworthy (UNAIDS RST ESA, 2010). But government claims for religions' contribution to Uganda's successes have been highly contested (Thornton 2008, Campbell et al 2007).

During the nineteen seventies communities in Uganda grew familiar with a disease they named 'Slim'. As American clinicians were beginning to identify 'GRID' connections were being made between the presenting illnesses in those American gay men and the condition emerging in central and eastern sub-Saharan Africa. Uganda's government resolved to respond to what was later termed AIDS and did so in a multisectoral fashion. This is a response recommended now by UNAIDS but in the 1980s was unusual and innovative. Adopting the 'ABC' strategy – Abstinence, Be faithful, use a Condom - Uganda managed to reduce prevalence from between 25 and 30

percent in major urban areas and 18 per cent in rural areas in the early 1990s to 6.5 per cent from 2001 onwards (UNAIDS 2011, UNAIDS RST ESA 2010). All sectors of society were involved in Uganda's response to HIV, including the religious groups, predominantly Catholic or Protestant Christian and Muslim, many of whom were not averse to bestowing on the ABC campaign a moral order - 'abstinence is best, faithfulness to one partner is second best, and use of condoms is a poor third' (Barnett and Parkhurst 2005). Accounting for the success, though, Uganda's President Museveni and his wife claim that the religious leaders' calls for abstinence and fidelity were largely responsible for the change in prevalence. Needless to say, this too is a contested position (Thornton 2008). Barnett and Parkhurst (2005) charge the Christian right in America with promoting an 'unproven' abstinence-only policy and tving it to project funding.² They point to a need to acknowledge and understand the multiple routes to HIV reduction. Thornton argues that strong civil society streams. for example, traditional social hierarchies at family and civic levels (including the restoration of the ancient kingdoms), unique to Uganda and compatible with its multisectoral approach, have had at least as much to do with any prevalence reduction as religious calls for abstinence. Increases in homophobic violence and recent high profile campaigns calling for the death penalty for gay men and lesbians (not confined to Uganda) and for the criminalization of non-intentional infection of a partner reflect declining concern for rights-based approaches to HIV prevention³ (National AIDS Trust 2011b, Guardian web site 2011, UHSPA).

There is a thwarting of consistency. Clearly, interfaces of meaning, identity and belonging, socio-political, economic and cultural differences impact and intersect with responses to HIV. Questions arise as to whether religious beliefs and teachings do influence approaches to, and experiences of, HIV. Are the beliefs taught and held helping or hindering public health responses to HIV, responses which are premised on principles of universal access to information, treatment and care?

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² More recently the ABC approach was abandoned by some agencies to avoid its moralistic associations. In 2003 the African network (ANERALA+) of an international association of religious leaders living with or personally affected by HIV and AIDS (INERALA+) set up to challenge stigma and discrimination, developed SAVE: Christian Aid, for example, adopted SAVE: Safer practices; Access to treatment; Voluntary counselling and testing; Empowerment. Christian Aid, a leading British and Irish development agency adopted SAVE (Christian Aid, 2010).

³ Uganda Health and Science Press Association, an LGBTI led network (<u>www.uhspauganda</u>) reported the appointment (April 2011) of the gay lobby group to a government committee tasked with streamlining health, human rights and gender rights in Uganda's public health policies and laws.

Distilling the issues and formulating the questions generated by a range of interrelated experiences and reports becomes the first task.

Developing the research proposal

In the summer of 1988 the Director of the World Health Organisation's Global Programme on AIDS, Dr Jonathan Mann, addressed participants at the Lambeth Conference, the decennial gathering of Anglican bishops. Urging 'resolute commitment to interdependence, communication and justice' and global mobilization, he said

AIDS has joined the central issues of our time in demanding solidarity ... the creative power of interdependence cannot be underestimated as a force against domination by the disease.

(Episcopal Press and News 1962-2006, 1988)

A resolution was adopted acknowledging the 'catastrophic threat' AIDS posed to every part of the world and the need to participate in encouraging prevention measures and compassionate care. It urged

- The promotion of, and co-operation with, educational programmes both of Church and state concerned with the cause and prevention of the disease, in a loving and non-judgemental spirit towards those who suffer.
- 2. The development of diocesan strategies: (a) to train and support pastoral helpers; (b) to give direct personal support to those living with AIDS; (c) to identify and try to resolve the social problems leading to and arising from the disease; (d) to reaffirm the traditional biblical teaching that sexual intercourse is an act of total commitment which belongs properly within a permanent married relationship.
- 3. The need to work together: (a) to encourage global co-operation between Churches, governments and non-government agencies in the fight against the disease; (b) to develop ways in which the Churches can share information and resources: (c) to press where necessary for

political action; (d) to promote prayer for all concerned, not forgetting those active in research to discover a cure.

(Lambeth Conference Archives 1988)

In a foreword to a local diocesan guide to HIV and attributing the quote to Jonathan Mann, (but attributed to the Archbishop of York, John Habgood, by Episcopal Press and News 1962-2006, 2008) a UK bishop wrote

'I do not know what the main topic of your conference agenda is this year, but I know that at the next Lambeth Conference in 1998 the main topic will be HIV/AIDS. This is because HIV/AIDS will have become such a serious problem that it will be dominating the agenda of every world conference.'

(Diocese of Leicester Board of Mission and Social Responsibility, 1992)

It was not the main topic of Lambeth '98, though, somewhat ironically, the focus of most media attention on Lambeth 1998 was the discussions concerning homosexuality. And Mann's and the resolution's urgings for Anglicans to engage in multi-sectoral and -dimensional responses to HIV were and continue to be largely unfulfilled in spite of there being millions around the world caught up in a web of HIV-related illness, poverty, discrimination and stigma.

Such concerns – social justice and wealth distribution – would normally claim the attention of all the world religions but with an emerging awareness of an HIV dimension, and apart from sensationalised headlines (Wellings 1988, Treichler 1999: 12 ff), concerns about the safety of the shared chalice and those increasingly divisive debates about homosexuality and gender, silence and inaction became the norm, although with some notable exceptions. CAFOD's (the Catholic Fund for Overseas Development) work in providing supportive care for people affected by HIV in East Africa and Latin America was well established by the 1990s and the ABC approach appealed to and was adopted by some faith contexts, including, more recently, by the leadership of the Association of Black-led Churches in the UK. Questions now arise as to the apparent persistence of some religious groups in including, if not elevating, references to sexual morality in their responses to HIV. Are not challenges to structural social injustice and the unfair distribution of resources credible and

necessary moral responses to HIV? Are the interdependent approaches advocated by Mann and supported by the Lambeth conference resolution and other religious statements on HIV undermined by religious appropriations of HIV as, first and foremost, an issue of sexual morality? Have religions foregone the opportunity to participate in and contribute to the global response to HIV? Is this fundamental tension in religion's dichotomous response to HIV symptomatic of HIV's capacity to expose incongruence amid modernity's complex and confusing diversities?

A number of faith-based initiatives providing care and support for men, women and children affected by HIV were established in parts of the developing world, mainly in the countries of sub-Saharan Africa. By and large, however, the responses of faith communities world-wide have been those of silence, denial and condemnation. It could be argued that supportive responses by faith groups in the industrialised world were proportionately even weaker than in African countries given that in the UK and USA sex between men, a taboo of high order in many religions, was understood to be the main route of transmission. In terms of religious belief and teaching it may be deemed more acceptable in UK communities to support Africa's children and their poverty-stricken mothers affected by HIV than local gay men or immigrant asylum seekers. Prevention strategies were already risking entanglement and disablement in a web of contested beliefs and competing realities. But what are faith leaders and religious teachers at grass roots levels saying about HIV? How are faith community members appropriating the teachings in the context of their beliefs? Reflections on these and the questions below helped inform the content and structure of a research proposal.

- Are public health principles and the prevention and care strategies and practices they inform undermined and access thwarted by sensitivities to personal and corporate philosophies, beliefs and traditions?
- How do religious groups/communities (leaderships and 'street') in the UK and internationally respond to HIV? What do people affected by HIV want from their faith group? What do religions offer a world with HIV?

- Can responses to HIV which conform to those of specific religious and cultural beliefs and contexts prevent transmission of the virus, ensure adequate care and treatment of those affected and have long term application and impact? Can the health of sexual minorities and other marginalised groups, women and their babies and girls be protected?
- If stigma is a major barrier worldwide to effective HIV prevention, treatment and care can HIV education and other prevention initiatives navigate the barriers stigma generates, particularly any religio-cultural fuelling of stigma, and work creatively and effectively within them?
- Where lies the potential for any necessary change when the beliefs and practices which are deemed to have served the well-being and survival of individuals, communities and societies for generations risk transmission of HIV, for example such practices as widow inheritance, wife sharing, Female Genital Mutilation, polygyny? Does religion reinforce the vulnerability of women to HIV and if so what options for change are available and effective?
- Do the beliefs of education and health and social care professionals
 influence the delivery and efficacy of strategic public health responses to
 HIV and people affected by it? Is there prejudice towards those with
 religious convictions and if so does it impact access to services?
- In a world with HIV can an allegiance to religion as truth incorporate an
 appreciation of religion as phenomenon? Can theologies accommodate the
 multiplicities and complexities of contemporary socio economic
 confusions and realities in responding to HIV?

With further background exploration efforts were made to present a single question with the capacity to incorporate the dimensions identified above.

Much of the research into religion and HIV has focused on countries and communities of high prevalence, particularly in Christian populations of sub Saharan Africa

(Kopelman 2002, Takyi 2003, Allen and Heald 2004, Kalichman and Simbayi 2004, Smith 2004, Agadjanian 2005, Hamra, Ross et al 2006, Santmyire and Jamison 2006, Adogame 2007, Bazant and Boulay 2007, Krakauer and Newbery 2007, Velayati et al 2007, Maman, Cathcart et al 2009, Trinitapoli 2009, Agardh et al 2010, Noden et al 2010, Ucheaga and Hartwig 2010, Izugbara et al 2011). But, the global dimensions of HIV touch the local in unavoidable ways. The challenge becomes one of engaging dialogically with macro- and micro- 'worlds of interaction' (Layder 1993, p 113) in order to assess more fully the complexities of religion-related responses to HIV. Furthermore, as far as this particular study was concerned, it was becoming clear, that such complexities could not be so assessed by appropriating a single discipline. Layder's 'worlds of interaction' invite the interdisciplinary dialogue implicit in this study's effort to foster mutual understanding and partnered action.

An initial plan to draw on the discourses of sociology, psychology and anthropology to construct and integrate a practical theological approach to the relevant and related concerns was favoured. Consultations with expert informants and further reflections by the author on aspects of her own professional experience and previous research brought empirical parameters to the fore and helped shaped a proposal in which an inter disciplinary study informed by international data and a small scale localised survey would investigate whether differing, if not contested, public health and religious realities impact responses to HIV. Notions of interdisciplinarity would be subjected to continuing reflection and consideration in the light of the literature review and the ongoing development of the research strategy.

Following the process described below, efforts were made to advance and further inform the presentation of a detailed proposal.

Draft proposal and outline methodological strategy

Consider any necessary applications for ethical clearances.

Conduct literature review and establish statistical and epidemiological history to inform contexts and theoretical bases of previous studies and current issues.

Locate and read key texts and relate to HIV in local and wider contexts (ongoing).

Undertake research training according to identified needs.

Refine research question, methodology and contextualize ethical parameters.

Consult faith leaders/representatives through existing networks eg local Council of Faiths and Churches Together groups, Faiths Regeneration Network, Hindu Christian Forum, Muslim Christian Dialogue Group, local Centre for inter-faith engagement and women's groups, as to how religious groups/communities (clergy/representatives and lay members) are responding to HIV and people affected by it.

Consult health and social care HIV service providers, statutory and voluntary sectors.

Consult people affected by HIV.

Assess data derived from consultation process.

Formulate and submit research proposal

This chapter's preliminary delineation of the key presenting issues has included accounts of

- the author's professional context and its initial exposure of potential tensions and collaborations between public health policy and practice and religioninformed responses to HIV prevention and care;
- the foundational placing of practical theology alongside public health within an interdisciplinary investigation and the author's reflections on it;
- increased diversity and its perceived impact on levels of stigma and and the associated complexification of religion-informed and public health engagements with HIV;
- the history and epidemiology of HIV, global and local, their disputes and contestations;

- conceptual conflicts in prevention and care strategies;
- the development of the research proposal.

The governing question -

Are present strategic public health responses to HIV prevention and care adequate to the multiplicity of psychosocial realities and needs of religiocultural diversity in a UK community? -

gathers together the substance of the complex realities and diverse needs identified thus far and opens an entry into methodological process and enquiry which continues with a comprehensive literature review at Chapter Two. This will help identify the wider contexts and concepts through which the study's construction and direction can be channeled and within which it can be placed. It will then be equipped better to proceed with a detailed formulation of the investigation's aims and objectives and the format for its data collection and tools for analysis.

CHAPTER TWO

Literature Review

Search strategy

The search strategy was based on established methods as documented for example in Ogier's Reading Research (Lanoë, 2002), in Greenhalgh (2001) and in Neuman (1994). In 2006 Medline and CINAHL databases were searched for English language journal articles, reviews or research using key words 'religious', 'religion', 'belief', 'beliefs', 'HIV', 'AIDS' and 'HIV/AIDS'. The Medline search, which was facilitated by the NHS Evidence Health Information Resources, was limited to run from the year 1985. CINAHL alerts ran from 1982. Alerts were then set up to run weekly. This arrangement with the NHS system ended in 2010 and alerts were then delivered via EBSCO Alert Notification from the MEDLINE AMED (The Allied and Complementary Medicine Database) through the University of Derby network.

Additional material has been gathered from a wide range of sources, not exclusively HIV-specific, in the fields of globalisation/development studies, international/national HIV/AIDS reports, religion and the discourses of sociology, psychology, social psychology, anthropology and theology. Manual and internet searches of data not normally indexed in the major databases, the researcher's personal collection, knowledge and experience of the contexts and networks of HIV/AIDS practice and approach were also put to use.

Retrieved resources are concerned variously with

- religious belief as personal coping resource and as an agent of well-being (eg Farber et al 2000, Siegel and Scrimshaw 2002, Lorenz et al 2005, Doyal and Anderson 2005, Cotton et al 2006, Ironson et al 2006, Litwinczuk and Groh 2007, Ridge et al 2008);
- the impact of prayer and other religious interventions (eg Crane et al 2000, Agate et al 2005, Chinouya and O'Keefe 2005, Bazant and Boulay 2007);
- the role of belief in risk taking and behaviour change (eg Maoulidi 2003, Gatrad and Sheikh 2004, Gray 2004, Hasnain et al 2005, Agadjanian 2005,

- Odu and Akanle 2008, Corbin et al 2009, Gillum and Holt 2010, Dowshen et al 2011);
- describing beliefs and practices to equip health and social care professionals
 for the provision of culturally sensitive care respectful of beliefs and values
 (eg Neuberger 1991, Balarajan and Soni Raleigh 1995, Ghalib and Peralta
 2002, Bruton 2005, Flikkema and Bierma 2007);
- responding strategically to HIV (eg UNGASS 2001a, 2011a, Department of Health 2001);
- responding theologically to HIV (eg Woodward 1990, World Council of Churches 1997, Cairo Declaration 2004, Esack et al 2004, Clifford 2006, Gill 2007);
- religious belief, attitudes and access to HIV information and care (eg Green and Rademan 1997, Gray et al 1999, Bègue 2001, Ashforth 2002, Barnett and Parkhurst 2005, Gańczak et al 2007, Bovens 2009, Abu-Moghli et al 2010, Ansari and Gaestel 2010, Chin et al 2005, El Feki 2006, Griffith et al 2010).

Many of the investigations into aspects of religion and HIV have focused on countries and communities of high prevalence for HIV (Surur and Kaba 2000, Takvi 2003. Maoulidi 2003, Kalichman and Simbayi 2004, Rankin et al 2005, Genrich and Brathwaite 2005, Agadjanian 2005, Santmyire and Jamison 2006, Rödlach 2006, Hamra et al 2006, Velayati et al 2007, Wanyama et al 2007, O'Toole et al 2007, Agadianian and Sen 2007, Ucheaga and Hartwig 2010). These studies are not irrelevant as many individuals in the UK and elsewhere have strong ties with parts of the world significantly affected by HIV/AIDS; with South Asia, for example, and the countries of sub Saharan Africa, the Caribbean and parts of Eastern Europe. A further body of work with helpful methodological data and discussion material focuses on religions' responses to HIV in the USA (Tesoriero 2000, Agate 2005, Chin et al 2005. Leong 2006, Miller 2007). A small but significant stream of contributions addresses the influence of religious belief on HIV-affected UK populations (Gatrad and Sheikh 2004, Chinouya and O'Keefe 2005, Doyal and Anderson 2005, Anderson et al 2008). Predominantly, though, their attention is directed towards migrant African Christians living with HIV and their religious leaders: a not insignificant focus given the levels of HIV infection among African communities in the UK and that the African

populations of some parts of the UK, along with 'other' minority and mixed groups, are predicted⁴ to experience the largest increases by 2026 (Barrow Cadbury Trust 2007) and well-informed responses to health needs, including sexual health, in respect of demographic change will be necessary. Although some UK studies note the potential for tensions between culturally specific and public health approaches to HIV prevention and care messages and advocate partnered work with faith leaders (Chinouya and O'Keefe 2005 and the work of the African HIV Policy Network in the UK), questions concerning the extent and impact of those tensions and their various dimensions, local and global, on strategic HIV prevention and care in UK contexts of religio-cultural diversity remain largely unexplored.

With increased interest over the years, researchers around the world have been engaging with HIV in a multiplicity of contexts and through a range of disciplines, locating the many dimensions of their various conceptualizations of HIV in both local and global frames of application and dissemination. The following review identifies and investigates some of the key issues raised in the literature and logs their associated themes and complexities.

Globalisation, religion and HIV

In most parts of the world established, new and emerging communities enjoy commercial, civic, recreational, cultural, religious and familial connections which, in sum, have a global reach. Plurality and complexity characterise the contexts of local and global responses to HIV. They are characterisations which shape the territory of enquiry when a shared global social and economic context, often experienced as an extension of western modernisation's institutions, not least those which boost the interests of capitalist economy, scientific rationality and technology, both facilitates and hinders openness to difference and social, including religious, change (Beyer 1994). Balancing socio-cultural with scientific approaches, the politically and economically expedient with local representation and need, social realities with moral decision-making (Stillwaggon 2002, Strassberg 2003) and the 'culturally contingent with the theologically essential' (Johnston 2001) exercises everyone to one degree or

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⁴ Based on the 1991 and 2001 Census definitions of 'other': Black other; other groups: Asian; other groups: other (1991); other Asian; other Black; Chinese or other ethnic group; mixed White and Black Caribbean; mixed White and Black African; mixed White and Asian; other mixed (2001) (Barrow Cadbury Trust, 2007).

another, not least public health practitioners and religious and political leaders throughout the world.

According to globalisation theory, global forces, mainly economic and driven by economic capitalism, have created a new unit of analysis by which to contextualise and know smaller sub units such as nation states, organisations, the local and religion (McDaniel 2003). AIDS has been described as the first 'epidemic of globalisation' (Barnett and Whiteside 2002: 4) with various analysts and researchers arguing that HIV/AIDS can only be understood and responded to appropriately in such global terms (Mann 1992, Hunt 2004, Karnik 2001, Barnett 2004a, Strassberg 2003, 2004, Allen 2004, Shadlen 2004, Putzel 2004). In the way that globalisation theory has been the subject of social scientific study since the 1970s (Beyer 1994), so has HIV emerged as a distinct phase and phenomenon in public health history and cannot be understood without setting any analysis of the local in the phases and phenomena of global and globalising economic and social contexts.

Global inequalities, lack of social cohesion, extensive diversity and poverty are identified as major factors in HIV transmission and those prevention programmes which take no comprehensive account of social justice, human rights and civil liberties can anticipate little impact (Mann 1992, Karnik 2001, Hunt 2004, Barnett and Whiteside 2002)⁵. There are calls for those responses to HIV which focus most specifically on sexual morality, and they are usually though not exclusively religious responses, to accept a radical shift of emphasis. The relationship between globalisation, free market capitalism and unjust power relations worldwide and the global dimensions of a pandemic which thrives on exclusion and poverty establishes a strong case for religions to set aside their concentration on sexual ethics and instead bring their theologies and authority to bear on transforming socio-political and economic inequalities (Hunt, 2004), on building a just world order and 'lessening the suffering of strangers' (Strassberg 2004: 459).

⁵ Rarnett and Whiteside in their analysis of the local/global economic dichotomy and the impacts on and of the transmission of HV and responses to it point out that the early transmission of the virus was among the "rich and more cosmopolitan in Africa and elsewhere". Travel and "easy access to 'local' people who were neither cosmopolitan nor wealthy" became their routes to infection (2002: 363).

Others, however, have argued for or noted the moral appeal of prevention strategies governed by sexual discipline and rights restricting controls (Chin, 2003; Allen, 2004). Whichever approach is favoured the local is to take account of the global and any appraisal of either requires reference to globalisation, its discourses and perspectives. Douglas M. Johnston (2001) provides a useful overview of religion's place in human experience of globalisation and a starting place for debate.

Although not addressing HIV/AIDS, Johnston's exposition, a chapter in a major analysis⁶, offers a transferable frame of reference. He cites a number of key exponents of the religion-globalisation debates including Samuel Huntington (1997) who, in Johnston's words, 'identifies religion as the most important defining element of any civilization (as contrasted with race, language or way of life)' and 'a defining element in future conflicts.' In their paper 'The True Clash of Civilizations', Inglehart and Norris (2003) argue that divergence in the valuing of self expression and human development and not political values is the real cultural fault line in any division between Islam and the West (and it is Islam and western [Christian] democratic expressions of polity which define the focus of Huntington's 'clash of civilisations' thesis). Inglehart and Norris refer in particular to gender equalities and sexual liberalisation. Charles McDaniel's (2003) analysis of religious approaches to modernity focuses on Islamic responses to economic, political and human rights globalisation and concludes that any 'clash' of civilisations issues from a process of enlarged religio-cultural engagement between societies at different stages of development. The potential for conflict is acknowledged but increased engagement also, he notes, offers opportunities for dialogue and mutually beneficial co-operation. In an article in *The Guardian* newspaper 14 April 2007, philosopher Julian Baggini categorises the 'clash of civilisations' debate in 'pragmatic relativism versus dogmatic certainty' terms. Peter Beyer's (1994) characterisation of religion/globalisation relationships takes a less dualistic line. His, essentially sociological, discussion, again

⁶ Douglas M. Johnston has served as the president of the International Center for Religion and Diplomacy and founder of the executive programme in US national and international security at Harvard University and also as executive vice president of the U.S. Center for Strategic and International Studies. The Global Century is the result of a multi-disciplinary enquiry conducted by analysts and academics drawing on a wide range of perspectives and opinions. Among others, the group included political scientists, economists, former ambassadors, historians, social scientists and policy analysts. The intention was to undertake a comprehensive analysis of globalisation, its strategic consequences and its policy implications and contribute to the literature, inform policy and stimulate further research on the effects of globalisation.

not specific to HIV/AIDS, understanding religion as one mode of communication among many, argues that, whether in engagement with or resistant to globalisation, religions' relationships with it will, at one and the same time, further globalisation and relativise religion. For Beyer a significant point of reference is the issuing of a *fatwah* in 1989 by Iran's Ayatollah Khomeini condemning to death the author Salman Rushdie after the publication of Rushdie's book *The Satanic Verses*. Beyer saw the event and its aftermath as illustrative of the world/religion relationship. With the Rushdie episode as a backdrop, Beyer draws attention to a changed and changing global social, political and economic environment characterised by:

- developments in scope and speed of communication technology;
- increased exposure of difference;
- social constructions becoming more visible as human constructions;
- a need to relativise in tension with a need to particularise;
- the redefinition of identities in the pursuit of power and meaning;
- the marginalisation of religion.

Responses to each phenomenon, Beyer argues, demonstrate the capacity of efforts to challenge if not constrain globalisation's reach and influence to result ultimately in its development. He posits a paradoxical symbiosis, citing religion's and globalisation's propensities to function and communicate as both universalist and particularist at one and the same time. Indeed this reflects the tension inherent to an eternal human quest: to be simultaneously both autonomous individual and in relation, to belong to the group and to assert a unique identity (Hull 1991: 48 ff). It is a need with which all religious traditions grapple in their various emphases on and appropriations of, both historic and contemporary, sacred texts, symbols, praxis and memory. Beyer appears to suggest that religion's power in a rapidly changing globalised world may be embedded in its capacity to resolve such tensions and to connect symbolically these dichotomous abstractions to both past and future, providing as they do so a link to a universalising and particularising present. It is as if he is pointing out that while religion draws from ancient wells globalisation's modernity splashes in puddles and the wisdoms and dogmas of the one could benefit from the spontaneity and pragmatism of the other. Furthermore, Beyer also argues that the impact of

globalisation can no longer be excluded from any analysis of socio-cultural phenomena. But does his focus on the role of religion in a world characterised by the parallel, often contradictory, competing and conflicting forces of relativisation, mutability, particularity and identity offer a realistic framework for understanding religion's response to HIV in a globalised world? In respect of the Rushdie events Beyer writes

...the central thrust is to make Islam and Muslims more determinative in the world system, not to reverse globalization. The intent is to shape global reality, not to negate it. More generally, religion within the global system can be antisystemic and prosystemic at the same time: it can further globalization in opposing its effects.

(Beyer 2004: 3)

He notes that the cost of a role in shaping globalisation is the relativisation of religion and religious identity and for many religious professionals and practitioners it is too high a price to pay for influence in modernity's secular fold. Religious responses to HIV which focus primarily on the most intimate and private dimensions of human relationship, that is sexual morality, rather than on the transformation of those global inequalities in which HIV transmission and prevalence are rooted illustrates something of this argument. Asking, then, what possibilities exist for religion to shape social institutions beyond the limits of individual belief and practice, Beyer locates their future in complex, emerging socio-cultural alliances with political and economic 'antisystemic' social movements as multi-faceted and differentiated as any system or structure globalisation can deliver. (Perhaps Beyer would see the 'Occupy Wall Street' campaigns and the revolutionary movements in the Middle East in these terms.) But whether choosing to be inside or outside globalisation's fold, according to Beyer, religion cannot escape globalisation's particularising and relativising tensions.

His wide reaching discussion attempts to cast a light on the changing and indeterminate complexities of religion's response to globalisation. Though writing in 1994 his work speaks powerfully to a twenty-first century world where Salman

Rushdie continues to elicit condemnatory statements⁷, where the fault lines of ideological tensions and conflicts make their presence felt and where the role of religion remains uncertain, whether to itself or to observers, not least in responses to plurality and change⁸.

A return to Johnston's contribution helps highlight further dimensions of the globalisation/religion discussion. Johnston challenges Huntington's apocalyptic 'clash of civilisations' thesis on two specific fronts. First, he contends that political interest will usually overrule religio-cultural allegiances. Second, he argues, making a case similar to Beyer's, that advances in direct communications world wide between individuals and organisations will improve if not homogenise cultural, religious and ethnic division, soften historic tensions and reduce the potential for conflict. However, in line with Huntington he concedes that religion features strongly in current global confrontation in contrast with the years of Cold War tensions when religion barely figured at all. Both capitalism and communism took their eyes off the religious ball, he might say. The end of the Cold War strengthened convictions that liberal democracy could not, citing Francis Fukuyama (1992), 'be improved upon' and that the world could anticipate a sure progress towards democratisation and rationalisation. Such idealising evaporated when emerging world conflicts during the 1990s showed that religion and culture were alive and kicking.

Johnston looks to Peter Berger (1996) and Mark Juergensmeyer (1993) to support his argument that western diplomacy's neglect of its own religious literacy reduced its capacity to respond appropriately to religious or secular confrontations anywhere. Drawing on the work of theologian John Milbank, Johnston posits the idea that 'a secular sphere free of religious influence is itself a theological construct grounded in the metaphysical debates of medieval academia' (Johnston 2001: 669). He quotes Milbank,

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⁷ The announcement in June 2007 that Rushdie was to receive a knighthood triggered a number of demonstrations around the world and critical comment by political and religious leaders.

⁸ The Church of England's confused response in the wake of global and local economic convulsions to the tented protesters on the steps of St Paul's Cathedral in 2011and Islam's mixed engagement with grass roots Arab uprisings chime with Beyer's argument.

Theology enters into the very construction of the new realities 'property' and 'sovereignty', helping to create a new space for human maneuver.

(Milbank 1993: 15 in Johnston 2001: 669)

and goes on to make the point that the world in both its religious and secular conceptualisations is theologically constructed and perceived. Globalisation then, and any enforcement of or confrontations within it, becomes sectarian acts likely to be understood and responded to as inter-religious conflict. Johnston's elucidation of this tension as a theological phenomenon sheds a further theoretical light on the reluctance some religious groups demonstrate in their unwillingness to engage with HIV/AIDS when perceived as a secular and potentially secularising public health issue with its distinct human rights and civil liberties features.

In 'Does God believe in human rights?' (Ghanea, Stephens and Walden eds, 2007b), Paul Weller's chapter (2007b) explores the complex and various relationships which pertain in a number of countries between state and religion and their various appropriations of 'secular' and responses to 'human rights'. It could be argued that appropriations of human rights-led responses to HIV/AIDS will be similarly complex and variable irrespective of UNAIDS and WHO anti-discriminatory policy requirements. For example, introducing a collection of papers first presented at a London School of Economics workshop in 2004 'Why don't HIV/AIDS policies work?', Tim Allen (2004, also Allen and Heald 2004) points out that although any failure to uphold human rights in responses to HIV/AIDS is widely deplored, in public health terms a commitment to human rights is 'potentially counterproductive' (Allen 2004: 1127). In contexts of increasing infection rates and mortality he notes the potential, even the need, for some governments to set aside human rights obligations in the interests of public health. Enforced segregation, condom use and testing, he argues, may have their place.

Similarly, Barnett and Whiteside (2002), while arguing that ineffective prevention policies are those which take no account of human rights and civil liberties, concede that inconsistencies exist. In the Philippines, for example, they suggest that the behavioural and moral restrictions of the Roman Catholic Church are perhaps an acceptable price to pay in civil liberties terms given the church's powerful influence

in maintaining social cohesion and a 'low and slow' HIV epidemic. It is a reality of public health/HIV complexity detectable also in Mary Hunt's presentation of Australia and Poland as good examples of countries where control of HIV has been well managed.

Hunt is an advocate of rights-based approaches to HIV prevention and care, but she fails to note that the Catholic Church wields significant influence in Poland. Religioninfluenced impacts on women's reproductive rights and condom use for protection against sexually tranmitted infections are missing from Hunt's analysis, as are Australia's continuing marginalisation of aboriginal peoples and the strict limits placed on immigration from those developing countries where prevalence for HIV can be high. Also, when contending that 'jobs and egalitarian mores not sexual sanctions and quarantines work to stem the tide when it comes to prevention and dealing justly with those infected' (Hunt 2004: 468), Hunt points to Cuba and Sweden as good examples. But in both countries control of the virus has been achieved to some extent by the strategic isolation of the diagnosed and by mandatory testing (AVERT, 2006; Fawthrop, 2003; Hoffman, 2004; WHO Europe, 2006). Hunt and Allen, Barnett and Whiteside lift a significant HIV and public health tension into view. If HIV were to threaten, or be perceived to threaten, populations and socio economic prospects in a developed country, as was the case in Sweden and the UK prior to the universalist Mann/WHO/UNAIDS era, would constraints on human rights and civil liberties be introduced? Indeed, in Allen's view, it would be surprising if they were not, given the challenges rights-based policies can present to some public health preferences for controls (see Introduction at page 7). Are public health professionals arguing for more controls?

For those in Northern/Western environments it would seem not. Sexual health is recognised as a legitimate dimension of the public health agenda. Holistic approaches which seek to foster a social climate more open to speaking of sexual and reproductive health are held to help limit inconsistent messages and facilitate increased access to information and services. Attention to lifting self esteem, particularly in young people, and enabling well-informed decision making and non-judgemental attitudes are characteristic of the prevention strategies which inform and

are informed by a model of sexual health provided by the UK Government's National Strategy for Sexual Health:

Sexual health is an important part of physical and mental health. It is a key part of our identity as human beings together with the fundamental human rights to privacy, a family life and living free from discrimination. Essential elements of good sexual health are equitable relationships and sexual fulfilment with access to information and services to avoid the risk of pregnancy, illness or disease.

(Department of Health 2002)

But strategies based on balancing wide socio-political and individually structured determinants including appropriations of personal and social responsibility can be thwarted by short termism and health service re-organisation and, as Weyman and Davey point out (Weyman and Davey 2007:160), by religious promulgations on sexual behaviour. There is a need to challenge at all levels, they posit,

a growth in fundamentalist movements which poses a real threat to sexual health and which are standing in the way of improvements in treatments and service.

(Weyman and Davey 2007: 164)

Although, then, there is evidence that some approaches to HIV will more readily accommodate traditional conservative religious approaches to the sexual transmission of HIV, professional voices in the (Northern/Western) debate call for religions to bring their theologies and resources to bear on redressing social and economic injustice as much if not more than insisting on (sexual) behaviour change. (Miller 2007, Hunt 2004, Barnett 2004, Campbell and Jovchelovitch 2000, Maoulidi 2003, Chin et al 2005)

Taking notions of inculturation from Christian mission contexts, Johnston goes on to ask whether it may be possible to separate the 'culturally contingent from the theologically essential' (Johnston 2001: 670). Without this separation, he argues, there can be no scrutiny of 'questionable' cultural practices justified on religious grounds

nor their separation from essential core beliefs. In confrontation with militants, he continues, or, it could be argued, religionists of any stripe, without that scrutiny and that separation there can be no legitimate moral claim by any party to the religious high ground. Johnston may have in mind jihadist or crusade-ist, Zionist or millenialist convictions, but, for researchers with an interest in the relationships between religions, culture and HIV/AIDS, it will be female genital mutilation and sexual and gender inequalities which claim a particular significance. For the authorities governing and requiring such practices and controls, it may be argued, are rooted in cultural rather than religious traditions.

Johnston appears to regard the issues he raises primarily in terms of Western (USA) Enlightenment over against the un-enlightened, un-reformed, pre-modern rest of the world. He acknowledges that accusations of cultural imperialism are inevitable in any advocacy of globalisation (as does Beyer 1994) or any imposition of secularist individualism's democracy over communitarianism, secular or religious. However, in his assessment of the pre-modern/modern disputes Johnston suggests it may be possible to open doors to mutual understanding, and, in a world of ever increasing diversity, give religion a reconciling role. Indeed, he exposes the potential for greater collaboration which could emerge from deep multi-sectoral theological dialogue.

Many of these seeming opponents of the human rights agenda are actually quite sympathetic to its underlying themes of justice and human dignity and could likely be turned into allies if the agenda were articulated in a way that is consistent with their religious and cultural norms (Johnston 2001: 671).

Some agreement among religious groups on the basic principles of social justice and the common good might be possible - indeed Hans Kung's work on a global ethic has taken the form of a Declaration of the Religious for a Global Ethic and was endorsed by the Parliament of the World's Religions in 1993 (Kung 1993). However, issues of human sexuality, the status of women, fertility, community power structures and HIV continue to defy consensus. As Strassberg (2003) points out, the 'knowing' on which ethical decisions are made may not be true. Further, how can religions' own intra and inter faith diversity respond with integrative force to a multitude of realities and develop a collaborative approach to cultural, social and political consciousness in

order to secure ethical competence? In an introduction to papers from a symposium called to explore 'The Potential of an Interfaith Science-Religion Dialogue on HIV/AIDS', the theologian James Moore (2003) asks whether, given the shifts in scientific understanding and the ever changing complexities of the relationship between the micro and macro units of global, local and environmental aspects of human experience, religions can re-appropriate traditional theologies to take account of such scientific and ethical diversities. According to Moore testing any reappropriation against the realities of an HIV/AIDS pandemic compounds the challenge.

Johnston is certainly positive about religions as peacemakers and as such being a positive force for change. He proposes the appointment in civic and diplomatic contexts of chaplains, religion-literate individuals. They would build relationships across sectoral, institutional and organisational boundaries and advise on cultural and religious dimensions and implications of decision-making, pro-actively identifying points of potential or actual tension and disagreement. Such calls for inter sectoral collaboration and dialogue find echoes in Marshall's World Bank report (2004) and in Karnik's call to bridge the gap between HIV as a socio-economic and political issue and HIV as a moral issue (2001). They are also in line with Moore's call for the morally and scientifically literate individual to effect necessary dialogue and change (Moore 2003).

Though innovative at national and international levels, in institutional environments Johnston's suggestion is a not unfamiliar model in well-established micro-chaplaincy contexts of local health, education and social movement organisations where individuals as agents and conduits of information exchange and trust-building can become catalysts for change and moral action (Petchey et al 1998). In Leicester it has been developed uniquely to meet support and awareness-raising needs in some local contexts of religion and HIV. The experience of global players, including Christian Aid and CAFOD, may point to similarly innovative models for their work in parts of the world with a high prevalence HIV epidemic. However, it is clear that any interrogation of globalisation's contributions to religion/HIV phenomena raises further questions about the preferred and most effective approaches to HIV (biomedical or social, exogenous structural impositions or collaborative community

development, universal rights-based or culture- and context-specific, religious or secular, for example) and about issues of, and responses to, global inequalities, and whether any analysis offers religion a significant and positive role in HIV prevention and care.

Inequalities, religion and HIV

According to Mary Hunt (2004) vulnerability to HIV predates the arrival of the virus. Referring to Dr. Jonathan Mann (1994) the founder in 1986 and director of the World Health Organisation's Global Programme on AIDS, Hunt notes that 'how we define a problem determines what we do about it'. For Hunt and Mann the realities of the pandemic are rooted in the worldwide inequities and prejudices of fundamentally uniust mainstream economic, social, cultural and political infrastructures. Tony Barnett, in a paper entitled 'HIV/AIDS and development concern us all' (2004a), as well as decrying the (at that time) scant engagement, particularly long-term engagement, of development and economic studies with the HIV/AIDS pandemic, also recognises that vulnerability to the impact of HIV will vary according to resources available and perceptions of the realities. These are the issues, Hunt argues, with which religions should be engaging in their responses to HIV. For her 'HIV/AIDS is a mirror reflecting injustice' (Hunt 2004: 471). If this is the case international efforts to reduce the gulf between rich and poor nations and to further human rights have a direct impact on efforts to address the global impact of HIV/AIDS.

Hunt's radical call to the religions for a moratorium on discussions about sexuality may be unrealistic given the diverse range and nuances of world views. What is more, that diversity and the psychological responses to self and other it generates may be the very factors constraining the shift Hunt commends. How far calls for a focus on issues of international and community development, supposedly less contentious for religious groups than issues in the sexuality debates, would generate a more conclusive and positive response to HIV is open to question. If Hunt's assertion that 'theology tends to reflect and serve the needs of those in power' (Hunt 2004: 469) is correct, religious institutions themselves, in weighing where their interests lie, may be unable to guarantee the bias towards the poor and excluded Hunt is inviting, given the weight of resistance to hegemonic re-alignment. Multi-dimensional themes of

authority, power and control are emerging as key components in collective responses to HIV. Whether they assume a role in individuals' responses will be discussed below at 'Identity, religion and HIV'.

In urging an application of Stuart Hall's (1993) model of hegemonic categorisation to the globalisation of disease and with special reference to the emergence of the HIV/AIDS pandemic in India during the nineteen eighties and nineties, Niranjan Karnik's study, 'Locating HIV/AIDS and India: Cautionary Notes on the Globalization of Categories' (Karnik 2001), traces the global movement of medical and scientific approaches to HIV and argues that biomedical scientific appropriations of meaning in disease become partial and inadequate when socio-cultural discourses and critiques are excluded. Referring to Hall's 'influential tripartite division of discourses into dominant hegemonic, negotiated and oppositional categories' (Karnik 2001: 325) Karnik confronts India's largely unquestioned importation of established, predominantly western characterisations of high-risk groups. He demonstrates how the hegemony of a western scientific HIV narrative was drawn uncritically into the dominant Indian metanarrative.

That western narrative defined (some would argue continues to define) global responses to HIV by asserting and positioning a first world, sometimes colonialist didactic, over against 'exoticised', 'sexualised' third world populations regarded as generators of disease. As an example Karnik points out that early Indian (though western), medical scientific responses deemed injecting drug use and sex between men, the targeted risk groups of western HIV prevention strategies, to be the behaviour of foreigners and so ruled out those groups as being neither valid subjects for research nor noteworthy as agents of transmission in Indian contexts. Similarly, David Arnold's account of sexually transmitted diseases and HIV/AIDS in modern India addresses the impact of British colonial rule on an independent India's approach to the prevention and treatment of sexually transmitted infections. His description of the Indian establishment's response to the arrival of HIV introduces a perspective which, while chiming with Karnik's account, is embedded more deeply in historically shaped and bound oppressions and disputes.

The legacies of colonialism and big power bullying die hard, and in seeking to maintain its independent status in medical as in other matters, India was loath to let its health care priorities be dictated by the West and by what was seen to be Western media and medical hysteria about an essentially 'Western disease'. India's political leaders, medical establishment and middle classes treated with complacency, even disdain, the idea that a pathogen identified with homosexuality and decadent 'gay' lifestyles could find a home in India: It was a white man's disease and not unfitting retribution for Western immorality.

(Arnold, 1997: 25)

HIV/AIDS was a foreign disease and prevention was to involve screening visitors from the west and Africa and avoiding sexual contact with foreigners. It is as if, at this stage, India is eschewing, for historical reasons, Western-defined approaches to HIV prevention and is determined on an India-specific response. But, according to Karnik, the hegemonic model remained intact, though historically if not culturally conditioned, as prostitution rather than homosexuality contextualised and defined targets of screening and investigation. The wider impacts of gender inequalities and poverty were not considered. Some prevention and care initiatives helped some women and their clients protect their health but, as Karnik points out, the opportunity to revise and, he would argue, make more effective, the relationship between narratives by incorporating the local negotiated and oppositional categorisations, is missed. In other words, more relevant risk factors remain hidden. Locally rooted and defined responses are denied when comprehensive socio-economic, demographic and cultural analyses are absent or partial and subordinated to dominant hegemonic, often though not always western scientific, HIV narratives. But in heeding calls for a more democratic approach, there lies the risk of endorsing religio-cultural-specific responses to HIV which may be in tension, if not in conflict, with public health principles of universal access, accurate information and consistent messaging.

Karnik's reference to research populations raises a particularly salient issue. HIV prevalence is generally higher among socially, economically and politically marginalised groups and research into their experience is arguably desirable, not least when improved services and wellbeing are the goal. Karnik's application of Hall's categorisations sheds light on hegemonic influence in HIV research. Mary Hunt

(2004) draws attention to the multi-national pharmaceutical industry and its unregulated selection of research populations. She points out also, that, in the USA, clinical trials are twice as likely to be conducted among white participants as among those communities where HIV is increasingly more prevalent, African American and Hispanic. On the other hand, vulnerable groups and individuals, not always easy to reach but widely identified and often liable to blame for transmission of HIV into the wider community, risk being subjected to burdensome and intrusive studies. Their lack of power and limited choices can render them 'exotic' and subject to disproportionate and inappropriate targeting as research populations. Such issues enter the field of research ethics primarily in the somewhat narrow and localised terms of research design and conduct (Ryen in Truman et al 2003, McLean and Campbell 2003) but Karnik (2001) and Hunt (2004) in their different ways bring alternative perspectives out of which there emerges a demonstration of the ease with which HIV, as both lived experience and as research topic, both masks and exposes the fault lines in any nexus of social power relations.

Responses to globalised HIV disease according to Karnik were wearing dominant western hegemonic clothes and shutting out socio-economic analyses of risk and the identification of alternative risk groupings. In India this top-down approach has been challenged, though not totally condemned, by progressive activist Shivananda Khan of Naz Foundation International. Karnik sees Khan's approach as a combination of Hall's (1993) hegemonic and oppositional categorisations, neither fully one nor fully the other and occupying the negotiated space. Karnik regards the combination in positive terms. In his view it enables an interface where it is legitimate to acknowledge, if not authorise, both the dominant, that is western, meta narrative in fields of global medical significance and the simultaneous development of a situational narrative bearing relevance and meaning to the local. It is, in effect, a necessary compromise. However, although broadly in line with Karnik's position but located in a different cultural context, Catherine Campbell's study (2003a, 2003b) notes the failure of a 'state of the art' multi-agency, grass roots led HIV prevention programme in a South African mining community. Her account, like Khan's, is persuasive and suggests that complexity and compromise assume a higher profile in HIV prevention and care programmes than even Karnik's 'cautionary notes' advise.

Campbell's South African programme (2003a, 2003b) was informed by social psychological perspectives and the kind of self reflexive medical scientific approach to difference and variability advocated by Karnik. It was designed and managed by a group of local residents in partnership with a multi-sectoral team including doctors, traditional healers, trade unionists and representatives of the national health department. But it broke down. Campbell's assessment of the project's failure points to issues of inadequate management capacity and intra group conflict. Of particular interest, though, in the light of Karnik, are her calls also for a reduced emphasis on bio-medical approaches to HIV prevention and more holistic emphases on social and cultural environments.

Much of Campbell's work is concerned with social change and public health. In a collaboration with Sandra Jovchelovitch (2000) she noted the continuing failure in both developing and developed countries to eliminate determinants of health characterised broadly as social exclusion. With simple divisions between richer north and poorer south complicated by globalisation Campbell and Jovchelovitch urged that attention be given to the contextualisation of and engagement with the local and the analysis of its particular exclusionary forces. Although health promotion theory takes serious account of poverty and material deprivation, in addition gender, disability, sexual orientation and ethnicity are to be included as indicators of exclusion and subjects of empowerment (Beeker et al 1998). There may be a case, also, for insisting that religious affiliation be factored into a community analysis. Pfeiffer, in a Mozambique-located study, concluded that it is in approaches to environments of healing, and in these he included what he named 'healing Churches', that the realities of community crisis are discerned (Pfeiffer 2002).

Despite their omission of references to religious influences, Campbell's with Jovchelovitch's commendation of community development and participation over exclusively biomedical and behavioural models resonates with a number of other studies (Stillwaggon 2002, Hunt 2004, Barnett and Whiteside 2002, Marshall 2004, Agate et al 2005, Maoulidi 2003, Beeker et al 1998).

Within the area of health promotion, in particular, recent years have seen 'a paradigm drift' away from biomedical and behaviourally oriented

interventions and policies towards a community development perspective.

(Beeker et al 1998 in Campbell and Jovchelovitch 2000: 256)

However, in her assessment of the failure of the South African mining community HIV prevention project, Campbell's discussion and conclusions suggest that a complex interplay of social stratifications of power and authority can frustrate even predominantly grass roots led multi-faceted community-specific initiatives. Karnik may have asked how can, in relation to one another, the dominant hegemonic, negotiated and oppositional narratives optimise the efficacy of HIV prevention initiatives.

Hall's categorisations of concepts posit the conservative and traditional, the bounded and the orthodox in the realm of the dominant hegemony. The negotiated and oppositional narratives are to be authored by the variable, the marginal, the different and the other. The former, Karnik notes, are in constant tension with the latter, threatening destabilisation and displacement. Applied to a religious context like Leicester's in which eastern and western, northern and southern patterns of cognition and relation seek to co-exist in harmonious community and respond to a sensitive public health issue, the categorisations expose hegemonic difference in new and sometimes uncomfortable ways; uncomfortable in that the question 'which category?' may challenge expectations.

Picking up a point already made above and noting religion's professed bias towards the poor and advocacy of the marginalised, a place in the negotiated/oppositional tent could be anticipated. And yet, although Karnik and others conclude that poverty is the global link in the HIV/AIDS experience, some will argue that, with HIV, those negotiated/oppositional narratives articulating the needs of the poor and excluded appear, paradoxically, to inhabit more often the dominant hegemonic territories of western scientific public health policy and human rights-based protocols (given global voice by UNAIDS' and WHO's strategic positioning and influence) than those of either majority-religion institutions or religio-cultural minorities. Why are so many religious groups expending their resources on bolstering prejudice towards sexual minorities and the subordination of women, the groups most affected by HIV, rather than scaling up efforts to reduce poverty, promote and protect human rights and

further peace? This hegemonic confusion, exacerbated by socio-economic inequalities and conflicts, has been discussed with primary reference to macro levels of international politico-institutional relations and economic development. Questions remain concerning how far it connects with the micro realities of religious believing, personal identity and HIV transmission.

Identity, religion and HIV

With their focus on a social psychological framework for participation and attention to 'social identities, social representation and power', Campbell and Jovchelovitch's work (2000) merits further examination as conceptualisations of identity move into the frame. For Campbell and Jovchelovitch those who and that which express and inform the local, its 'realities' and 'systems of knowledge' (2000: 258), are to be central to community development initiatives. Dialogue, they argue, between local knowledge and traditions and the so-called 'dominant' knowledge of health promotion and development professionals and institutions is to be encouraged in efforts to raise awareness and empower the local and the excluded to participate in, if not generate, action for social change. This process finds echoes in Paulo Freire's calls for conscientisation (1977, 1985), a connection which surfaces also in other aspects of this literature review.

Weaknesses are discussed, particularly those relating to intra-community marginalisation and exclusion (Campbell and Jovchelovitch 2000: 263). So limits to participation are acknowledged, but the authors make no explicit reference to the involvement, or non-involvement, of religious groups, even though it is known that some religious groups are significantly non-representational in their structures and leaderships with, in some contexts, the exclusion of women and young people a commonplace. However, in this regard, of particular significance to HIV prevention and care are the authors' warnings about idealising local knowledge and the need to allow for, and be alert to, differing if not competing realities and representations.

It is necessary to ask questions about the condition under which participation is enacted. These questions point to the power differentials between different social actors and to how they may have unequal access to the material and symbolic resources most likely to equip them in forcefully negotiating projects

(Campbell and Jovchelovitch, 2000: 266)

Although mindful of diversities within communities and of the need for negotiation Campbell's and Jovchelovitch's discussion does not ask how the health needs of the stigmatised are to be met when the risk of further exclusion and marginalisation may be the unbearable result of raising one's voice. People with HIV fall into this category, in particular, women and children, sexual and other minority groups. The paper argues that the participation of communities of the marginalised in conscientisation initiatives increases the potential for a reduction in health inequalities, but the formation of communities of activists with HIV in low prevalence settings, particularly conservative and religious settings, can be notoriously difficult to achieve let alone sustain (a reality to which Leicester's early response to HIV attests – see Chapter Three at page 97).

Advocates may be the answer but advocacy risks collusion with a discredited top-down approach to health promotion and the reinforcing of existing barriers to the inclusion of people with HIV and the creation of new limits to their participation and self-representation. The capacity of marginalised individuals to reconstruct religious orthodoxies in the interests of social change and access to participation may be limited (Hunt 2004: 469). However, it can surely be argued that a failure to note religion's influence, both in its orthodoxies and in its subversions, in shaping identity and asserting conformity places constraints on applications of theoretical and practical propositions. Whether or not of the kind posited by Campbell and Jovchelovitch, those applications, in their constraints, will then risk losing sight of dominant players in constructions of and responses to reality.

Working with different populations and from different perspectives both Andrew Yip (2005) and Kristin Aune (2006) address issues of hermeneutical reconstruction and its attendant self-negotiation. Yip's research with non-heterosexual Christians and Muslims and Aune's with Christian evangelical heterosexuals assess the ways

⁹ This is Yip's term. Acknowledging it is contentious, he argues for its use by asserting its dissident quality in contrast with 'heterosexual'. He decides against 'lesbian, gay and bisexual' on the grounds that principles of inclusivity require the addition of other 'labels'. Yip uses non-heterosexual to represent all the identities in his study: 'lesbian', 'gay', 'bisexual', 'homosexual' and 'queer'.

individuals create coherent meaning and identity in those religious contexts which assert strict conformity with orthodox teachings on gender roles, sexual identities and intimacy.

Yip's paper is the more detailed in its considerations of biblical and Qur'anic texts and their significance in the historic constructions of human sexuality. He describes the diverse ways in which sexual minorities seek to manage the tensions between their non-heterosexuality, their religious beliefs and their religion's role in reinforcing their exclusion and stigmatisation. Strategies involve the publication and increased use of sexuality-affirming texts, hermeneutics and liturgies. Yip compares the scope for giving non-heterosexual religious identity an authoritative place in Christian theological discourse with the limited options presently available in Islamic texts and culture. In his analysis of data drawn from two studies involving interviews with lesbian, gay and bisexual Christian (n61) and Muslim (n42 and two focus groups) men and women, Yip concluded that the approaches taken by participants to reconcile the 'seemingly contradictory sexual and religious dimensions' (Yip 2005: 51) of their identity, their social relationships and support networks can be described as 'Defensive', 'Offensive' and 'Creative'. In broad terms, and significantly more prevalent in Christian than in Muslim contexts, these involve

- appropriating and expounding alternative theological interpretations;
- exposing, challenging and re-interpreting hermeneutic hegemony;
- ascribing non-heterosexual characterisation and identification to the texts or, using Yip's terminology, 'Outing' and 'Befriending' the texts
 (Yip 2005: 56).

The defining connection between all three according to Yip's argument is the emergence of personal experience and the self as principle reference points in the making of religious meaning, truth and nurture. It is this process of hermeneutical deconstruction and reconstruction constituting a self reconciliation or new coherence which tracks aspects of Aune's work.

Kristin Aune's study involves a highly conforming congregation of Christian evangelicals with a leadership committed to traditional conservative gender roles and to marriage between a man and a woman as the only model for intimate sexually active relationships. Aune set out to explore the impact on evangelical Christians, married and unmarried, of contemporary secular influences on gender roles and expectations. Aune's data was drawn from participant observation and interviews with most of the twenty-five members of a small congregation in the UK. Her analysis places appropriations of the primary evangelical notion of 'headship' alongside postfeminist theory. The former, often interpreted as sacrificial service, insists on the leadership, decision-making and ultimate authority of husbands. The latter describes the concept which holds both to feminist ideals and, at the same time, a former non-feminist gender order.

Aune sets out to test how far postfeminist tensions – feminism's coexistence with tradition's backlash - characterise evangelical marriage. She found that male headship is interpreted and practised variably according to the relationship and may not involve significant role differentiation. Describing those marriages as 'postfeminist partnerships' (Aune 2006: 654) Aune advances the notion that postfeminist individualisation is evident in the evangelical congregation she investigated. Although less individualised than those who are less religious, egalitarian secular influences are filtered through biblical texts and teachings to create, according to Aune, a self reflexive appropriation of evangelical belief. This elevating of the heterosexual evangelical Christian self into a position of hermeneutic authority chimes with Yip's findings above for non-heterosexual Christians and Muslims.

Questions can now be raised as to how far the need for reduction or avoidance of dissonance can be stretched? Are the drivers for coherent identity and belief or world view birthed in Freire-like processes of conscientisation, in the cultural, secular and/or religious mediation of normative relationships and identities or in the stuff of personal experience and history? Does cognitive dissonance *per se* drive personal and socioreligious change or does coherence reside in and emerge from a multiple-identity-related religious incongruence (Greenwald and Ronis 1978, Festinger et al 2008, Jaspal and Cinnirella 2010, Chaves 2010, Read and Eagle 2011)? Similar questions about the displacement and assimilation of beliefs in Kenya and other African

countries are raised by Heald (in Ellison et al Eds, 2003). Citing Mwanzo (2000) and drawing on Peel (1977) she asks whether in those African contexts religious believing is to do with conversion *to* or conversion *of*. How do religious people respond to HIV? How do people with HIV appropriate religious belief?

Religion and people living with HIV

As noted above (at pages 33, 34, 37, 38 and 39) a number of authoritative studies explore religious responses to HIV. The majority relate to Christian contexts with many focussing on American or sub Saharan African experience. Recent publications include studies and reports from the Middle East and South Asia (El Feki 2006, Iriyama et al 2007, Todd et al 2007, McGirk 2008, Mohammadpour et al 2009, Hazarika 2010, Rahangdale et al 2010, Tocco 2010, Kostick et al 2011, Machine 2011) Many, not all, papers expose a conservative traditional approach based on that which is regarded by most leaders and members as orthodox teaching and practice. HIV is deemed primarily a result of proscribed sexual behaviours and those who hold such beliefs will often respond to people affected by HIV in prejudicial and discriminatory terms. Robert L. Miller's paper (2007) incorporates various aspects of these several dimensions and offers an insight into the experience of African American church members living with HIV

With a qualitative approach, Miller discusses the relationships between that which he describes as an homophobic, AIDS phobic, heterosexist Christianity and ten African American men living with HIV. Using in-depth interviews he traces the men's religious affiliation and their eventual rejection of the Black Church. Miller's study reports the interviewees' experiences of close and long term largely active, familial and historic ties with their churches and a regular condemnation from the pulpit of same-sex relationships. A growing awareness of their own gay identity and the forming of relationships, some with other gay church members, would result in an integrative process which enabled an accommodation between their church affiliation and their sexual identity. Ultimately it was their churches' attitudes to HIV/AIDS which determined the break which all the interviewees made with their respective churches. The primary purpose of Miller's study is to inform social workers of the vulnerability to oppression and loss experienced by African American gay men with HIV/AIDS. He points out the difficulties social workers face, particularly African

American social workers, in spite of their advocacy experience and sensitivity to the vulnerability of marginalised populations, in challenging religious organisations and their leaders concerning homophobia, heterosexism and AIDS phobia.

Challenging black clergy about their theological position on homosexuality may constitute a paradigm shift for African American social workers. For some workers confronting black clergy may feel like confronting 'God's messengers'.

(Miller 2007: 59)

Like Yip and Aune, Miller also introduces wider questions of theological and sociopolitical and social psychological interest. He notes the various responses of Black American churches to HIV/AIDS. While some will provide support irrespective of the nature of need, some cannot engage meaningfully due to those particular dogmatic biblical and doctrinal interpretations and approaches which endorse homonegativity and heterosexism. Others find ways of negotiating the tension between a wish to sponsor HIV support services and prevention education and a concern about supporting, in their view, an unacceptable lifestyle. It is a tension, nevertheless, which Miller notes 'diminishes effective service provision' (Miller 2007: 53). He attests to the highly negative impact of homophobia and heterosexism not only on the selfworth and self-esteem of gay church members and those 'who love them' but also on the ability of Black American gay men to engage effectively in HIV prevention and care. Miller's explicit link between the incompatibility between religious oppression and the undermining of public health approaches to HIV prevention and care is noteworthy. His examination of the dichotomy between a church's commitment to liberation and justice and its oppression of sexual minorities touches a serious debate and in identifying the protagonists as theology and social justice and the victims as public health and personal dignity Miller acknowledges the need for further research.

Pamela Leong (2006) also encounters the tensions elucidated by Miller. Her study explores a model of Christian believing and belonging for African American people with HIV alienated from religious ideologies and institutions prejudiced towards their health status or lifestyle. Unlike Pargament et al (2004) who concentrate on programmatic solutions to religious coping and Tesoriero et al (2000) who use

descriptive statistical methods to uncover churches' roles in HIV awareness and service provision, Leong's ethnographic focus relates to a particular congregation's socio-cultural strategies for reconciling religious struggle and conflict. The congregation's members are predominantly African American lesbian, gay, bi-sexual and transgendered people and the church, located in south Los Angeles and known as Unity Fellowship Church, was founded by an openly gay pastor in 1982 with the primary purpose of responding to the religious and spiritual needs of gay and lesbian African Americans. The pastor also founded the Minority AIDS Project (MAP), understood to be the first community-based HIV support project for black people. Leong finds that social, economic, cultural and religious marginalizations are common and shared experiences of Unity church members. The clergy estimate that between twenty and fifty per cent of church members live with HIV though in earlier years many more church members were living and dying with AIDS.

The church's ideological and theological base is a radical liberation theology. Its principles, consonant with freedom from oppression for all, govern the work and worship of the church. Leong ascribes to the church leader a fundamental re-working and revising of traditional Christian ideologies, concepts of God, rituals and hermeneutics. As a means for encouraging dialogue and open discussion, taboo subjects, not least sex and sexuality, are often addressed during sermons. Leong takes the view that inclusive language and a teaching that acknowledges religion's propensity for oppressive and violent outcomes raise awareness of that which is suppressed and helps open the way for transformation and a coherent believing based on self understanding and appreciation rather than on condemnation. Some dissent from the generally wide support for Unity's approach came from a transgender member who thought the church was 'a little too liberal...' (Leong 2006: 306). She was concerned that the behaviours of some members were not consonant with Christian teaching and that this perpetuated the notion among mainline churches and outsiders that 'gay-affirming churches such as Unity' were 'inauthentic and illegitimate...promoting wanton sexuality and other "irresponsible" behaviours' (Leong 2006: 307). These comments expose a significant tension which Leong addresses in a brief analysis of responses to difference.

Referring to Lorde (2000: 503), she anticipates difference will be handled in three ways: by ignoring it, by copying it when it is deemed to be dominant and by destroying it when it is deemed to be subordinate. But Leong noted other responses at Unity. Difference was redefined, legitimised or resisted. With echoes here of Yip's 'creative', 'defensive' and 'offensive' strategies, Leong observed how religious contradictions were subjected to a creative theological revision which helped establish an affirming harmonisation between individuals' identities and beliefs. Leong takes the view that such a redefinition constitutes a dismantling of mainstream theologies and practice rather than, as marginalised liberationists struggling to transform mainstream traditions would see it, a shift, albeit definitive shift, in theological, ideological and political connections and emphases. She ascribes to Unity a unique legitimation of difference, a legitimation most evident in the support for the 'nonnormative' (Leong 2006: 308) relationship or identity. Resistance, she notes, took the form of continual open opposition to mainstream religious discourse and culture. In conclusion Leong acknowledges the marginality and the authenticity of the Unity church and its success in meeting the spiritual and social needs of its oppressed members and calls for Unity to serve as a model for other religious institutions.

American religion, predominantly Christian, is accustomed to competition, to creating and exercising choice, a product of modernity which has been named rational choice theory or RCT (Davie 2007). Leong's account of Unity's history and her readiness to urge Unity Church as a model for other religious groups suggests a familiarity with religious innovation which resonates with and points to sociology's RCT. According to RCT the wider consumerist influences of economic and cultural choice common to global capitalism and a paradigm of individualism extend to American religious allegiances at all levels. The opportunities to establish idiosyncratic churches will be culturally feasible. 'If one church does not suit me I will find or establish another'. A western continental European model of secularisation theory, however, conforms, in varying degrees according to the particular context and history, to the notion that increasing modernisation means less religious believing.

The British experience sits between the American and the European, with elements of both in its religious life. But changes in peoples' appropriations of religion are occurring in European societies. 'Belonging without believing' gives way to

'believing without belonging'; obligation gives way to consumption and voluntarism, and then Davie's notion of vicarious believing (Davie 2007) begins to characterise religion's relationship with some, not all, European populations. Analyses of data and any discussion generated from an American research base and context are to be considered by non-American readers with these differences in mind. Limits on institutional choices, whether perceived or actual, for example, may account for the need felt by Yip's and Aune's interviewees' to reach a self-referential hermeneutical equilibrium, or dissonance reduction (Rosenfeld 2010), within their existing religious context. The interviewees may have felt there was nowhere else to go.

Many studies of the religion-HIV relationship offer an American Christian focus. There are also those which explore or, at least, include, Asian, Pacific Islander, Buddhist, Hindu and Muslim responses to HIV (Chin et al 2005, Genrich and Brathwaite 2005, Ghalib and Peralta, 2002, Tesoriero et al 2000). The identification of tensions between religious teachings and HIV's association with sex and sexuality is noted in a number of investigations (Corbin et al 2009, Griffith et al 2010).

Chin et al's study is the more unusual in that it demonstrates the innovative potential and motive to change within a conservative religious setting. With four organisational dimensions of a prevention framework which Chin et al identified as 'community need', 'organisational purpose', 'external acceptability' and 'internal acceptability' they applied organization development and change theory to facilitate religious engagement with HIV. Some responses to HIV and the need for integrated prevention and care strategies, the authors pointed out, will be ill-informed and contradictory and that even some of those seemingly open, more informed responses may emphasise that information messages would have to conform to religious teaching about sexual behaviours, creating potential for conflict with public health messages about HIV.

Chin et al argue that this potential for conflict, or, what may be described as cognitive dissonance or schema maladaptivity in pshychotherapeutical discourse (Young 2010a, 2010b, Hull 1991, Festinger 1957, Young et al 2003), could itself generate innovation. If new information indicated that some of the most effective methods for preventing HIV included non-judgmental consideration of forbidden sexual behaviours and the required levels of tension were created between desires to meet the community's

needs on the one hand and to maintain the tradition on the other, organisational change could follow. An intervention is suggested involving 'internal change agents' (Chin et al 2005: 500). These 'change agents' would be those to whom other members of the organisations could turn for advice, an interpretation or teaching and support (Eng and Parker 2002, Kelly et al 1991, Kelly et al 1992). This suggestion chimes well with ideas posited by Johnston (2001), Petchey et al (1998), Marshall (2004) and Moore (2003) of community or organisation-based individuals or 'chaplains' who could facilitate multi sectoral partnerships and discretely cross institutional boundaries.

There are other studies also from contexts where religions other than Christianity characterize the enquiry. These include Bharat and Aggleton (1999), Gibney et al (1999), Gifford et al (1999), Gray et al (1999), Bhattacharya (2004), Esack et al (2004), Gray (2004), Clifford (2006), El Feki (2006), Gańczak et al (2007), Talukdar et al (2007), El-Sayyed et al (2008), Aga et al (2009), Esack and Chiddy (2009), Abu-Moghli et al (2010) and Hazarika (2010). Salma Maoulidi's study (2003) presents an Islamic perspective and a female response to female needs.

Maoulidi is a lawyer and the founder and Executive Director of a Muslim women's organisation, the Sahiba Sisters Foundation. With reference to a specifically Tanzanian context, her paper (2003) makes visible the needs of Muslim women in HIV prevention. She points out that HIV prevention programmes in Tanzania focus on four main themes: condom use, monogamous relationships, reduced number of sexual partners and treatment for sexually transmitted infections. These prevention messages, with commercial sex workers (CSWs) and adolescent girls at school as the main target groups, are widely disseminated via various communications media including health professionals and peer educators. Resonating here with Karnik's (2001) paper above, Maoulidi notes how, in her view, Tanzania's strategic combination of prevention themes and target groups ignores wider socio-economic and cultural contexts and diversities, and excludes other vulnerable groups, not least the country's Islamic communities and, more particularly, Islamic women. She points to the potential for immediate alienation between state and public health governed prevention programmes and Islamic approaches when any promotion of condom use is seen by religious leaders as promotion of casual sex and in conflict with moral

teaching. This pushes the religious leaders (not only Islamic) to make counter claims about the efficacy of condoms in HIV prevention and masks other more significant aspects of the prevention debates, especially those which relate to women.

The efforts of the Islamic women's development network, Sahiba Sisters Foundation, have encouraged the Tanzania Muslim Supreme Council to adopt an HIV/AIDS programme. Reported by Maoulidi as not fully operational and only able to provide voluntary support for people with HIV, she draws attention to the continuing absence of opportunities for the Islamic community to respond to 'the pandemic in a meaningful way' (Maoulidi 2003: 376).

Maoulidi notes the traditional reluctance to address issues of sexuality, risk behaviours and reproductive health. She argues that the exclusion of women from the forums where decision making and religious debates are conducted perpetuates women's vulnerability to HIV. It is noticeable that a number of issues she considers in depth receive limited attention in other studies addressing HIV transmission and prevention in Islamic contexts (Gray 2004, Gatrad and Sheikh 2004, Gańczak et al 2007).

- Women are more vulnerable to infection than men;
- as mothers and grandmothers women are the main care givers of infected individuals and families;
- family honour requires Muslim girls to be married young and with no information on sexual or reproductive health they will have limited, if any, rights to ensure unhealthy and/or harmful behaviours are not practised (whether or not in the name of religious requirements):
- women's personal and sexual rights are unclear and their access to institutional clarification is restricted; consequent tensions between protecting their health and maintaining religious conformity and obedience impose additional burdens on the women and their children;
- Qur'anic interpretations can increase the vulnerability of women: emphasis on the legitimation of polygyny without a corresponding emphasis on restrictions

- and responsibilities create a tolerance of male sexual license and place women at risk of STD/HIV;
- girls unable to continue their education will be less able to question their subservient status;
- with limited access to HIV information Muslim women involved in caring for people with HIV and presenting the dead, according to traditional practice and ritual, for burial are vulnerable to inadvertent infection.

In spite of this catalogue of difficulties, Maoulidi identifies several opportunities for change, the main impetus for which has to come, she argues, from Muslim women themselves. Looking to the model being developed by the Sahiba Sisters, Maoulidi urges the establishment of organised groups through which Muslim women can offer mutual support, further their knowledge of and address critically Islamic teachings which restrict their rights, educate and inform one another about reproductive health and HIV and develop their communication and lobbying skills and resources. Maoulidi advocates also the cultural institution of the Somo, an older woman who accompanies a younger woman through puberty to motherhood giving advice and information. In turn the wives could teach their husbands about attitudes and practices harmful to health. Given the wider context she describes, on the face of it, Maoulidi appears to place undue optimism in the efficacy of the Somo mentoring role. The older women may have as deeply an entrenched conservatism as the male leaders of the Islamic community and little interest in any overt intention to build the confidence of the younger women and improve their health and well-being. On the other hand (following Chin et al 2005), a relationship familiar to, and acceptable within, the community and favourable to the leadership, has the potential by default, even within its traditional cultural and religious boundaries, to generate a new concern about health and its links with discrimination.

Maoulidi concludes her analysis by charging the Islamic community with ignoring the UN's follow up International Conference on Population and Development's agreed need for 'information, education, skills, services and social support to reduce women's vulnerability to ill health and serious diseases.' (Maoulidi 2003: 378). In calling for cultural appeals to 'the conscience as a vital step in nurturing the will to

change' as well as for objective approaches to the 'de-politicization of women's lives' (Maoulidi 2003: 379). Maoulidi's final remarks point to the intractability of religious conservatism in addressing the needs of women, perhaps especially, though not exclusively, Muslim women, in a world with HIV.

That Maoulidi makes no reference in her paper to the Islamic practice of male circumcision, usually regarded as a religious obligation, raises some important issues to be considered in the context of religion and HIV. Nnko, Washija et al (2001) investigated the increasing acceptance of circumcision in northwest Tanzania. The study was conducted among the Sukuma ethnic group who, traditionally, do not practise circumcision. Of the Muslim Sukuma twenty six per cent had not been circumcised. Christian Sukuma, whose religion carries no doctrinal requirement to circumcise, had higher circumcision rates. A number of Muslim men regarded some of the more recently introduced Islamic practices, including circumcision, as incompatible with their traditional religion. However, although practice is clearly inconsistent and the picture confused, among the Sukuma men the study found an overall increase in and acceptance of male circumcision. Nnko's paper refers also to women's and men's, school girls' and school boys' beliefs that uncircumcised men could contract and transmit STDs more easily than men who have been circumcised.

In the early years of this century, at the times of both Maoulidi's and Nnko's studies, emerging evidence was suggesting (since confirmed [Roehr 2007, UNAIDS 2007a, WHO 2007] by the results and early closure of randomised controlled trials in Uganda, [Gray, Kigazi, Serwadda et al 2007]Kenya [Bailey, Moses, Parker et al 2007a, 2007b] and South Africa, [Auvert, Taljaard, Lagarde et al 2005]) that male circumcision offered some protection for men against HIV infection from women. Male circumcision is now advocated as a legitimate prevention intervention. But before and for some time after the UNAIDS/WHO endorsement circumcision's efficacy continued to be challenged.

The BMJ 10 March 2007 reported (Moszynski 2007: 498) a study led by Devon Brewer (2007a) which examined data from national surveys of young people in Kenya, Tanzania and Lesotho who had never had sexual intercourse. The circumcised young people were more likely to have HIV than uncircumcised young people. The

researcher concluded that HIV was being transmitted non-sexually possibly through circumcision procedures. Daniel Halperin, at the time a senior research scientist at the Harvard University School of Public Health, challenged Brewer's conclusions (Moszynski 2007) pointing out that groups which routinely perform ritual circumcision have significantly lower rates of HIV infection. Brewer insisted that the resources to conduct circumcision safely were not available throughout most of Africa (Moszynski 2007, Brewer et al 2007a, 2007b).

Clearly, the potential for further confusion and mixed health messages increases with the ever shifting interfaces between modern influences and traditional beliefs. At the same time the vulnerability of women and girls, also men and boys, to infection and their need for access to accurate information and the means to protect their health become arguably more urgent.

Conclusion

Chapter Two's literature review has set out the substantial contours of religioninformed and public health engagements with HIV and the pluralities and the complexities with which they have to contend. Globalisation's impacts have been identified, and the extents and realities of hegemonic dominance in responding to HIV have been raised into view (Mann 1992, Beyer 1994, Johnston 2001). Inequalities and the significances of religio-cultural identity and belonging have been given consideration (Hunt 2004, Aune 2006, Yip 2005). The potential for alliances between strategic public health approaches of both the conservative and social democratic kind and the tensions which can present at international, national and local levels have been explored (Barnett and Whiteside 2002, Allen 2004, WHO Europe 2006, Weyman and Davey 2007). Power relations and the realities of hegemonic dominance were made apparent (Arnold 1997, Karnik 2001). Religious responses to gender and sexuality and several impacts on preventing and living with HIV in a variety of religious contexts have been been discussed (Maoulidi 2003, Leong 2006, Miller 2007). That disputed assessment of ritual circumcision's potential for increasing transmission and confusing sexual health messaging with which the review ended (Brewer 2007a 2007b, Moszynski 2007) starkly exposes the very contestations and associated tensions this study is addressing.

A wide range of cross cutting approaches is offered throughout the literature review with which to question and know religions' relationships with HIV prevention and care. Issues of power and authority, including those attaching to stigma, diversity and identity, emerge as interconnecting themes of analysis. Religious teachings and biomedical systems contest each other's truths. The global and the international, the local and the personal realities of HIV locate the investigation in multiple fields of discourse where a range of realities competing for control of painful histories and uncertain futures can be interrogated. The key themes exposed by the literature review are set out in Table 8 below.

Chapter Three continues with the identification and assessment of the methodological options.

Table 8. Identifying the realities of living with HIV: a thematic map.

Globalization, in	equalities and HIV	Identity/belonging and HIV	Living with HIV	
Scientific, rational and secular v belief in supernatural	Socio-cultural, myth, metaphor, ritual, symbol at risk	Reconstruction of religious orthodoxies by marginalised	Social injustice, inequalities and oppression of women and minorities	
Force for social justice, human rights, civil liberties	Unjust power relations	Negotiated coherence	Justice, compassion and giving voice to the silenced	
Uniformity, increased homogeneity, standardisation	Culture/context specific	Redefining identities in pursuit of power and meaning	Quest for coherent believing	
Exposure of difference	Biomedical v social	Reconciling contradictory dimensions of identity (sexual and religious)	Self appreciation v self condemnation	
Universal, rights- based access	Collaborative community development models	Self as hermeneutic authority, principle reference point in making of meaning	Legitimation or denial of difference	
Dominant hegemony defining sociopolitical and economic priorities	Interplay of complex social, culturally-specific layers of power and authority	Gender roles	Variabilities in moral codes and relational norms	
Exogenous imposition v indigenous control	Dialogue between dominant knowledge and local and traditional leading to social change	Conscientisation (as Freire)	Stigma: protecting, defining, controlling social norms and traditions	
Ideological and philosophical relativising and particularising incl of religion	Education, commercialization, industrialisation		Insider, outsider	
Capitalism, market forces, individualisation	Unfair distribution of resources			

CHAPTER THREE

Methodology

Introduction

The literature review has charted a research terrain characterized by features both discrete and interconnecting: the global and the local, the personal and the communal, the scientific and the existential. In so doing it suggests that the development of an inter-disciplinary understanding of religious engagement with HIV prevention and care which draws on and integrates discourses of anthropology, (social) psychology and sociology can usefully mine the existential epistemologies of religious and public health realities in responding to HIV and shape the development of a new approach to doing theology. It may be reasonable, therefore, to suppose that this investigation will be assembling and juxtaposing such resources to appraise the global and local impacts of HIV and responses, particularly religious responses, to it. It is an approach supremely relevant to the nexus of issues which HIV exposes and with which an investigation into and an analysis of religious engagement with HIV prevention and care must engage and any conclusions connect. It is also relevant to the informing of religion/health partnering in culturally diverse contexts in the delivery of HIV prevention and care.

Hypothesizing that neither public health nor religious responses to HIV are adequate to the multiplicity and complexity of the realities and needs apparent in the literature review, a preliminary research model will be outlined and developed. The various considerations relevant to the design of a research method to facilitate a study heavily characterized, in the diversity of its contexts, conduct and concepts, by a need for both further complexification *and* for specificity are set out below.

Preliminary model

In the light of the literature review and after further reflections on the questions outlined at pages thirty-two and thirty-three the shape and focus of the study become more clearly defined. With an aim of providing an authoritative contribution to the understanding and efficacy of HIV prevention and supportive care policy and delivery in a context of religious pluralism and low prevalence for HIV (low prevalence, that

is, in global terms: <1 per cent in pregnant women, but in UK terms, higher than 1.7 or 2 adults per thousand population [HPA 2011b, 2011c])¹⁰ the study's objectives can be described as

- noting the global and local epidemiological backgrounds and mapping the key issues in and relationships between religious and public health responses to HIV;
- placing issues in a localised context of demographic, including religious,
 profiles and identifying inter- and intra-community points of strength and tension;
- identifying and exploring the various ways local faith groups and their members appropriate and express religious beliefs and teachings in their responses to HIV;
- documenting, analysing and discussing data;
- setting out any implications for public health HIV prevention and care policy and making recommendations to faith communities and other groups and agencies responding to HIV.

Progress would be subject to

- NHS and University ethical parameters and clearances,
- harnessing the resources of both established and new networks,
 secondary and primary research data and
- identifying the discourses of anthropology, sociology and psychology consonant with inter-disciplinary principles of a practical/social theology.

¹⁰ The terminology and measures used to define prevalence levels vary and may often be used in unscientific ways, for example sub Saharan Africa as high prevalence, UK as low prevalence, without reference to or knowledge of scientifically verified epidemiological measures. A UNAIDS publication (2009: 60-70) identifies a low-level HIV epidemic as the 'epidemic state in which HIV has never spread to significant levels in any subpopulation although HIV infection may have existed for many years. (HIV prevalence has not consistently exceeded 5 per cent in any defined subpopulation or in the general population.)' A concentrated HIV epidemic is described as that where HIV prevalence is consistently >5 per cent in at least one defined subpopulation, for example sex workers or men who have sex with men, and is <1 per cent in pregnant women in urban areas. A generalised epidemic will have HIV prevalence in pregnant women consistently recording >1per cent and be firmly established in the wider population. For the purposes of this study the chosen UK measure, a prevalence of >2 diagnosed HIV infections in one thousand, is that at which wider testing policies are recommended (HPA 2011c).

Pursuant to the objectives above, the study was setting out to

- examine, review and contextualise epidemiological, demographic and religious perspectives on HIV as international and local phenomena;
- anchor the study and its findings in a local experience by using small scale purposive sampling and questions ranged in corresponding patterns to gather and record, code and analyse responses to HIV through data provided by questionnaires to local faith group leaders/representatives, semi-structured meetings with small groups of lay people from the faith communities and interviews with local people living with HIV and in so doing enable a range of narratives and perspectives, not least those of people with the virus, to be collated, themed and analysed (Miles and Huberman 1994, Lacey and Luff 2001);
- discuss primary and secondary data, demonstrating any relationships between religious and public health responses to HIV, identifying and discussing interfaces of realities and needs;
- ask how far there is potential for collaboration and partnership in the HIV
 prevention and care initiatives of public health policy and the responses of
 religion to HIV;
- describe contributions to knowledge and any limitations which point to the need for future work.

This outline model was reviewed, developed and refined in the light of the issues discussed below.

Formulating a research strategy – paradigms and philosophies Qualitative, Quantitative

Fundamental to any assessment of methodological value and strength is how far the methods proposed help to complexify and deconstruct perceived realities in readiness for critique and interpretation (Swinton and Mowatt 2006: 167). Many of the studies, both cited and discussed in the Literature Review at Chapter Two (page 37) adopt a primarily discursive theoretical approach in setting out their arguments and drawing

their conclusions, for example, Beeker et al (1998), Johnston (2001), Hunt, (2004) and Karnik (2001). Others have conducted surveys and used statistical analysis, that is, 'quantitative' methods, to test a foundational hypothesis and inform their discussions (Tesoriero et al 2000, Gray 2004). Concerned as they are with capturing attitudes and beliefs, conceptualisations and participant narratives many of the studies discussed at Chapter Two and others relating to religious beliefs and HIV adopt a qualitative or mixed methods approach (Pfeiffer 2002, Genrich and Brathwaite 2005, Agadjanian 2005, Campbell et al 2005). It was anticipated that this study would require a substantially qualitative as opposed to a numerically based quantitative approach (Miles and Huberman 1994: 1, Neuman 1994: 71, 317 ff, Fetterman 1998, Green and Britten 1998), but qualitative methods have their detractors.

With charges of 'unscientific', 'subjective', 'unreliable' and 'anecdotal', questions about validity and rigour stalk any qualitative study, not least in contexts of health and social care where deductive replicable testing of null hypotheses rather than inductive exposure of meanings and experience sit higher in the hierarchies of evidence (Ward, Jones et al 2006, Lacey and Luff, 2001). That, historically, quantitative researchers have struggled to 'acknowledge the limitations of rationalist frameworks' (Bassett and Stickley 2010: 3) is no doubt a factor but Matthew Miles comments

The most serious and central difficulty in the use of qualitative data is that methods of analysis are not well formulated. For quantitative data, there are clear conventions the researcher can use. But the analyst faced with a bank of qualitative data has very few guidelines for protection against self-delusion, let alone the presentation of unreliable or invalid conclusions to scientific or policy making audiences. How can we be sure that an 'earthy', 'undeniable', 'serendipitous' finding is not, in fact, wrong?

(Miles 1979: 591 in Miles and Huberman 1994: 2)

And from Basset and Stickley's Voices of Experience

Historically, in health research, peoples' stories are considered to be the weakest kind of evidence. In Health Talk, however, peoples' stories are offered as expert evidence.

(Basset and Stickley 2009: 3)

'Health Talk' is a mental health recovery project. Participants contribute to Basset's and Stickley's book 'Voices of Experience' (2009) in which narrative is posited as an authoritative evidence-based methodological contribution to health research. These arguments in favour of narrative warrant further consideration.

Narrativist, Positivist

Some of the differences between qualitative and quantitative can be described also using the terms positivist and narrativist. Positivist and statistical approaches to research characteristic of analyses drawn from, and central to, statutory health provision are challenged by those who argue for the inclusion of narratives and perspectives consonant with the diversities of interpretive, comparative and ethnographic accounts (Neuman 1994: 71, 317ff; Fetterman 1998; Kesby et al 2003). For example, in their book, *Narrative Based Medicine*, Trisha Greenhalgh and Brian Hurwitz (1998) point to modern medicine's unfamiliarity with discernment of meaning beyond scientific and diagnostic frames of reference. They urge the merits of story and perception and the place of anecdote in helping to reduce the tendency of clinicians to 'see the expected and unconsciously dismiss the anomalous.'

Since patients almost invariably place their most important experiences – birth, death, grief and illness – within very different narrative streams than do doctors, it follows that doctors and patients often assign very different meanings (and different streams of causality) to the same sequence of events.

(Greenhalgh and Hurwitz 1998: 11)

Those 'narrative streams' will include the many individual and collective histories which inform identity, belonging and meaning. But the reliability and rationality of so-called non-scientific studies may be criticised for being anecdotal and subjective. However, it can be argued that without relational and phenomenological dimensions conclusions remain partial and incomplete, epistemologically biased and potentially discriminatory (Humphries et al 2003, Moch and Gates 2000; Kesby 2003; Denscombe 2010). An argument emerges in favour of employing multiple discourses (for this study anthropology, (social) psychology and sociology) to interrogate data, in particular data from a specific UK source, affirming, thereby, both the earlier more

tentative conceptual framing and direction for the design of this study. Similarly, as noted above at 'Qualitative and Quantitative' (page 74), questions concerning the methodological and epistemological validity of theological conceptualizations and appropriations are relevant also to the study's design, analysis and findings.

Perhaps there were always those who argued that it is not the qualitative researcher's task to take responsibility for 'generalisability' and that 'meaningful knowledge can be discovered in unique non-replicable experiences' (Swinton and Mowat 2006: 43-46), but a widespread commitment to the qualitative paradigm has generated the narrative and dialogical means, significantly the ethnographic and the feminist, by which the perspectives of the many, not least the excluded and the powerless, could take their place in schema of knowledge and understanding. It can now be demonstrated that the methodological scrutiny which has accompanied the development of qualitative studies has initiated a body of work which offers philosophical and practical grounds for the legitimate framing and design of data collection and analysis (Coffey 1999, Richards 2009).

Interdisciplinarity – making epistemological and practical theological connections

These qualitative approaches and their associated challenges have become familiar research issues in social scientific contexts in which the experience and the voice of individuals, groups and communities can now be articulated and interpreted and their contributions to knowledge and understanding assume an authoritative place. The combining of perspectives is being recognized as essential to the development of effective responses to HIV. The introduction to Ellison, Parker and Campbell's collection of essays is entitled 'Learning from HIV and AIDS: from multidisciplinary to interdisciplinarity' (2003). They argue that the synthesizing of multidisciplinary approaches to HIV and the promoting of interdisciplinary engagement are essential to 'understanding the disease in all its complexity' (Ellison et al 2003: 21). Apart from practical theology's expressed commitment to dialogical engagement (Graham 1996: 200), such approaches have been less familiar within the methodological discourses of theology.

This study's interest in the contributions of religious beliefs to the shaping of realities and needs in responses to HIV and people affected by it requires some engagement with theological interpretations. But theology carries its own methodological hierarchies: those between 'systematic and applied or pastoral theologies' (Graham, Walton and Ward 2005: 3). A developing interest in the practical theology of pastoral engagement and reflexive practice has argued for a phenomenological interpretative approach to knowledge and truth and for the blurring of the hierarchical distinctions between traditional systematic theology and the relational dialectics of encounter and narrative. It is an approach which is distinctly qualitative, seeking to 'complexify the world' and 'render the familiar strange' (Swinton and Mowat 2006: 32) in order to influence practice and bring about transformation and change. However, it must be noted here that although Swinton and Mowat provide a comprehensive resource for research design in practical theology, pressing for qualitative methods and interdisciplinary analysis, their arguments and conclusions are rooted in a Christianspecific epistemology and ontology. Although advocating support for 'critical correlation' (2006: 82) and for the social sciences as 'critical dialogue partners' they seek theological grounds to assert the priority of theology over social sciences.

How can a system of knowledge created by human beings challenge a system of knowledge that claims to be given by God? [Author's italics] If mutuality truly means that both parties have an equal voice in the research process and the social sciences can actually override theology on central issues, then the danger of idolatry becomes a real possibility.

(Swinton and Mowat 2006: 83)

As the researcher is drawn to principles of partnership and equality such attempts to privilege one discourse over another give some unease. Furthermore, the multicultural and multi-religious travel of this study and the attendant sensitivities, not least those relating to the researcher's professional role as an Anglican priest, and the need for reflexivity-rich approaches to data collection and analysis, call for a discerning if not sceptical approach to claims, particularly religious claims, of distinction if not supremacy. Researcher positionality has to be forefronted as a constant cautionary check (Denscombe 2010: 302; Gross 2000: 168 ff).

Graham, Walton and Ward in their book 'Theological Reflection: Methods' (2005) also present the development of qualitative method in the cause of theological enquiry and its relationship to and impact on believing and practice. But again, the Christian myth and language characterize the thrust of their arguments and are central to their propositions. This is not surprising given their background and identity as Christian theologians and ministers. However, in the latter part of the book their several radical representations in favour of methodological and hermeneutical openness and dialogical engagement with the secular and the marginalized deliver a shift from the familiar apologetical and missiological tone of Christian theologies (Graham et al 2005: 192 ff). Citing Chung Hyun Kyung's controversial presentation to the World Council of Churches in 1991 where she was criticised for drawing into synthesis a variety of religo-cultural identities (not least those of the marginalized, the indigenous, the different and the female), and Robert Beckford's advocacy of Black liberation theology using culturally distinctive art forms, Graham et al lift into view those anti-dialogical and hegemonically sealing charges of syncretism and failure to advance Christian distinctiveness amid local diversity (2005: 219-222).

Researchers, religious and non religious, require more than the discourses of social and human sciences and existing faith-specific theologies to account for and understand better those research contexts of religious complexity and plurality. A credal statement is one thing, its appropriation and application, in support or denial of a multiplicity of realities, is another. Echoing Hunt (2004), 'Whose theology?' becomes the question when efforts to bring understanding and meaning to various identities and experiences in a diversity of contexts are mediated by religious interpretations and/or confusions.

Efforts to generate and describe shared theologies remain underdeveloped, as do other interdisciplinary collaborations, an underdevelopment given a sociological treatment by Sylvia Walby in her 2009 publication *Globalisation and Inequalities*. In the meantime, research findings, perhaps especially interdisciplinary findings, and the theories and policies that they inform will include no more than a passing reference to theological dimensions of behaviours and outcomes and will, therefore, struggle to secure democratic authority and legitimacy when a significant characterizing discourse, theology, is not, or cannot readily be, incorporated into discussion. These

observations, of course, draw attention again to those questions raised by Beyer (1994) about the relativising and particularizing tensions of religion's place in a globalised post modern world.

In recent years in the UK significant resources have been committed to inter-religious dialogue and encounter in the interests of good community relations, community cohesion and equal access to services and opportunity. For example in the UK there are the Inter Faith Network, the Multi-Faith Centre at the University of Derby, the St Philips Centre in Leicester, the Woolf Institute in Cambridge and professional bodies such as the College of Health Care Chaplains. There are also international bodies such as the World Congress of Faiths and the older Parliament of the World Religions. The theological roots of such initiatives will be planted either in the soil of self-interest or in the theoretical and philosophical soils of discourse, experience and analysis that are social and political science (Weller 2009: 63-81). Inter- and intra-religious conflicts and tensions are initially described and understood using the language of human and social sciences. The theological drivers have been characterized later and in terms largely exclusive to the particularities of their respective religious communities. It may now be time to focus on creating and making visible held-in-common theologies of encounter, community, friendship and solidarity; held-in-common theologies which take seriously the realities of difference, injustice and oppression and engage more fully with the secular in the interests of furthering consensus and bolstering the benefits of public policy and mutual understanding.

With religious diversity and difference within communities and families increasingly the norm how far can the boundaried orthodoxies of religions and theologies and the parameters of social policy or indeed, public health decision-making, claim continued authority at a time when boundaries elsewhere are so often blurring and barriers falling? Mary E. Hunt's feminist approach through the 'Women's Alliance for Theology, Ethics and Ritual' (2004, 2009) represents one commitment to democratic cross-cultural, inter-disciplinary research and Michael Taylor (2006), in his calls for an interreligious 'Social Theology' engaging with secular discourses, another. The question, though, and others like it will surely surface again during the course of this study as the present relationships between social policy, theologies and the common

good present for interrogation in the light of Walby's (2009) claims for and critiques of complexity theory.

Emerging typology

Although subject to further research and reflection and consultation with expert informants, that early qualitative model for the gathering of local data is being affirmed. Ascertaining the responses of faith community leaders to HIV and people affected by it is emerging as a key component of any useful and appropriate localised data collection and analysis.

Training

The design and the conduct of the research was further informed by attending the University and Faculty Based Research Seminars and the research training modules provided by the University Hospitals of Leicester NHS Trust. Subjects included legal rights and responsibilities, research ethics, quantitative and qualitative problem solving, critical reading and thesis writing and preparing for a *viva voce*. In addition advice was sought and training undertaken on the use of SPSS 16 and NVivo 8 software for data recording and analysis purposes.

Funding

No conflicts of interest occasioned by funding issues were anticipated. Applications for small grants from the researcher's professional body and a diocesan education fund were planned (and agreed). Apart from these and a small donation from the bishop's office the study was financed in full by the researcher. Other than the usual research governance and liability arrangements no conditions were applicable and no contracts entered into. While limits on resources would be reflected in the scope of the study, any reduced risk, though not its elimination, of corrupting power dynamics, influence and bias on the conduct of the study and its findings was regarded as ethically and professionally desirable (Neuman 1994: 441 ff, May 1993: 35, Lee 1993:12 ff, 100 ff).

A methodological case study - strategies and outcomes

A useful account of methodological design, conduct and decision making, involving such contexts and issues as those described above, is noted in a particular case study,

driven by the social exclusion agenda and a concern to address ethnic health inequalities, carried out by McLean and Campbell (2003). Centred on an ethnically diverse town in the south of England¹¹, McLean's and Campbell's study set out to explore how recruitment strategies impact recruitment outcomes. They found that resources relating to participant recruitment in diverse populations were scarce and especially so in a UK context and for small scale studies. Noting that much of the literature fails to address the heterogeneity of ethnic, cultural and social identities within communities McLean and Campbell stressed the need on the part of researchers for extensive cultural knowledge and sensitivity when designing recruitment methods. Drawing on socio-cultural theory and attending to local networks and influences they examined factors affecting community participation in three ethnic groups - African-Caribbean, Pakistani-Kashmiri and white English. The study, though, raised issues beyond those which have a direct bearing on the recruitment of minority groups to research programmes. It showed also that experiences arising from efforts to recruit research participants from ethnic minority communities became a route to understanding the extent and scope of local community representation and participation.

McLean and Campbell collected data through semi-structured three-hour interviews, offering a £20 payment for potential participants. Interviews were conducted by a team of six researchers, resident as far as possible in the communities of interest and matched by ethnicity and gender with interviewees. The main methods of recruitment were

- advertisements placed in local newspapers, various shop windows and notice boards;
- approaching members of local voluntary organizations;
- informal referrals through existing contacts.

Ultimately six main factors were identified as influencing the recruitment processes:

¹¹ Noting that McLean and Campbell chose not to identify the location of their study informed this author's reflections on whether to avoid naming her field research location. See Chapter Seven of this study, *Naming the research location and issues of participation identification*, at page 259.

- 'informants' organisational affiliation,
- honorarium payment,
- informants' gender and age,
- institutional context,
- style of interview (length, semi-structured nature),
- previous experience of research'

(McLean and Campbell, 2003: 45)

In further examination with interviewees of the six factors identified above, McLean and Campbell concluded that differences of identity and socio-cultural networks accounted for differing recruitment experiences. From their detailed summary some points are particularly noteworthy. The honorarium alone did not influence participation except at times among English interviewees. Interest in the study itself usually prompted participation. Respectful and polite behaviour towards older participants was important as was clarifying the purposes and ownership of the research. The three-hour length of the interviews was an inhibiting factor, although the semi-structured, informal style and the opportunity given for free expression of views were appreciated. Building personal relationships and contacts within a recruitment population not highly represented in community networks and organisations was essential. Where gender and age differences in access and participation may be influenced by community mores and networks, mediated introductions were helpful. The age of the interviewer could influence recruitment. An older interviewer in some contexts may have been more acceptable. Negotiation with male family members was necessary to conduct interviews with some female participants at home.

Rather than negatively affecting participation due to research 'overload', McLean and Campbell found that where some communities had previous experience of research studies, recruitment benefited from researcher-access to established contacts and an understanding of researcher needs. The multi-lingual expertise of the interviewer team was valued by several Pakistani-Kashmiri informants. For McLean and Campbell the matching of interviewer and interviewee was essential, in ethnic terms, to the participation of the African-Caribbean community and to securing their confidence in

the results of the study and allaying expressed concerns about potential misrepresentation. This contrasted with the reservations about matching drawn by Elam and Fenton (2003: 23) and by Lee (1993: 100) concerning a sensed risk to anonymity, under-reporting and limits occasioned by social division.

The study usefully exposes some of the social complexities in research participation and the need for 'systematic and theoretical attention' (2003: 57). McLean and Campbell argue that a socio-cultural approach to recruitment requires a different process for different communities on the basis that it reflects the realities of peoples' lives. They stress the complexities of community diversities, the value of researchers' personal networking to recruitment outcomes and the different responses to recruitment attempts in different communities. McLean and Campbell also point to the need for a range of recruitment methodologies and careful contextual research prior to researchers committing themselves to a recruitment plan. There is no uniform 'one-size-fits-all' approach to recruitment, they argue, in contexts of ethnic diversity. They omit, however, to note religion's role in informing identity and its capacity to cut across ethnic groupings. Moreover, in highly charged contexts of local and international politicisation of identity and community relations, the conduct of sensitive research may require, if not demand, a uniformity of approach in line with more traditional sampling methodologies and with the explicit intention of emphasising inclusion. This researcher's contextual appraisal built on personal networking and grass roots connections would result in an initial approach weighted in favour of uniformity, consistency and inclusion.

Discussion in McLean's and Campbell's study of the potentially greater difficulties and more stubborn obstacles to recruitment when particularly sensitive topics are the subject of research - domestic violence, for example, child protection issues, sexual health and HIV- is absent. Stigma and silence, denial and fear of linkage may hinder access to communities and to individuals within them. Anxieties about confidentiality alone, especially where disclosure of HIV status is the risk, may create impenetrable barriers to access. Strategies routed through specialist organisations and associated networks of support and care, both voluntary and statutory, may then yield greater participation than the methods set out by McLean and Campbell.

Sensitivity

Where HIV/AIDS and religion are the topics of communication and research, reference to a wide range of difficult issues can be anticipated, impacting individual respondents, the researcher and, potentially, the wider population: the emotional demands, for example, of speaking about religious beliefs, traditions, practices and moral codes, referring to intimate relationships, sexuality, HIV diagnosis and loss; the anxieties raised concerning possible or actual misrepresentation and misunderstanding given the religio-cultural, ethnic and linguistic differences involved; and the fears about disclosure. For the study under discussion, it became clear that key methodological issues related significantly to that which could be categorised as 'sensitive', in Lee's terms that which involves '...potential costs to those involved in the research, including, on occasion, the researcher'. He goes on to qualify this, adding

While there are cases where research makes demands on participants which are quite substantial, the potential costs in the case of sensitive topics go beyond the incidental or the merely onerous.

(Lee 1993: 4)

Drawing extensively on Lee's characterisation of sensitivity (Lee, 1993) and their own research with black and ethnic minority groups into sexual attitudes and lifestyles, Gillian Elam and Kevin Fenton (2003) offer a comprehensive review of efforts to address issues of sensitivity in qualitative and quantitative studies. Taking sensitivity as

a substantial threat, the emergence of which renders problematic for the researcher and/or the researched the collection, holding and/or dissemination of research data

(Lee and Renzetti 1993: 5)

and 'intrusion, sanction and power' as the three ways in which that threat may be categorised and assessed, Elam and Fenton provide an analysis of noteworthy relevance to this study.

Intrusive topics can be described as those which are difficult to talk about: those which are emotionally charged, personal, private and sacred; those where concepts and language are unfamiliar to both researcher and respondent. Sanction relates to anxieties about disapproval and judgemental attitudes, about unfamiliarity with cultural norms and taboos. Power threats may restrict the sharing of information, raise concerns about undermining the status quo, about the dissemination and impact of results and the potential for unrepresentative and stigmatising conclusions to be drawn. Enquiries about HIV and religion, particularly those conducted face to face, cut across all of these. Indeed, the stigma associated with HIV, a global phenomenon, can be expected to heighten sensitivity. With the preliminary design of the localized data collection in mind - questionnaire to faith leaders, group discussions with congregants and interviews with people living with HIV - the above challenges to data collection and analysis, to accuracy, ethical practice, reliability, security and to the researcher's integrity, to one degree or another, were informing this study's research strategy.

Returning to Lee (1993), this study is 'costly' in that it would be seeking to engage face to face with people directly affected by a stigmatising diagnosis and to request their help in disclosing to a researcher who is also a religious professional details of their beliefs and their personal history, a potentially distressing process for both interviewee and researcher. Support issues, including the needs of a transcriber, were to be addressed in ethical and research governance terms as well as in terms of sensitivity to well-being.

Another arm of the study would involve contact with local religious leaders or representatives in ascertaining their views on HIV/AIDS and their own and their wider religious group's (the two may be at variance) teachings and beliefs. As such a process, however it may be constructed, can be expected to address issues concerning also sex and relationships, issues known to create barriers to participation (Ryen in Truman et al, 2003), initially a decision was taken to distribute a questionnaire rather than conduct person to person meetings at individual or group levels (Denscombe 2010: 141). Though of particular relevance to an interview process, careful note, nevertheless, had to be taken of cross-cultural complexities risking 'methodological discrimination' and the impact on data quality. The researcher's frame of reference,

social order issues, gender inequalities and perceptions could all contribute to the potential for misunderstanding (Ryen in Truman et al, 2003: 220 ff; Bhopal in Truman et al. 2003: 75). Furthermore, a researcher, perhaps especially a female researcher, known to those, usually male, leaders and representatives involved in inter faith initiatives set up to foster good community relations, may experience difficulties in negotiating access. In the process of doing so she may also risk her own reputation given the topics and sensitivities involved, a phenomenon Lee describes as 'stigma contagion' (Lee 1993: 9). Similar 'gatekeeper' issues concern access to groups of lay people from the faith communities. Woven throughout all aspects of the data collection were concerns about community relations and the need to avoid any suggestions that one faith community is more affected by HIV than another. Elam and Fenton emphasise the need to address issues of sensitivity when findings are presented and published. A dissemination strategy, including media training, they argue, is essential. Issues of dissemination and publication, as raised by Elam and Fenton and noted above, are significant in this study's environment of multiple diversities.

Elam and Fenton conclude that conducting and managing research into sensitive topics requires careful preparation in collaboration with the research community. Their own research into sexual health provides a transferable experience and body of knowledge applicable to the study of sensitive issues in this and other research contexts.

Ethnicity and diversity

Elam and Fenton explore also whether ethnicity adds a further dimension to sensitivity. Contextual issues, including immigration status, age, gender, socio-economic and political circumstances, may impact perceptions and experiences of ethnicity-related sensitivity. Although understood to risk exacerbating the impact of sensitive issues on the recruitment of participants, this researcher, on grounds of scoping diversity and religious affiliation/ethnicity connections, decided to request from questionnaire respondents and interviewees a brief biographical outline, including race/ethnic background and country of birth. It was made clear that giving personal details was optional. [Well-established as a surveillance tool in the USA, gathering ethnicity-related HIV/AIDS data remained controversial in Europe on the

grounds of potential misuse, misinterpretation and fuelling xenophobia and stigma until the beginning of the century. Although increases in heterosexually-infected individuals with HIV originating from high prevalence countries were noted, European surveillance systems still had not taken account of the 'diversity of the ethnic backgrounds which occur in a population' until a WHO initiative was introduced in 2001. Without this data, it is argued, a population's health problems and needs cannot adequately be identified (del Amo et al 2001: 13).]

Elam and Fenton set out a range of general sensitivity-reducing strategies and identify specific considerations while at the same time pointing out the limitations of 'formulaic approaches' (Elam and Fenton 2003: 21) given the diversity of ethnic contexts and research topics. Recurring emphases urge

- consultation and collaboration with the research population in the purpose,
 design, conduct and resourcing of the research project;
- discussion of ownership and publication of data;
- familiarisation with racial, ethnic, social, cultural and political contexts including communities' perspectives and values;
- development of strategies to address sensitivity and ethics relevant and appropriate to the particular study and research population;
- continual review and negotiation throughout the study.

They stress the importance of flexibility and of utilising a range of methodological tools, not least those which involve community members. All of the above informed this researcher's design of the field data collection, consulting widely with community members and including clinical, religious, voluntary agency professionals and people directly affected by HIV. She has participated in local inter community, inter faith, inter cultural and service equality networks, including those of lesbian, gay, bisexual and transgender people (LGBT), over many years as a practitioner and service provider. However, contrary to expectations given the literature's stress on variability and flexibility in facilitating data collection among diverse groups (Elam and Fenton 2003, McLean and Campbell 2003), the consultation process exposed no challenge to the proposed uniformity of documentation and procedures designed by this researcher

to invite and inform participation in the study. Local knowledge suggested to her that in the context of this particular study, with its HIV-specific sensitivities of stigma generation and the fostering of prejudice, different approaches to different communities and individuals, while expressing an acknowledgement and respect for differences in conceptual appropriation and communication, could also be perceived in terms of community status or repute. In the context of HIV/AIDS, such perceptions risked assumptions of linkage which the present author deemed an undesirable risk with its potential for long term implications. Stigma sticks. Options to introduce any changes as the data collection process progressed would be kept under review, but in the event the same documentation obtained across all groups.

In a similar vein questions about the benefits and disadvantages associated with the ethnic matching of interviewer and interviewee had to be considered. Arguments in favour of ethnic matching follow those of McLean and Campbell (2003) but Elam and Fenton (2003:23) describe disadvantages:

- the risk of placing so high a value on ethnic matching that other sensitivities, including those relating to gender, class, conflict and status, may be neglected;
- the difficulties an interviewee may experience in speaking openly to someone of their own background of cultural conflicts and taboos;
- the tendency to restrict responses in the belief that the matched interviewer is acquainted fully with the interviewee's experience;
- an ethnically matched interviewer over stepping researcher/respondent boundaries;
- interviewees' concerns about confidentiality;
- the placing of unreasonable expectations on matched interviewers to bring greater knowledge and fulfill a wider role, for example as translators and expert informants.

No resources were available to this researcher for matched interviewers or for translation or interpretation services. The researcher raised the issue during consultations with informants. However, although it was acknowledged that some potential participants would be excluded on these grounds, given the absence of

resources and clinicians and other professionals reporting a rare need for translation and interpretation services in face to face meetings with service users with HIV, the study design proceeded on a no-match basis. Later references by some participants with HIV to 'gossiping' and their expressed anxieties about disclosure within their community provided an unanticipated affirmation of the no-match aspect of the interview process.

Localising data collection

Leicester, a UK Midlands city of high religious diversity and familiar to the researcher was chosen to source localised data. Given the need to investigate a range of realities, this introduction to the study's methodological strategy and contextualisation continues with a demographic outline and a brief history of the city's statutory and grass-roots-led voluntary sector HIV prevention and care resources.

Context - Leicester's ethnic, religious and HIV prevalence profiles

The city is an ethnically diverse, multi-cultural, multi-faith community. The 2001 Census figures set the city's population at 279,923. Data from the 2011 census is not yet available but using 2001 data and providing comparison sets for England and Wales, the ethnic and religious profiles of Leicester's 2001 population are set out at Tables 9 and 10 below.

Since the collation of the 2001 data significant demographic changes have occurred: increased Somali migration from Europe and Africa, people fleeing Middle Eastern and African conflicts and new arrivals from Eastern Europe due to EU enlargement. Corresponding shifts in religious populations could be expected. Some population estimates by ethnic group for local authorities (similar estimates are not available for religion) published in May 2011 but not relating to the 2011 census give a helpful indication of trends in Leicester. They put the city's total population at 304,700 and estimate increases for most ethnic groups except Indian Asians where there is a fall of several thousand. This may be due to increased numbers of Asian residents relocating from the city to suburbs and other areas in the county.

Resident population by ethnicity		Leicester		England and Wales	
Asian or Asian British	83,751	29.82%		4.36%	
	Indian 72,033		25.73%		1.99%
	Pakistani 4276		1.53%		1.37 %
	Bangladeshi 1926		0.69%		0.54%
	Other Asian 5516		1.97%		0.46%
Black or Black British	8595	3.08%		2.18%	
	Black Caribbean 4610		1.65%		1.08%
	Black African 3432		1.23%		0.92%
	Other Black 553		0.20%		0.18 %
Chinese and other ethnic groups	2330	0.83%		0.86%	
White	178,739	63.86%		91.31%	
	White British 169,456		60.54%		87.49%
	White Irish 3602		1.3%		1.3%
	Other White 5681		2.03%		2.59%
Mixed	3380	2.32%		1.27%	
	White & Black Caribbean 2841		1.01%		0.46%
	White and Black African 539		0.19%		0.15%
	White and Asian 1908		0.68%		0.36%
	Other mixed 1218		0.44%		0.30%

Table 9. Census 2001: Ethnic composition. Area Profile for the City of Leicester: Demographic and Cultural. [Census 2001 (2011a) Leicester City Council. Area Profile for the City of Leicester: Demographic and Cultural]

Religious affiliation	Leicester	England and Wales			
Buddhist	0.23%	0.28%			
Buddnist		0.28%			
	638				
Jewish	0.15%	0.50%			
	417				
Sikh	4.21%	0.63%			
	11,796				
Muslim	11.03%	2.97%			
{	30,885				
Hindu	14.74%	1.06%			
	41,248	-			
Christian	44.72%	71.75%			
	125,187				
Other religions	0.42%	0.29%			
	1,179				
No religion	17.43%	14.81%			
	48,789				
Religion not stated	7.07%	7.71%			
	19,782				

Table 10. Census 2001: Religion. Area Profile for the City of Leicester: Demographic and Cultural. [Census 2001 (2011b) Leicester City Council. Area Profile for the City of Leicester: Demographic and Cultural]

Asian or Asian British	102,500		
	Indian		
	56,900		
	Pakistani		
	14000		
	Bangladeshi		
	2800		
	Other Asian		
	5800		
Black or Black British	11,600		
	Black Caribbean		
	4800		
	Black African		
	5800		
	Other Black		
	1000		
Chinese and other ethnic group	9500		
White	195,300		
	White British		
	183,000		
	White Irish		
	3200		
	Other White		
	9100		
Mixed	8800		
	White & Black		
	Caribbean		
	3100		
	White and Black		
	African		
	900		
	White and Asian		
	2900		
	Other mixed		
	1900		

Table 11. Estimated resident population by ethnicity (Experimental population estimates by ethnicity 2011)

A briefing document prepared by the Barrow Cadbury Trust (2007) and based on research by Danny Dorling and Bethan Thomas of the Department of Geography, University of Sheffield, shows increasing trends towards ethnic plurality, that is, no single ethnic group comprising a majority of the city's population, with the white population down from 70.1 per cent in 1991 to 59.5 per cent in 2007 and to a projected 44.5 per cent by 2026. The 2009 estimated falls in numbers of Indian Asians living in Leicester appear to challenge Dorling's and Thomas' projections.

The city enjoys a well-established multi-sectoral commitment to the celebration of diversity and the fostering of good inter-faith and community relations, but it is the twentieth most deprived area in the UK and one of the most diverse. 'Around 45 per cent of the city's population are under 29 years old and English is not commonly spoken as a first language by almost one in five people' (NHS Leicester City 2011a).

Since 1986 a local Council of Faiths has pioneered efforts to encourage inter-faith understanding. It has also given voice to minority faith/cultural communities in representing their interests and needs to the city's institutions in education, housing and policing, for example, and in commercial, cultural, health, social care and hospital services. However, according to Hussain et al in 2003 this was 'not a culturally integrated city' and there remained evidence of parallel lives (Hussain et al 2003: 124) and the potential for tension in some aspects of community relations. More recently (2010) a march by the English Defence League, a group which opposes, in the words of their mission statement, the 'creeping Islamisation of our country' and the 'desire to implement an undemocratic alternative to our cherished way of life: sharia' (English Defence League 2011), was challenged by a united community response (Leicester Mercury, 25 September 2010a; 13 October 2010b).

Like other sectors, the city's health and social care agencies have sought to respond ever more effectively to the changes in service provision and delivery which a culturally diverse community requires. Sensitivity to religious belief and observance, to styles of dress, to communication needs and gender norms, to name a few has grown over the years as greater awareness of diversity and the realities of discrimination, exclusion and prejudice have seen exponential growth.

By the end of 2009 there were an estimated 86,500 people living with HIV in the United Kingdom (Health Protection Agency, 2010a), a quarter of whom did not know of their infection. In 2010 over six and a half thousand individuals were newly diagnosed with HIV in the UK bringing the total number of people living with diagnosed HIV infection to 69,424, almost half of whom were men and women infected via heterosexual contact. Sex between men accounted for 43 per cent of diagnoses. The East Midlands, the South Central and the East of England regions reported the highest proportion of newly diagnosed individuals who acquired their infection heterosexually and identified as Black African. Northern Ireland, the North West of England and Scotland reported the highest number of individuals who acquired their infection through sex between men and were of white ethnicity (HPA 2011e) In the East Midlands 3142 individuals with HIV accessed care.

HIV East Midlands: by ethnic group	Year 2010
White	1274
Black African	1515
Black Caribbean	56
Black Other	31
Indian/Pakistani/ Bangladeshi	105
Other Asian/Oriental	50
Other/Mixed	75
Not known	36
Total	3142

Table 12. HIV-diagnosed persons seen for HIV care resident in East Midlands Strategic Health Authority (SHA) by ethnic group: 2010. Survey of Prevalent HIV Infections Diagnosed (SOPHID) East Midlands data tables. (Health Protection Agency (2011d)

Leicester's NHS website reports that in 2008 the town recorded one of the highest rates of infection for HIV outside London (NHS Leicester City 2011b). This remained the case with 3.38 diagnoses per 1000 population in 2010 (HPA 2010c). The table

below gives 2010 figures with exposure category for the East Midlands. Details for local authority or PCT are not available for publication.

HIV East Midlands: Exposure category	Year 2010
Sex between men	831
Injecting drug use	95
Sex between men and women	2046
Blood/blood products recipient	38
Mother to child transmission	70
Other/not known	62
Total	3142

Table 13. HIV-diagnosed persons seen for HIV care resident in East Midlands SHA by exposure category: 2010. Survey of Prevalent HIV Infections Diagnosed (SOPHID) East Midlands data tables. (Health Protection Agency (2011d)

An early ecumenical consultation in the UK was convened by the British Council of Churches and the Free Church Federal Council in 1988 to foster ecumenical cooperation and careful consideration in the Churches' responses to HIV. The consultation included representation from people living with HIV (Ward 1989). The momentum generated by the event and its report delivered a number of specialist clergy HIV support appointments and church projects. The momentum faltered over the years as the immediate anxieties about infection reduced with the development of treatments and the UK's relatively low rates of infection. Similarly, in phenomenological terms, HIV's presence in the life of Leicester, in its local and global networks, has become silently embedded in its multi-religio-cultural history. Records of other health events have found their way into the archives of local, national and international history (Arnold 1997, Frizzelle and Martin 1971). Whether HIV will be accorded its place or remain largely invisible like the venereal disease challenges of the past remains to be seen, but the next stage of this study involves the researcher's personal account of Leicester's HIV history.

Context - perspectives on a city's HIV history

The first death in Leicester known to be due to an HIV-related illness occurred in 1987. Since that time various prevention and care services have been established. Over the years statutory secondary and primary care provision has developed in an evolutionary way in response to identified need. Initially, existing generic resources struggled to respond appropriately to a new disease which was rapidly assuming unique social and moral characteristics. Health and social care professionals were not immune from the prejudice and discrimination attaching to HIV; immune neither from the attitudes towards them as carers of people affected by HIV nor as individuals with their own prejudices and misunderstandings. In due course HIV-specific services were introduced and improved training helped dispel prejudice.

There were several initiatives to develop non-statutory provision. Some have been short-lived, responding to particular but temporary circumstances. Others have survived and developed over many years and have become integral to local if not national HIV prevention and care strategies and planning [Leicestershire AIDS Support Services (LASS), New Futures formerly Women's Health in Prostitution (WHIP), Faith in People with HIV, Faith in Families with HIV, TRADE an information and support organisation for men who have sex with men].

One of the earliest, if not the first, 'lay' initiatives (as opposed to those established and managed by health professionals and statutory agencies) to raise awareness of HIV and express concern about the lack of support for those affected was taken by the wife of the man who died. As well as being a regular speaker at community and church events she raised money to provide a fund, now managed by LASS, for those with HIV who experienced financial hardship on account of their diagnosis. In those days it was not unusual for someone with HIV to lose their job if they disclosed their status to an employer or colleague. Illness was more common and early retirement due to ill health and disability was not unusual. The fund continues to be a much needed source of support. Deprivation, exclusion and isolation were early characteristics of responses to HIV in this city as in other parts of the world. Fear of or actual estrangement from partner, colleagues and family on account of HIV continues to feature, divisions often exposed most painfully at the time of death and in funeral arrangements. However, there were also those occasions when the disclosure

of both diagnosis and sexual orientation became catalysts for supportive change and reconciliation.

That first death drove a small number of individuals, mainly, but not only, gay men and lesbian women, to explore the feasibility of setting up a support group and telephone help line for people affected by HIV in the county. The first chair of the LASS management committee was an Anglican. Leaving the city after a year the still embryonic organisation then elected another ordained woman (the author of this study) as its chair. LASS's continued development has adjusted to the shifting profile of service users and their various needs.

Leicester's designation as a centre for asylum seekers and refugees in the year 2000 brought immediate and sometimes difficult to manage change. Service users with multiple practical, physical, emotional and psychological needs associated with flight from conflict zones, economic desperation, political persecution, ill health, sexual assault and adapting to an unfamiliar culture made new demands on the organisation (see also Figure 1, page 12/13). Religious belief and belonging are important to many LASS service users. LASS is not a religious organisation and yet its purpose and practice in offering non-judgemental, open access to all sections of the community irrespective of background and identity, at one and the same time both chime with and offend a range of religious constituencies, teachings and beliefs. LASS's experiences of this dichotomy and associated marginalities reflected those of its service users, its staff and supporters.

With an agreement to share the LASS building a Body Positive (BP) group for people with HIV was set up in 1989 but closed three years later. For a while alternative self-help support activities, funded by the local Area Health Authority and local authority social services departments, were developed through LASS's appointment of an HIV Peer Support Development Worker. The Black HIV/AIDS Forum (BHAF) was established to offer culturally specific responses to the needs of Black and Asian people affected by HIV and to mount appropriate prevention initiatives. Organisational difficulties resulted in its closure in 1993.

A number of studies into the reasons for the struggles of organisations involved in HIV support to continue functioning have been conducted (Petchey et al. 1998; Weeks et al. 1996; Gaffney, 2004). Capacities to cope with policy changes, with issues of stigma and cumulative loss were identified as significant factors. Exacting organisational, administrative and managerial demands on a diverse group of people with, in the case of BP groups in particular, a life-limiting condition seeking to identify, provide and sustain the most appropriate self-help, also played their part. How far religious beliefs contributed to or mitigated any difficulties is not known, but during these years of extensive activity, comment and development and not least the author's personal engagement as pastor and priest with people affected by HIV, religion began to surface as a significant player in local, national and international responses to HIV. It became clear in Leicester that without a specific initiative raising the profile of supportive religion and challenging the negative, inconsistent messages risked undermining the city's public health prevention and care programmes. Recognised as part of the Health Authority's integrated strategic response to HIV, with the director committed to the non-judgemental and open access terms of local HIV service provision and policy and licensed as the Bishop's Chaplain for People Affected by HIV, the project Faith in People with HIV was launched at the beginning of 1994. The process and the project evidenced the potential for authentic emancipatory collaboration and shared praxis within and between the domains of religion and public health in the interests of HIV prevention and care.

The organisation embarked on a programme of distinctive support as outlined at Chapter One, pages one to three. Although emerging out of a specifically Christian response to HIV and occupying an Anglican 'home', the service was open to anyone irrespective of any religious affiliation or none and sought to engage with all the faith communities of the city, county and a neighbouring county.

A noteworthy feature of this organisation resides in its generation, growth and survival as a service straddling institutional boundaries: Church boundaries, both denominational and doctrinal; inter faith boundaries; boundaries of religion and culture; the religious and the secular; boundaries between voluntary sector and statutory service provision; between conceptualisations of health; between ethical formulations and moral codes; boundaries of language, ethnicity, gender, sexuality,

gain and loss, life and death. Echoing the collaborative principles of practical theology and public health set out in Chapter One, page eight, the work involves continuous movement and dialogue, negotiating space within and between with varying degrees of success, and is often marginal to mainstream representations and power. It is this movement and dialogue and their associated interfaces which, over many years, have exposed to the researcher the tensions central to this study and which have informed the questions being asked and the approaches being adopted.

- Are there implications for strategic Public Health HIV prevention and care policies in religious contexts (of this city)?
- Do the religious beliefs of individuals with HIV and their experience of their respective faith groups/communities and/or other faith groups in relation to HIV help or hinder public health HIV prevention and care programmes (in the city)?
- Are the strategic Public Health responses to HIV prevention and care adequate to the psycho-social realities and needs of religio-cultural diversity in a UK community?

Method

Introduction

Consultation continued and a central focus of the local data collection – gathering the responses of religious leaders to HIV and people affected by it – pointed increasingly to the qualitative characterisation of the proposed study (Denscombe 2010). That preliminary sense that a questionnaire to local religious leaders inviting mainly open responses would be an appropriate course of action (page 74) was affirmed. Without the resources to cover all the religious groups in the city it was decided to limit recruitment to Christian, Hindu and Muslim communities, the three largest faith groups in Leicester.

Triangulation

With the need to record and describe in detail constructions of reality and interpretations of experience and place meanings and potential contradictions under scrutiny, the preference for a triangulated method to diversify responses and augment

the questionnaire data emerged. Triangulation, the collection and analysis of data from additional sources, offers a means by which, not only to demonstrate rigour in qualitative studies, but also to bring additional perspectives into the necessary critical conversation between the experience of individuals and the inter-disciplinary hermeneutical process under consideration (Denscombe 2010). Interviews with people with HIV from the three chosen faith backgrounds and facilitated group discussions with 'lay' people from Christian, Hindu and Islamic groups would make available a wider and fuller range of perspectives when added to, and compared with, questionnaire responses from faith leaders and representatives, providing legitimate additions to the data collection and analysis proposals.

Recruitment, ethics and research governance

After wide consultation with informants, a questionnaire for postal distribution was drafted. It included a range of open and closed questions with space for comment and opinion (Neuman 1994: 355). Some of the closed questions would provide a small quantity of numerical information. Respondents were asked to give the name of their religious group. Outline biographical information was requested but, unless disclosed independently by the respondent, no other personal information was required. The development of the questionnaire's format and content is described in full below as this account of the methodological positioning proceeds.

The particular sensitivities of this study (religion, HIV, sex and sexuality, cross-cultural enquiry) required assurances for participants of confidentiality and, subject to any ethical constraints, anonymity. Communication with questionnaire respondents (and also with small group participants and interviewees with HIV) stressed that, although some direct quotes may be used, nothing would be reported or published which would identify respondents or participants. On that basis summaries of the study's findings would be made available in due course and, if possible, presentations would be arranged with local faith networks and HIV service providers. Identification codes, not names, were used in the researcher's indexing and recording of questionnaire responses and group/interviewee transcripts. With a letter of invitation to participate and full information about the study and the researcher, assurances concerning anonymity were given along with basic information about HIV and a list of support and information services. The final versions of these can be found at

Appendices B1- B4. Even if the person in receipt of the invitation pack chose not to respond, the inclusion of HIV information ensured some raising of awareness and, if filed, availability for future reference should it be needed.

The intervals between religious festivals when faith leaders and representatives can expect an inflated work load impacted upon decisions concerning distribution and return dates. Respondents were invited to return completed questionnaires within six months with a card reminder sent after three months and a further questionnaire and short letter towards the end of the return-by period. This researcher sought to design and demonstrate a uniform process which, in initial attempts at data collection, would facilitate as open and as frank responses as possible to questions of a sensitive and potentially unfamiliar nature.

The questionnaire would be used also to frame the audio-recorded and transcribed semi-structured interviews with people with HIV and small group discussions. With qualitative data analysis methods in mind during the design stages and in line with established pre-analysis familiarisation requirements and coding techniques (Lacey and Luff 2001), it was anticipated that the reading and re-reading of questionnaire responses, interview transcripts and group discussion notes would expose a range of themes. Analysis of data would enable the combining and refining of categorisations and concepts.

In the early stages the recruitment for interview of participants with HIV would be conducted via the Departments of Genito Urinary Medicine (GUM) and Tropical Medicine and Infectious Disease (IDU) at the Leicester Royal Infirmary. Accordingly, as well as University of Derby ethical permissions, NHS Research Governance and submissions to the Central Office for Research Ethics Committees (formerly COREC, now the Integrated Research Application System, IRAS) were necessary. The other participant groups would be accessed through community networks not NHS departments. The recruitment of interviewees through local voluntary agencies with their grass roots connections and community-led approaches to service provision could have been the chosen design, bypassing the need to engage with the lengthy COREC process. Indeed, such a recruitment strategy will sometimes be advocated as a preferred route where marginalised and minority groups are involved (Fetterman

1998: 32, Campbell and McLean 2003). However, it was decided that, given the sensitivities involved and the researcher's close association in several roles, including that of Anglican priest, and over many years with the organisations, staff and service users/patients involved, NHS permissions and recruitment arrangements would attest to the authenticity and conduct of the study in a way which a less rigorous approach could not (Elam and Fenton, 2003). Issues of researcher bias (Lee 1993: 97 ff, Neuman, 1994: 250-252) and participant pressure (Humphries et al 2003) were of foremost concern. Furthermore, NHS policy required the researcher to take full and careful account of confidentiality issues including the secure storage of data, the disclosure and reporting of harm, lone worker practice, taking consent and having proper concern for the well-being of interviewee, researcher and transcriber given the potential for distress at issues under discussion.

It was anticipated that the exacting requirements of NHS approvals would prove particularly challenging to a qualitative study making enquiries into relationships between religious belief and HIV. The NHS procedures are structured to accommodate the more usual quantitative studies including those for drugs trials and treatment interventions. However, the rigours of NHS procedures and the required delineation of ethical concerns and choices enabled a helpful honing of the method design. In the event, favourable ethical decisions were granted.

Unfortunately, the NHS channels of recruitment failed to elicit the proposed number of responses (between twenty and thirty) and local voluntary agencies were then approached. At this stage a further consideration emerged. LASS and Faith in People with HIV, the organisations concerned, received a proportion of their funding from the City Primary Care Trust (PCT) and the local authorities. The researcher sought advice as to how far organisations with such funding, when approached by researchers to access service users, were subject to the research governance procedures of their statutory part-funders. The voluntary agencies granted permissions, though neither was aware of their funders' requirements nor had policies in place to cover specific research requests. Their decisions were taken with reference to a range of generic policies and practice. After further enquiries by the researcher, clarification and permissions were sought from and agreed by the Research and Development Manager of the area Primary Research Alliance and the City Council's Research Governance

Officer for the Local Authority Social Services Department. An application for non-substantial amendment was necessary also under NHS research ethics procedures.

Gatekeepers to research populations.

Identifying the appropriate individuals to be invited to complete a questionnaire or participate in a small group discussion and selecting those community 'gatekeepers' and expert informants best placed to distribute information and invitations and advise on the process required careful consideration. It was clear from the start that identifying and bringing on board some key individuals was important to the desired community-wide participation in the project, the subject of which, however, would inevitably deter some individuals from becoming involved. There could be no progress without at least a basic understanding of each community's organisational structures (May 1993: 42; Lee 1993: 119 ff).

Christian denominations have by and large adopted a hierarchical model of organisation following biblical patterns of leadership. Adaptations and changes have occurred over time but church institutions have remained substantially faithful to a vertical structuring of authority. Some independent and new churches have developed more democratic or horizontal models of governance. In their commitment to the participation of the poor and the marginalised, the Methodist House Groups of eighteenth century England and the Catholic Basic Communities of Brazil radicalised ways of being church. Both, however, foundered when growth and the need for organisational accountability and decision making ushered in the very hierarchical systems from which they had cut loose. In a mixed economy of leadership and governance models Christian churches conform to a more or less uniform acknowledgement that the priest/minister/pastor has responsibilities for the conduct of worship, the pastoral support of the congregation and the management of a discreet organisation which may or may not be part of a wider institution. To a greater or lesser degree there will be participation with colleagues, lay and ordained and with the governing body, whether local and/or national and/or international. An outsider wishing to access the leadership of the organisation would usually find roles and responsibilities clearly defined and understood.

In Hindu communities the priests rarely have responsibility for the running of the Mandir, the worship centre, and any associated community activities. The role of the priest is ritualistic. In a UK context it is not unusual for the priest to have been invited to take the role by the managing committee of the Mandir and may have come from India. His (the priest is usually a man but women are not barred from the role) experience of British culture and knowledge of English may be limited. Although there are some organisational structures, the Association of Hindu Priests, the National Council of Hindu Temples and the Hindu Council of the UK for example (Weller 2007d), different temples will reflect different Hindu emphases and pan Hindu representation is under developed. Visits by *gurus* or teachers will occur from time to time. These will become occasions of great interest and it is not uncommon for large numbers of devotees to gather for religious teaching.

In Islam a similar system operates. Although training for *imams* is now available in the UK some mosques invite *imams* from other countries to lead the prayers and preach sermons. Some *imams* have responsibilities for teaching the children and young people in the schools or *madrassas* attached to most mosques. However, it is the senior officers of the mosque committees who usually represent the mosque to the wider community. Some national and international organisations exist (the Muslim Council of Britain, the Muslim Association of Britain), but the umbrella bodies are usually local and representative of particular Islamic groupings in a specific area. For example the Federation of Muslim Organisations has a significant representative role in the research location as does the city's Council of Mosques.

Local conversations and enquiries found that the Faiths Regeneration Development Officer had compiled a list of faith organisations and worship centres in the city. A cross-referencing exercise was undertaken using the local Churches Together list held by the County Ecumenical Development Officer. As this produced the most comprehensive data base at that time for faith groups in the town, a request to use it for the distribution of questionnaires to local religious leaders and representatives was made. Permission was granted. Some details were absent: the name or role of addressees was not available for every address. Although some directories will give names (Weller 2007d), there can be no guarantee that such data is current, making contact with the relevant person more uncertain. Therefore, the letter forwarded to

worship and/or community centres inviting a response to the questionnaire included a request that it be passed to the person with responsibility for helping the congregation or community understand their religion's teachings and to whom people may go for guidance when they have problems. Consultations with community members were held and, in the absence, described above, of uniform structures and roles, this was deemed to be the preferred method of contact. It was anticipated that recruitment to small groups also would involve negotiation with faith community 'gatekeepers'.

Researcher bias and reflexivity

The religion and professional background of the researcher were also factors with implications for the influencing not only of recruitment but also data quality (Lee 1993: 97 ff, Humphries et al 2003). The researcher's identity as a Christian clergywoman was known to a number of potential respondents in each community - 'leaders', lay people and people with HIV. This could bias both reluctance and willingness to participate on the one hand and researcher expectations on the other. Her professional relationships with health and social care professionals in various statutory and voluntary service provision domains would also require attention. At one level the knowledge of the faith and health communities was a significant asset but at another level the familiarity with the context and the individuals involved required particular attention to the potential for bias and the need for the researcher to build an element of 'distance', or 'strangeness' as Coffey puts it, into the research design (Coffey 1999: 28 ff). The recruitment to interview and to group discussions required particular consultation and critical reflection.

The chosen recruitment sites, then, became hospital departments with department staff taking responsibility for the distribution of invitations to participate and information packs, with the later additions of two voluntary sector organisations. Care with boundaries was deemed essential to avoid the charges of inauthenticity and analytical corruption which can beset qualitative studies. But a necessary attention to the boundaries, if too rigorous, can also, if the researcher's self-awareness is inadequate, result in inappropriate researcher invisibility in the data collection, the analysis, and the report (Coffey 1999: 31-35).

Researcher positionality, or bias, is a significant issue in research design and analysis (Neuman 1994, Lee 1993), perhaps most significantly where race and gender are concerned. There is an argument that welcomes efforts to reduce bias, calling on researchers and respondents to function in a consistent and equitable way. Others argue, particularly, though not exclusively, in the field of social science and feminist approaches, that neutral researcher and participant behaviour and presentation are neither possible nor desirable (Lee 1993: 117, Greenhalgh 2001: 172, Truman et al 2003: 14 ff). However, qualitative research methods are more likely than positivist to raise questions of researcher integrity (Lee 1999). Power is of particular significance in the relationships between the researcher and the researched, not least when various paradigms of social classification are in play – ethnicity, culture, language, status, gender, education, beliefs and codes of behaviour (Humphries et al 2003). In order to address issues of bias, an awareness of potential pitfalls in the study's design and analysis must be subject to constant review and researcher reflexivity with an accompanying openness to changes of direction (Humphries et al 2003: 14).

Gender

Although a mixed group of participants was desirable, gender sensitivities could have generated changes to the methodological design. It was not anticipated that the female gender of the researcher would be an issue for questionnaire respondents given the anonymity structured into the initial distribution design. Indeed this was a significant aspect of the design process. When considering the best way to gather the religion-informed views about HIV of faith leaders or representatives it was clear that face to face meetings would certainly be prohibitive at a resources level. It was also clear during the consultations with informants that there could be an impact on recruitment from some faith contexts due to the gender of the researcher. A postal questionnaire with mainly open questions became the preferred option even though, in methodological terms, it appeared incompatible with the phenomenological paradigm to which the researcher was drawn.

Similar considerations applied to the face to face interviewees and lay groups, where reluctance on the part of male potential participants to speak with a female researcher could be foreseen due to the study's concerns with HIV, perceived sexual connotations and the religio-cultural differences (Lee 1993, Elam and Fenton 2003).

The researcher's consultations with Hindu, Muslim and Christian community members and colleagues suggested there could be an impact on recruitment and consequently on the gender profile of the sample groups. However, early responses to invitations to participate were assessed according to the gender of respondents, but with a clear gender mix a decision to amend the method to invite all-female participation was deemed unnecessary.

Had the switch to all-female recruitment been required it would have represented an interesting reversal of the emancipatory research paradigm advocated by Humphries et al. The switch would have seen limits placed on access by a female researcher to male participants, whether or not inadvertent, as opposed to limits (the more usual occurrence according to Humphries et al) placed on access by male researchers to female participants, whether or not inadvertent. Humphries et al argue that an emancipatory approach to research design and recruitment delivers the increased participation in, the interpretation of and the benefits from, research which are essential to the empowerment and inclusion of women (Humphries et al 2003: 7 ff).

The gender profiles of questionnaires respondents, group members and interviewees with HIV are provided below at Chapter Four.

Terminology

A range of terminological considerations surfaced during the research design stages. There were expectations that questions about sex and sexual health would be asked. Consultation with local informants as to the most appropriate language to use delivered 'intimate relationships' rather than 'sex' or 'sexual relationships'. It was felt, however, that the questions to participants relating to sexual health and relationships education in schools should not use the term 'intimate relationships' due to an existing familiarity with the curriculum's terminology. Other terms of particular significance involve conceptual appropriations of 'health' and 'healing' language; of faith, religion and belief; of multi-, inter- and plural in describing relational aspects of faith relations and academic disciplines. Some discussion of each is offered below.

Health and healing

Concepts of health and healing find expression and appropriation within most religious traditions and indeed may be central to those which include notions of salvation in their frames of reference. Few, however, will draw on the languages of allopathic health to shape, describe, understand and communicate their conceptualisations. The languages of the abstract, of ancient myth and poetry, music, ritual and symbol, will be the more familiar and trusted conduits of communication. Clearly, there is potential in cross-cultural contexts for misunderstanding. Great strides have been made in recent years in the provision of diversity training and information resources for health professionals, managers and administrators but these have focused predominantly on rites of passage, on food and on the cultural and religious practices at key stages of life and at death (Neuberger 1991, Henley and Schott 1999, Firth 2001, Sheikh and Gatrad 2000). And although research into the impact of religious beliefs on coping and health outcomes is extensive (Parkes et al. 1997, Koenig et al 1998b, Matthews et al 2000, Pargament et al 2000, to name a few) less attention is paid in care and treatment settings to the constructs which religious beliefs bring to apprehensions of health, of ill-health, suffering and death, whether or not, for example, there is belief in the healing power of intercessory prayer, whether there is a sense that illness is a punishment for sin or whether there is belief in an afterlife and the implications the presence or absence of these may have for the experience of illness and treatment.

Faith, religion and belief

Is the word faith as in, 'faith community', 'what is your faith?' synonymous with religion as in 'religious community', 'what is your religion?' In the same way, does the use of 'beliefs' refer to religious 'beliefs' and religious 'faith'? Are 'beliefs' and 'faith' one and the same? Are references to religion, faith and beliefs consonant with the religious connotations and assumptions of both believers and non-believers? Some exploration of these questions is necessary in order to inform the research method.

There is an understanding of 'faith' which appears to assume a holding of beliefs about or an assenting to propositions about God and belonging to a group which holds those beliefs in common. Indeed, it could be argued that faith understood in this way can only be discussed in religious terms, using religious concepts and language. It

would then follow that 'faith' can only belong to and be the concern of those who subscribe to or who are conversant with, however firmly or vaguely, religious discourses and traditions. Following this understanding of 'faith' a faith community is a community of the faith or a community of the religious ones or of those who subscribe to or identify with a particular religion. Furthermore, in some religious traditions, Christian and Buddhist for example, the term 'religious' community usually refers to a group of individuals (known collectively and individually, indefinitely and definitely as a or the 'religious') living together in community, in the same building, complex of buildings or enclosure, according to the precepts of a particular founder's, saint's, guru's or leader's rule or order. Some religious communities are closed to the outside world. So a religious community is a 'faith' community.

Another view will hold that all people have faith; that faith is to do with making, maintaining and transforming meaning and is not necessarily expressed in traditionally religious ways. This is a view advocated by Wilfred Cantwell Smith (1979) in his elucidation of modern confusions in uses of faith, belief and religion language. Smith argues for distinctions between all three, but at the same time emphasises the faith-religion relationship. He asserts that a named and complex tradition incorporating symbol, belief and practice such as Christian, Hindu or Islamic

becomes religious as it expresses or elicits men's faith. It is faith that generates the tradition in the first place and that continues to be its *raison d'être*.

(Smith, 1979: 5)

And it is religion which is the cumulative traditional expression of it (Smith 1978: 165). This 'faith', Smith holds, is at home among the secular humanist and the religious. It is about ideals and identity, values and interpretations, about the essential human project of orientation to self, neighbour and world. Understood in this way, 'faith' is not limited to or bound by concepts located in the world religions, nor is it enjoyed and appropriated only by religious people. It is an interpretation more in keeping with inclusive and holistic principles of public service access and delivery

than an interpretation which places 'faith' entirely in the realm of the traditionally religious.

A commitment to such an inclusive definition takes seriously the beliefs and values of everyone irrespective of traditional religious dimensions. It could be argued also that the inclusive definition can facilitate dialogue and the better accommodate at individual and institutional levels inter- and cross-disciplinary communication and in so doing reduce the potential for polarisation and conflict. Furthermore, it allows an holistic appreciation of belief and the authenticity of each person's quest for physical and emotional equilibrium regardless of whether it is sought or expressed in religious ways. Definitions of religious and non-religious appropriations of a world-view could then be included in any use of the term 'faith'. Though pre-dating Smith, Sir Francis Younghusband clearly had similar concepts in mind when establishing the World Congress of Faiths in 1936. He chose the word 'Faiths' in order to open membership to humanists and New Religious Movements and to those who claim no particular allegiance to traditional religious groups (Weller 2001: 81).

However, in its common and popular usage 'faith' is understood as being to do with religion or religious beliefs, and faith community as the wider association of individuals in a society who identify with a particular religious tradition or group. 'Faith community' is now commonly used in this way at many levels of local, national and international communications. In order to facilitate communication in this research context where the potential for confusion and anxieties around terminology and self-expression is high, the use of the word 'faith' in questionnaires, interviews and correspondence with research participants will refer to religion and religious beliefs. Elsewhere the terms of use and definitions will be clarified within the text.

Multi-, inter-, plural

This study's first working title included the term 'multi-disciplinary'. It referred to the researcher's initial hypothesis that existing Public Health theories of and responses to HIV prevention and care are inadequate to the complex macro and micro psychosocial realities and needs of religio-cultural diversity and her view that no single discourse can engage fully with the range of issues and frames of reference identified.

The researcher's professional experience suggested that a dialogical and integrative approach to the study, mirroring the cross-cultural realities of grass roots HIV support work, would be required. This is not an entirely novel approach, particularly in terms of pastoral engagement and the theorization of diversities and inequalities, but with an increased focus on religion's impact on community relations and public services, the appropriation of language in the conceptualisation of the issues in terms of community identification and associated social policy responses has received significant attention. These debates include the use of multi-, inter- and plural and have had a bearing on this researcher's reflections on the study's title and wider use of these terms.

At the most basic level 'multi' interprets uncontroversially as 'many'. In respect of multicultural society, a society of many cultures, 'multiculturalism' has been coined to describe a UK approach to diversity which emphasises equality and anti-discrimination and, as policy, came increasingly to be associated by some with reinforcing differences rather than similarities (Cantle 2005: 11). Parallel lives, it was argued, weakened any sense of mutual belonging. Multiculturalism, according to Cantle (2005), exacerbates community tensions and requires a new commitment to community cohesion, common values and behaviours. 'Multi' in these terms can suggest boundaried and immutable agency rather than dialogue and engagement. In February 2011 the UK Prime Minister David Cameron declared 'State multiculturalism has failed' (BBC News 5 February 2011, The Telegraph 5 February 2011).

'Pluralism', with its preference for separating public from private, is looked to for an alternative and more amenable model but is discounted when agreement falters over that which constitutes private and that which constitutes public (Cantle 2005: 84, Malik 2002). Not only are these issues highly relevant to wider UK and local society, they speak also to HIV strategy and service provision. The researcher's conversations with service users have suggested that the needs of some new communities, not least those disproportionately affected by HIV, for example in the East Midlands almost fifty per cent of those diagnosed and accessing HIV care are from sub Saharan Africa (see Table 12, page 83), are perceived by some to take priority over those of established, though in some respects similarly marginalised, groups.

Although not an entirely comfortable transfer, the 'multicultural' debate prompts the notion that 'multi-disciplinary' may be an inappropriate term by which to refer to the range of discourses and critiques through which this study seeks to cast its analysis and conclusions. The researcher is not a specialist in anthropology, psychology or sociology neither is there a proposal to employ those disciplines in distinct and separate analyses. Rather, the intention is to allow several critiques to interrogate and inform one another in order to enrich the work and its conclusions, not dissimilar to the principles underpinning Layder's 'social domains theory' (Layder 1997), the notion that society and social life comprises

...a number of important dimensions that have varying and distinctive characteristics and that these differing "social domains" are interlocking and mutually dependent on each other.

(Layder 1997: 2).

Is 'inter-disciplinary', therefore, with its connotations of dialogue, the better term to use when new theory and practical prescriptions are the objective? Inter's 'between' offers the movement, negotiation and exposure of interfaces and tensions which have consistently characterised the researcher's experience and knowledge of HIV in contexts of diversity. Arguments in favour of changing the title of the study from 'Competing realities, diverse needs: a *multi*-disciplinary approach to religious engagement with HIV prevention and care' to '...an *inter*-disciplinary approach' became more appealing and the change was made. (The study's working title for some time was 'Competing realities, diverse needs: a multi-disciplinary approach to religious contexts of HIV prevention and care in ...' It then became '....an *inter*-disciplinary approach....' before being given the present title.)

Additional primary research

Conversations with experts in the fields of HIV support and care, in religion and with local informants were a continual feature of this study. Existing networks, local, national and international, of religious practitioners and HIV service providers would be consulted in order to ascertain issues and developments impacting the fields of this enquiry.

Secondary research

A wide ranging literature review was conducted (see Chapter Two) with continuing follow-up.

Towards a questionnaire

Taking account of the methodological concerns set out above and looking to the study's aims and objectives, following principles of inclusion and consultation and concerned not to link any single group in the community with HIV, a questionnaire was designed for distribution within the largest faith groups in the city - Christian, Hindu and Muslim. In line with triangulation's capacity to enrich perspectives and strengthen rigour the questionnaire would be used also as a guide to interviews with people with HIV and group meetings with 'lay' people from the three faith groups.

In the absence of existing and appropriate context- and subject-specific models the question 'What do we need to know?' was used to prompt and formulate appropriate and relevant questions. During this process a range of themes was identified including:

- knowledge of HIV;
- religious teachings and their influence on responses to HIV and attitudes towards people affected by it;
- talking about HIV and knowing someone with the virus;
- relationships between religious teachings and beliefs and access to HIV information, testing and care;
- opinions on sexual health education for young people;
- the role of religious leaders in raising awareness of HIV.

A copy of the questionnaire and the adaptations used to guide small group discussions and interviews with people with HIV can be seen at Appendices A4 and B3.

Towards data collection, organisation and analysis

In line with Tuck's and Thinganjana's (2007) application to qualitative text of content analysis theory, the local data would be recorded 'anonymously and in great detail' (Tuck and Thingajana, 2007: 155) and checked repeatedly for accuracy. The initial

organization of this study's questionnaire responses was conducted manually by the researcher using an Excel format (that is to view and organise, not process, data). Recorded interviews and group discussions would be transcribed verbatim and then organised and coded using manual methods and, later in the research and analysis process, NVivo 8 software. In order to maximize the use of the researcher's time a transcriber was contracted to draft preliminary transcriptions of audio-recorded data. By repeatedly running the recordings, these drafts were then completed by the researcher. The transcriber committed to a confidentiality agreement (Appendix C1) and the use of password protected access and the secure storage of any data in her possession. The numerical data, though anticipated to be limited in scope, would be analysed using SPSS16. Returning numerous times to the data, the reading and rereading of transcripts and texts would enable participants' responses to generate the identification of codes, emerging categories and themes (Miles and Huberman 1994: 29, Neuman 1994: 41 ff, Lacey and Luff 2001, Greenhalgh 2001) ensuring that the analysis would be both grounded in the multiple realities of the participants' various religio-cultural experiences of and responses to HIV and identified with key theoretical streams (Examples of the process can be found at Appendices D1 - G1).

Conclusion

This chapter has explored the methodological parameters, methods and applications relevant to this study's aims and objectives. A qualitative paradigm was the preferred and appropriate choice from the outset but resource and contextual limitations, mainly those of

- finance,
- time,
- sole researcher status.

placed some constraints on the options open to the researcher: matched interviewers, interpretation and translation services for example. Her professional background, the religio-cultural diversity of the localised data collection, the ethical parameters and the various sensitivities associated with the research topic itself, particularly those relating to enquiries into the beliefs of respondents, the stigma associated with HIV

and the vulnerabilities of those affected, and anxieties about anonymity and confidentiality, have required particular attention.

However, further reflections on qualitative typologies have persuaded the author that an interdisciplinary and emancipatory approach would be appropriate to this investigation's sensitivities and the deep interrogation of complexities which can be anticipated. It is notable that the language and the principles of dialogical engagement which characterize practical theology's stand with transformative praxis and UK/Leicester's public health policies for HIV prevention and care assume a discernable presence throughout the Chapter.

Following the original outline of a methodological strategy (at pages 72 – 74 above) a research proposal was duly submitted and accepted by the University of Derby early in 2006 and registration was confirmed in July 2008. A detailed account of the data collection and organization with preliminary analysis is set out in Chapters Four and Five following.

CHAPTER FOUR

Recruitment, Data Collection and Analysis

Characterising the study's collection of local data

It is important here to revisit the characterisation of the study pursuant to its local data collection. It is not intended to make authoritative comparisons between the three chosen faith groups: Muslim, Hindu and Christian. The study is concerned not so much with a comparative analysis of the beliefs and teachings drawn on by the three religious groups in their responses to HIV and people affected by it, but more with an analysis of how far those beliefs and teachings, as appropriated by the faith leaders, the 'lay' groups and the interviewees with HIV, inform and are assigned authority over a person's attitudes and behaviours. In other words the comparative exercise is not that between the different religious groups, although that will constitute an aspect of the analysis in terms of identifying dominant agenda, those, for example, between the conservative and the progressive. The comparative exercise is primarily that between 'authorities', that is, those authorities which determine perceived realities. In this study's context, that means the authority of rights-based public health approaches to HIV prevention and care and the authority ascribed to religious belief and teachings in approaches to HIV. Which authority dominates? Which hermeneutical framework is appropriated in response to HIV? Which hegemony dominates? Not only do these questions concerning power and authority have a local significance but they resonate in different analytical and contextual formats within much of the literature's international and global realities and complexities. For example, the literature notes

- there are those who stress and will not own any compromise of strict religious calls for sexual and relational discipline (sex only within marriage, perhaps, and/or fidelity to the marriage partner);
- there are those who appear to modify strict religious beliefs/teachings on sexual and relational discipline with simultaneous calls for compassion towards those affected by HIV;
- there are those who take a self-referential approach, i.e. the individual is the hermeneutic authority often challenging and defining orthodoxy in opposition to either liberal or authoritarian 'official' religious teachings.

The study is concerned with the appropriation and cognition of religious principles and teachings in terms of how they speak to multi-dimensional themes of authority and identity in respect of HIV/AIDS. The analysis may include reference to theological conceptualisations but neither primarily nor necessarily in 'comparative religion' terms. Rather it will draw more significantly on the resources of psychology, sociology and anthropology to assess the place of religious authority in supporting or undermining the adequacy of both religious and public health responses to HIV prevention and care in a context of extensive, including religious, diversity. It is less about the *content* and more about the *process and nature* of theological construction and appropriation and articulating its potential for influencing responses to HIV and people affected by it.

After a thorough appraisal of methodological theories and options set out in Chapter Three the various preparations for the next stage of gathering local data were undertaken.

Questionnaire

Design

As described above the researcher's reflections on her experience, the literature, her professional access to the expertise of voluntary and statutory sector practitioners, consultation with local informants and the maximization of available resources together informed the local data collection and the content and structure of the questionnaire. Clearly, the primary and 'simple' objective was the gathering of views on relationships between attitudes towards HIV and religious beliefs and teachings, but the questionnaire design would not be a simple task. As well as seeking respondents' views on sensitive issues there was the cross-cultural environment to consider and the potential for ambiguities and confusions. And with Humphries et al's (2003) emancipatory and feminist principles shaping a process which would encourage wider reflection and extended responses, the researcher favoured a questionnaire characterized by open questions rather than the closed typologies used to deliver deductive statistical analyses and findings of causality (May 1993: 86). The

questionnaire would need to be a tool for the collection of ideas and meanings in line with the phenomenological arc of the study's data collection and analysis. It was to be regarded as a quasi-interview, avoiding the perceived constraints of a face to face encounter (gender, cultural, limited resources) but offering respondents the opportunity to express views freely, confidentially and anonymously. It was anticipated that some information would provide the basis for a degree of numerical analysis but the primary focus would be participants' responses to the open questions.

Several questions would relate to similar themes. Although lengthy questionnaires are not recommended, in its various and repeated enquiries about the applications of those beliefs and teachings, it was hoped this questionnaire would then become also a means to discerning more accurately the coherent strengths and/or discordant weaknesses of the beliefs and attitudes expressed and provide a more informed bridge between the local and the general (Coffey and Atkinson 1996: 162). After further consultation with informants in the faith groups and a small pilot with people affected by HIV, a set of questions was formulated with a mixture of closed questions and options for 'open' responses. The intention was to use the same model as a guide to the semi-structured in-depth interviews with people living with HIV and the meetings with small groups. Looking ahead to the stages of analysis, an initial coding structure was identified within the questionnaire outline presented below at Table 14 (page 120). Further development was anticipated as conceptual complexities emerged and as interviews and focus group discussions were conducted, transcribed and coded (Neuman 1994: 225). But this outline, together with a request for demographic data, supported the contextual characterisation of the study and, ultimately, the development of a broad thematic framework. A copy of the complete questionnaire can be found at Appendix A4.

Distribution and recruitment

On completion of the design and consultation with informants packs containing a questionnaire, letter of introduction, basic information about HIV, contact details of HIV support agencies and a stamped envelope for returns to the researcher were distributed to potential respondents in May 2007. Copies can be found at Appendices A1 to A4.

Number	Question sets	Coding sets - examples
1,2	Routes of transmission HIV as public health issue	Knowledge of HIV Sources of HIV information Beliefs about transmission Routes of transmission Prevention and care messages
3,4	Beliefs and teachings about HIV Beliefs and teachings about intimate relationships	Teachings about HIV Teachings about intimate relationships (Hetero)sexual rectitude, traditional morality Non-judgemental, compassion, care
5	Beliefs and teachings influencing relationships of people in community	Religio-cultural authority Compassion Condemnation Appropriations of beliefs and teachings
6,7	Beliefs and teachings influencing responses to HIV	As above
8,9,10	People talking about HIV	Faith group talking about HIV Faith leaders talking about HIV Talking to health professionals etc
11,12,13	People affected by HIV talking to someone in faith group, leader	Faith leaders talking about HIV Talking to religious leader Talking to health professionals etc
14,15,16	Support for people affected by HIV	Support from faith group-HIV disclosed, not disclosed Support from other agencies
17,18	Knowing someone with HIV	Knows person with HIV Knows person with HIV in faith group Support from faith group Talking to religious leader
19	Prevention messages	Prevention message for faith group Prevention message for local community
20	Views on sexual health education in schools	About sex education Conduct of intimate relationships Teachings re intimate relationships
21	Matters what religious leaders say about HIV?	Religio-cultural authority
<u>~ 1</u>		1

Table 14: Questionnaire design with anticipated preliminary themes for analysis

Accurate representative sampling was neither attempted nor anticipated given the unstructured and 'mobile' or transient nature of some faith groups and the consequent difficulty of maintaining up-to-date contact registers, nevertheless the focus on the three largest communities with their relatively well-established networks and administrations, here particularly the mainstream Christian (Anglican, Catholic, and Free Church) and Hindu groups (those using Shree Sanatan Mandir and Shree Jalaram Prarthana Mandal) and the communities connected with the Central Mosque and Masjid Umar) offered the potential for involving a number of local mainstream and, to a lesser extent, marginal religious responses to HIV.

Using the contact list of the Faiths Regeneration Project¹², a joint City Council and Diocesan initiative to include and involve as many faith groups as could be identified in local development proposals, a total of 217 questionnaires were sent out to the listed Muslim, Hindu and Christian faith groups – 47 (21.7per cent) Muslim, 28 (12.9 per cent) Hindu and 142 (65.4 per cent) Christian – in May 2007.

Addressees were asked to return completed questionnaires by the end of October 2007. Contextually, Neuman's view that researchers using postal questionnaire methods should anticipate a rapid response turn around with a reminder after the first week and another after week two (Neuman 1994: 241), would have been inappropriate. There were two main issues. The first concerned the naming of individual addressees and the second the variabilities of leaders' responsibilities and resources particularly concerning the realities of increased work levels during significant religious seasons and festivals. For example, it was more likely that questionnaires sent to named faith leaders at their homes or the office of their religious premises, which is the normative addressee detail made available through mainstream Christian directories, would reach the appropriate 'desk' more immediately than those questionnaires intended for leaders or representatives of groups for which there was no named individual on the data base. Other than their

¹² The comprehensive resource 'Religions in the UK Directory 2007-2010' (ed Weller, 2007) was not available when the study began and the earlier edition was out of date. However, the updated Directory was used to check some contact details when a further round of questionnaires distribution became necessary.

larger, though few, worship and community centres, this was more likely to apply to minority faith groups.

Similar resource and structural implications applied in terms of religious festivals and special seasons when far less time would be available for completing a questionnaire. Although between May and October 2007 the Christian communities' main religious observances for Lent and Easter were avoided, for some leaders there would have been additional commitments around the time of Pentecost and summer holidays. Ramadan and preparations for Eid would have created pressures for potential Muslim respondents, and the Hindu Navratri and Diwali celebrations were imminent. Regular commitments to the ritual expressions of other special and seasonal obligations, responses to bereavement and pastoral need could be expected to have at least 'routine' impact on available resources. An argument can be developed here for compiling and distributing short questionnaires with the minimum amount of supporting information (Neuman 1994: 237 ff) and for a staged distribution, but given the researcher's knowledge of the context and a preferred strategy not to make methodological distinctions between the city's faith communities the initial distribution of questionnaires followed the six-months-to-reply plan. However, in the event, responses were low and slow and, as reported below, an augmented distribution proved necessary.

Included in the questionnaire pack was a request that those recipients who felt unable to respond use the reply envelope to give brief reasons for non-participation.

Assurances of anonymity and confidentiality were stressed. A reminder card, 'a note for the diary', was sent with a 'quality' paper clip in August 2007 and a further questionnaire and stamped envelope for replies distributed early in October. A total of 39 Christian responses were received at phase one, one from a Hindu and none from Islamic leaders. A further recruitment exercise followed using local informants and networks. As a result eight completed questionnaires were returned from Muslims and one other from a Hindu leader. Another Hindu leader registered a preference for a face-to-face meeting with the researcher due to an expressed inability to write their responses in English. Additional efforts to invite responses through Hindu networks delivered no further returns and at this point (January 2008) the distribution of questionnaires was closed. A total of fifty completed or part-completed questionnaires

was received with five returned blank. One of the five was sent with apologies and a note of having no time to participate. Redirected to the researcher's new address (there was a house move during 2009), a further blank questionnaire was returned, with apologies, three years after the initial distribution. This was not counted.

Interviews

On receipt of ethical clearances, consultations with informants including department heads, clinical and administrative staff and the conducting of pilot interviews with people affected by HIV, the recruitment to interview of people with HIV was channeled in the first instance through the reception staff at Leicester Royal Infirmary's Department of Genito-urinary Medicine (GUM). In this too, recruitment was slow. Consultation with those distributing questionnaires suggested three main reasons:

- a reluctance on the part of those patients and service users to engage with religious issues,
- difficulties with translation,
- an unwillingness to carry or possess any or additional material containing explicit references to HIV reflecting anxieties about disclosure.

A decision to extend the recruitment to another department at the hospital and to two local voluntary agencies was taken during and towards the end of 2007. The closing date for potential participants to make contact with the researcher was extended to the end of March 2008. At the same time the initial anticipation of between thirty and forty interviewees with HIV was revised down to between twenty and thirty to reflect recruitment realities. In the event thirteen individuals made contact with the researcher and of the interviews conducted seven were with Christians from countries in Africa. The outline biographical information of the thirteen interviewees is presented below at Table 16 (page 125)

Groups

Information about the study and invitations to participate in small groups were circulated through local faith networks including the Muslim/Christian Women's

Group and those working in multi-faith contexts, for example in education and health. This method by-passed community leaders, 'gatekeepers' to recruitment, to a greater extent than may have been the case had the original plan to channel invitations through the religious leaders been followed.

genine digrange consistent in the section of		<i>N</i> = 50
Gende	>T	
Cilu	Female	18
	Male	29
	Not known	3
Age	Tiot Mie Wi	
Age	20-29 years	1
	30-39 years	4
	40-49 years	12
	50-59 years	16
	60-69 years	10
	Over 70 years	3
	Not known	4
Religi		
itong.	Christian	39
	Hindu	3
	Muslim	8
Race/	ethnicity (terminology used by respondents)	
1cuou.	White, British, English, UK, anglo saxon, European	
	British, English, Polish	37
	Asian	3
	Indian, Indian Gujarati	6
	Descended from Adam	1
	Not known	3
Coun	try of birth	
000	UK/England	36
	India	6
	Pakistan	1
	African country	2
	Other	2
	Not known	3
Educa	ation	
•	Secondary	3
	FE, HE	27
	Post grad	12
	Not known	8

Table 15. Biographical information: questionnaire respondents (N = 50)

a entre entre en		N	
Gender			
Fe	emale	9	
M	fale	4	
Age			
30)-39 years	5	
40)-49 years	3	
)-59 years	4	
60	0-69 years	1	
Religion			
	hristian	7	
	indu	3	
	(uslim ^a	-	
Fo	ormer Christian	3	
Race/ethr			
	lack African	7	
W	hite British	3	
In	dian/Asian	3	
Country of	of origin		
Zi	mbabwe	6	
	anzania	1	
	ganda	1	
	dia	2	
E	ngland/UK	3	
Education	n		
	o school	1	
	rimary	1	
	econdary	6	
FI	E, HE, Post grad	5	
^a No interstudy.	viewees identifying as Muslim and positive for H	HIV participated in the	

Table 16. Biographical information: interviewees with HIV (N = 13)

The researcher met with two Hindu groups (n=6, n=10), three Christian groups (n=7, n=5, n=2), two Muslim groups (n=10, n=2). One Christian individual wished to participate but could not meet at the time set for the group so, in order to demonstrate a welcome and gratitude for this willingness to participate in circumstances of low recruitment a separate meeting with the researcher was arranged. Similar arrangements were made for two Muslims who wished to be involved but preferred not to speak in a group. This discussion stage involved a total of 45 participants, 8 of whom were male, 37 female. A biographical outline is provided at Table 17.

			in a commanda de communidado de la compunencia della compunencia d
Gende	er		
	Female Male		37 8
Agea			
		between 30 and 90 years	
	Hindu participants Muslim participants	between 18 and 70 years between 19 and 45 years	
5 11 d			
Religi	Christian		15
	Hindu		16
	Muslim		14
Race/e	ethnicity ^a		
	Christian participants		
	• •	Indian, Asian, White British, Other	
	Muslim participants	Black African, Pakistani, Indian,	
Count	ry of birth ^a		
	Christian participants		
		UK, India, African country	
	Muslim participants	African country, India, Pakistan, UK	
Educa	tion ^a		
	From 'School' to Post	t graduate/PhD	
a Deta	il not requested of each	individual participant. Researcher's estimate	mation of range
only.			

Table 17. Biographical information: group participants (N = 45)

Numerical data

Questionnaire

A total of 55 (25.35 per cent) questionnaires were returned, including five blank sets (9.1 per cent of total valid returns, 2.3 per cent of the total distribution). Respondents were asked to describe their religious identity. Three identified as Hindu (10.7 per cent of Hindu distribution, n = 28, 1.38 per cent of total distribution, 6 per cent of total valid returns), 8 as Muslim or Islamic (17.0 per cent of Muslim distribution, n = 47, 3.69 per cent of total distribution, 16 per cent of total valid returns), and 39 as Christian (27.5 per cent of Christian distribution, n = 142, 17.97 per cent of total distribution, 78 per cent of total valid returns).

Distrib	ution	Religion			Returns	3
N	%		n	% (n/N)	% valid returns	% total distribution
28	12.9	Hindu	3	10.7	6	1.38
47	21.7	Muslim	8	17.0	16	3.69
142	65.4	Christian	39	27.5	78	17.97
	<u> </u>	Not valid	5			2.30
217	100	Total	55		100	25.34

Table 18: Distribution of questionnaires and returns by religion.

Behind the original plan to include closed questions in the questionnaire lay an intention to designate those responses, although small in volume, to numerical formatting and assessment. With material from the responses at the open questions an assessment of frequencies and the identification of possible associations between a range of variables using SPSS 16.0 software would offer additional dimensions and substance to the data, the analysis and the findings. However, as will be seen below, the low numbers of returns drew relatively weak numerical data with very little evidence of statistical significance. With an extensive amount of opinion and narrative described at the open questions a decision was taken to focus primarily on those narrativist responses.

Categorised in nominal terms, the numerical data was described as frequency summaries and subjected to univariate analysis using SPSS 16.0. Chi squared tests were chosen to indicate strengths of association between closed questions. A summary of the relevant numerical data is offered below.

Frequencies

Christian-identified respondents represent several denominations. The majority were Anglican/Church of England. As well as being the largest Christian group on the mailing list the returns may to some extent reflect also the fact that the Anglican Diocese of Leicester and its Bishop are associated with the community-based chaplaincy HIV support project (see above at Chapter Three, Context - perspectives on a city's HIV history: page 99) and through which HIV awareness has been communicated over recent years. Other Christian groups include Baptists, Methodists, Catholics and Independents. One Muslim specified Sunni and one Hindu identified as a Krishna devotee. All but two of the Christian respondents identified as White British or English and of those Muslim and Hindu respondents who gave information all described their ethnic identity as Indian or Asian. Although the distinctions between roles and the nomenclature 'clergy', 'leader' and 'lay' vary in the different communities, 73 per cent of respondents described their role as clergy or in other leadership terms. Others (27 per cent) participate in or take some responsibility for the religious life of the community in other ways, for example as 'Church Secretary' or 'assistant teacher'.

Of those who provided information, 29 (61.7 per cent) respondents are male and 18 (38.30 per cent) female with ages ranging from 25 to 80 years. Respondents are almost equally divided between those over 55 years and those below. More than two thirds of the respondents (67 per cent) are aged between 45 and 64 years. Some information on education levels and qualifications was requested. Almost 88 per cent indicated graduate, post graduate and professional with the remainder describing 'O' and 'A' level attainments.

Asked whether the teachings and beliefs of their religion influenced the responses of the faith group to HIV/AIDS and to people with HIV, 67 per cent agreed. Between 49

per cent and 55 per cent also thought that those beliefs and teachings influence (through media reports, books, conversations, attitudes etc) the responses of people outside their religion. According to 56 per cent of respondents people in their faith group do not talk to one another about HIV/AIDS, though a similar proportion (57.14 per cent) of respondents answered 'Yes' in response to the question 'Do <u>you</u> talk to anyone in your group/community about HIV/AIDS'? When asked their opinion as to whether anyone in their faith group affected by HIV would feel able to talk to a member of the group about their concerns more than five times as many replied 'Yes' (81.63 per cent) as replied 'No' (14.29 per cent).

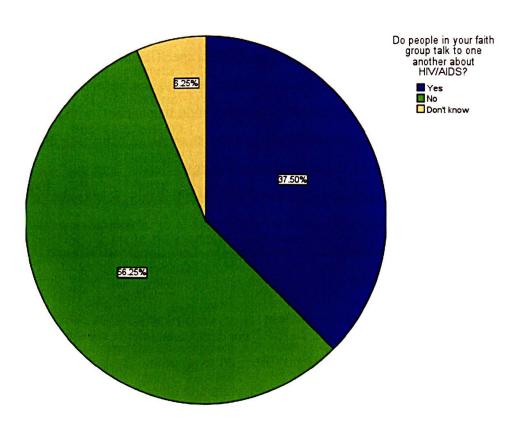


Figure 2. Do people in your faith group talk to one another about HIV/AIDS?

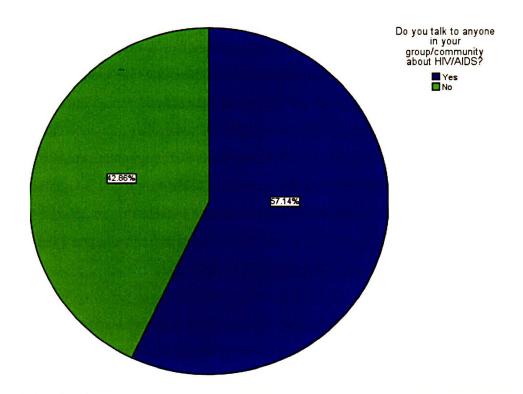


Figure 3. Do you talk to anyone in your group/community about HIV/AIDS?

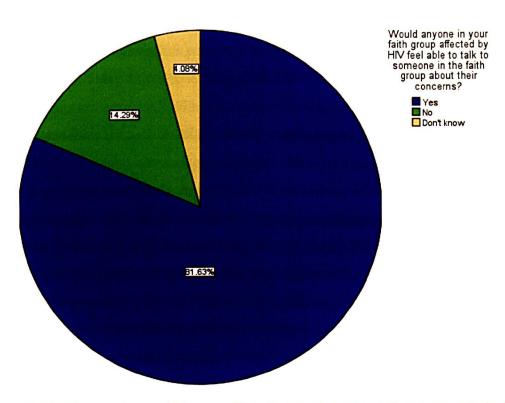


Figure 4. Would anyone in your faith group affected by HIV feel able to talk to someone in the faith group about their concerns?

Fourteen (28 per cent) respondents had been approached by someone to talk about HIV. They were divided equally (49 per cent) as to whether or not their religion's teachings and beliefs influence talking about HIV/AIDS and 43 per cent of respondents said that their religion's teachings and beliefs had been an influence in their speaking of it to someone in their faith group. Whether that influence can be described as compassionate or disapproving, supportive or judgmental, cannot be deduced from the frequencies data. In some respects neither approach is significant. The key issue is the extent to which religious beliefs and teachings are deemed by respondents to have influence. The thematic examination through Chapter Five of the responses to open questions will offer evidence in this regard.

Those who attach importance to that which faith groups and faith leaders say about HIV/AIDS – that it matters – numbered 44 (almost 90 per cent). As many (43 per cent) thought beliefs and teachings influenced people in their community in deciding to approach health professionals or teachers about having HIV information as influenced people in deciding not to approach them. However, a larger proportion (49 per cent) thought that their religion's beliefs and teachings did not influence a person speaking with health professionals and teachers about testing for HIV. A little more than half those who responded stated that their religion influenced their talking to a member of the faith group about HIV/AIDS but the reverse was true when asked about talking to health professionals or teachers about HIV information and testing (53 per cent and 77 per cent respectively). These results offer some evidence for cognitive ambiguities between religious concerns/contexts and health concerns/contexts, that is the separation or compartmentalization of health and religious 'worlds'. Indeed, some respondents in their comments did suggest that anyone concerned about HIV would go to their doctor, not their religious leader. Others took the view that the shame a person felt would prevent them approaching anyone, especially making an approach to a person within the religious group. These views will be discussed more fully as the data report and thematic analysis are developed below with the presentation of open question responses.

Fifteen respondents know someone with HIV.

Measures of association and statistical significance

All respondents irrespective of gender, age or other demographic characteristic agreed HIV was a matter of global public health concern. Few results, though, provide measures of statistical significance (p < 0.05). For example, although all of the 15 women (100 per cent) who answered the question thought HIV is a public health concern for Leicester only 85.7 per cent (24 of the 28 men who answered the question) agreed. However, the difference in opinion between males and females was not statistically significant (p = 0.124, that is not less than 0.05). The significant associations are described below.

'Role' as independent variable (with 'role', described as 'clergy/leader' or 'lay') All those identified as clergy/leader who answered the question agreed that HIV is a public health concern in the UK while of the lay respondents only 83 per cent agreed (p = 0.016). Similar associations occur in the case of HIV being a public health concern for the city (96.8 per cent versus 70.0 per cent, p = 0.013) and for their faith group (72.7 per cent versus 33.3 per cent, p = 0.016) suggesting that the clergy/leader group have greater access to HIV information than lay respondents or saw it as their responsibility as a leader to acquire such information, particularly if HIV had been raised by someone in their faith context. No lay respondents have been approached by someone in the faith group to talk about HIV, but a third of clergy/leaders who answered the question have been approached (p = 0.021). None of the lay respondents know anyone with HIV while 39.4 per cent of clergy/leaders know someone with HIV (p = 0.010).

'Education/qualifications' as independent variable (with 'graduate, post graduate, professional' as one category and 'to O/A levels' as the other).

More than twice as many of the graduate/professionals than those with 'O' and 'A' levels thought a person in the faith group would feel able to talk to someone in the faith group of their concerns about HIV (93.9 per cent *versus* 40 per cent, p = 0.001). Significantly more of the graduate/professionals think it matters what faith groups and faith leaders say about HIV/AIDS (97.1 per cent *versus* 60 per cent, p = 0.003).

Some responses in the educations/qualifications category draw close to statistical significance. More graduate/professionals than the 'O/A levels' group agreed HIV

was a public health concern in the UK (97.2 per cent *versus* 80.0 per cent, p = 0.094). And of those graduates/professionals who responded, more think that the teachings and beliefs of the religion influence the responses of their faith group to HIV/AIDS (78.1 per cent *versus* 40 per cent, p = 0.074).

'Gender' as independent variable.

No statistically significant associations (p < 0.05) emerged from the chi square calculations when gender was associated with a number of closed questions, though some results suggested scope for further investigation. For example, more women than men (40.7 per cent *versus* 66.7 per cent) think their religion's teachings and beliefs influence whether or not people in their faith group talk to one another about HIV/AIDS (p = 0.088). More men than women (92.9 per cent *versus* 75.0 per cent) think a person in their faith group affected by HIV would feel able to talk to someone in the faith group about their concerns (p = 0.097). And more women than men (44.4 per cent *versus* 20.7 per cent) know personally someone with HIV (p = 0.083).

In all a wide range of variables was tested for measures of association and strengths of significance but no marked associations could be made to enhance the findings or bolster connections. It may be possible to assert that those with a higher level of educational attainment were more informed about HIV, its impact and their religion's responses to it and that women adopted a more open approach to HIV but the data base is small and findings therefore tenuous. Indeed, given the low number of postal questionnaire returns and the immediate value of the numerical data rendered so dubious and with the predominantly phenomenological thrust of the study (Denscombe 2010: 94), this has proved a weakness in the data collection process. Clearly, anticipating neither the low number of returns nor acknowledging the potential flaws in the process, the research design would, in hindsight, have been more appropriate to the context and the reality of its purpose and locality if the closed questions had not been included (Fetterman 1998: 103-108). A number of bar charts are available at Appendix D1a.

Attention was then redirected to the content analysis with a particular focus on the responses of religious leaders and representatives to the postal questionnaire's open questions together with data generated by the group discussions and the interviews with people with HIV. A detailed examination of the local material was undertaken in order, ultimately, to connect and engage more fully and authoritatively with the general, not to 'generalise' findings, a claim rarely valid for small qualitative studies, but to support a wider epidemiological and theological relationship (Coffey and Atkinson 1996: 162 - 163).

The remaining local data is organized below at Chapter Five and in sub-sections following the key 'trees' of the coding process. The 'trees' are set out at Appendix G1.

CHAPTER FIVE

Local field data: reports and preliminary analysis

Introduction

Questionnaire responses to open questions, transcripts of interviews with people living with HIV and the transcripts of discussions with small groups were read and reread. Initial organisation and coding were undertaken manually but later the NVivo8 software programme was used to create and facilitate a more manageable and accessible process. NVivo8 offers a wide range of tools by which to organize qualitative and quantitative data. For this researcher, given the nature of the study and the late stage at which the resources of NVivo8 became available, the key advantage in its use lay not so much in the software's capacity to provide a 'home' for extensive and various sources of data and the production of charts, models and matrices (although some of these were useful), but more in its facilitation and on-screen displaying of well organized, thoroughly coded and easily accessible data storage.

The coding process was lengthy and time consuming. Texts were revisited repeatedly as participants' responses to questions and the narratives they engaged were distilled and key themes identified. Codes were generated which reflected both broad and also particular responses to the open questions and which exposed issues which elicited an engagement with personal history. Some merging and clustering of codes, or 'nodes', into 'trees' (to use NVivo's terminology) enabled distinctions to be made between various concepts, patterns and issues (Bazeley 2007: 104 ff). The tree code structure is represented at Appendix G1. But following, in general terms, the coding structure outlined at Table 14 (page 120), this iterative approach gradually exposed a number of nuanced connections from a diversity of perspectives and began to suggest a theoretical clustering based on the themes outlined below at Table 19.

A closer examination of the themed content of participants' responses and the consequent emergence of this early theoretical outline will follow.

		COMPLEXITY		
		DIVERSE NEEDS		
Multiple Identities	Diversity		Inequalities	Power Relations
		RELIGIOUS AUTHORITY		
	Compassion		Stigma	
	DISSONANCE		COHERENCE	
		COMPETING REALITIES		
		COMPLEXITY		

Table 19: Early theoretical outline

By and large the themes and narratives are set out consecutively with the views of the Questionnaire respondents followed by those of the lay Groups and then those of the Interviewees with HIV. To assist the reader in identifying participant categories a bold and italicised Arial font is used as an initial indicator.

Themes and narratives

HIV knowledge and beliefs

The questionnaire began with a request to describe the routes of HIV transmission and its impact at global, UK and local levels. Many **questionnaire respondents** state that 'unprotected sex' is the main route of transmission. Others responded in more religious and/or moralistic terms: 'illegal and unnatural sex'; 'failure to observe religious standards'; 'low moral standards'; conduct contrary to biblical teaching'; 'sexual immorality'. One respondent referred the researcher to a biblical text at Jeremiah 8.9 adding 'our national condition is much the same as in Jeremiah's day'. 13

Other respondents point to inequalities – 'poverty', 'misogyny and homophobia',' lack of opportunities' and the absence of resources to acquire condoms, clean needles and

¹³ The text (not provided by the respondent) reads 'The wise shall be put to shame, they shall be dismayed and taken: since they have rejected the word of the Lord, what wisdom is in them?' (New Revised Standard Version Bible, 1989) Alternative versions of the Bible will give different translations and emphases. The version of the Bible used by the respondent is not known.

treatments. Two refer to the Roman Catholic Church's prohibitions concerning condom use ¹⁴.

A number of respondents gave injecting drug use, contaminated blood products and mother to child transmission as main routes of infection in the UK and in Leicester. This suggests a need for widening access to and distribution of accurate information given the realities of the exposure data presented below at Table 20 showing sex between men and heterosexual transmission as the main transmission categories in the UK and the East Midlands.

HIV UK: Exposure category	Year 2010	HIV East Midlands: Exposure category	Year 2010
Sex between men	29,647	Sex between men	831
Injecting drug use	1,565	Injecting drug use	95
Sex between men and women	34,312	Sex between men and women	2046
Blood/blood products recipient	530	Blood/blood products recipient	38
Mother to child transmission	1,473	Mother to child transmission	70
Other/not known	1,897	Other/not known	62
Total	69,424	Total	3142

Table 20. SOPHID Table 2: Numbers of HIV-diagnosed persons seen for HIV care in the UK by country, SHA of residence and exposure category: 2010. Survey of Prevalent HIV Infections Diagnosed (SOPHID) Data tables 2010. [Survey of Prevalent HIV Infections Diagnosed (SOPHID) Data tables 2010]

References are made to ignorance, complacency, silence and apathy. Immigration and diversity, 'lack of care for the other' and 'poor direction from the church' are issues for some respondents as is the 'silence re real patterns of behaviour'.

¹⁴ News reports in November 2010 (BBC News Europe 20 November 2010) suggested that the Pope, during an interview for a book by Peter Seewald (2010), was softening his position on the use of condoms to prevent HIV. The Catholic Truth Society published the text of the interview. 'Are you saying, then, that the Catholic Church is actually not opposed in principle to the use of condoms?' asked Seewald. 'She of course does not regard it as a real or moral solution, but, in this or that case, there can be nonetheless, in the intention of reducing the risk of infection, a first step in a movement toward a different way, a more human way, of living sexuality' replied the Pope (Catholic Truth Society, 2010). The Pope's meaning was unclear. His apparently positive reference in the interview to a male prostitute using a condom raised questions about the use of condoms by HIV discordant couples. Father Federico Lombardi, head of the Holy See Press Office, explained the Pope believes it is better to use a condom rather than not to use it and risk the lives of others (Vatican Radio, 21 November 2010).

Small group participants also registered a range of suggestions as to how HIV is transmitted. Some correctly understood unprotected sex to be the main route world wide. One person referred to HIV being known as the 'gay disease' and another reported that sexual promiscuity and sex between same sex partners were against the teachings of the church but that it was important not to judge. A similar view was articulated in another group

... so obviously we're not saying that HIV is only related to homosexuality but it might run a bit more, you know, it might be higher amongst the gay community ...

Apart from a later reference to a high prevalence non-African country and to India most answers to questions about the global picture related to HIV in Africa. Someone, a white participant, spoke of the impact of poverty and Africa's 'structural polygamy' with male partners moving and living away from home in order to find work and of HIV being 'hot wired into the network of peoples' relationships, the mesh of them.' One person said they had not come across HIV in Leicester but had heard of it as a concern in Africa. Another white person, referred to what he called the 'irresponsible African personality' resulting, in his view, in sexual promiscuity. An Asian participant took the view that the national and local incidence of HIV was due to immigration from sub-Saharan Africa and the diversity of the local community. HIV transmission in the UK was seen by some as mainly due to injecting needles or contaminated blood used for transfusions.

Some responses were expressed in terms which suggested a bias for acknowledging HIV only as a developing nation concern with some reluctance to regard it also as a UK national or local issue, indicating a preference for distancing oneself from the entire HIV phenomenon and, more especially, from its being a sexually transmitted infection.

Indeed, one group noted this in their own exchanges.

Lum, well, what I'd heard and understood was that in our western society it's more um by drugs, like sharing needles or, you know, and unclean needles and

things rather than, um, passed on by sex. Whereas maybe in the third world it isn't so much about drugs. It was more about unprotected sex.

- I think you'd already said that in the developing countries the issue is more about, um, transmitted sexually and that's, as I say ... the most thing I hear about it is via the news and everything and, um, the cases and obviously in the developing countries there's a lot of cases of rape and goodness knows what so, um, yes, it's tragic really that, um ...
- But are we happy to think that ours is all from drug related and not sexual in this country? Is that a wrong perception that we have? Is that more acceptable to us to think that it's drug related?

One spoke of her anxiety about the risk of transmission by mosquito bites; others referred to the risk from walking with cuts on their feet where there is blood on the floor; another about the blades used by barbers. Several referred to mother to baby transmission. As above, there was little awareness that these latter are the least likely ways to contract HIV in the UK or in Leicester. A small number spoke of the tendency to assume, if a person's HIV status became known to others, that the infection had been acquired sexually.

- ... if I hadn't met through the church people who have HIV ... my experience of thinking I might know people with HIV would be restricted to goss ... gossip about ... colleagues who were known to be homosexual and speculation about their bouts of ill health.
- If you're unmarried especially and you are found to have AIDS then people might question all sorts about your purity and your decency and your morals ... especially if you come from perhaps a religious background ... where it's not widely accepted to have sex before marriage.

Another group participant acknowledged that she may not have known about the anxiety of a friend's relative after a needle stick injury at work if the route of potential transmission had been sexual.

But if someone has sex and contracted it then maybe they wouldn't be so open about it. I - I think it's how you – how you got the HIV rather than the HIV itself.

Interviewees with HIV spoke of transmission in different terms. The facts of transmission were personalised and woven into their story in various ways. Risk behaviours were now well known even if there had been little awareness and few prevention resources to draw on at the time of infection.

- I am thinking that I got it from the first man that I go with or from the second man that I go with. So I'm thinking between the two persons. That's why I am thinking because I didn't get it from myself ... So I don't know between these two people.
- ... when they get drunk and they are more happy, they forget about protecting themselves. That's when they spread the disease because they don't know what they are doing.

For some, infection was understood to have been beyond their control. There was more than one reference to the behaviour of men: to women being faithful to their partners but the men having many partners.

I think ... the main reason why people are infected is not being faithful to each other because I can see sometimes a woman are faithful to men but sometimes you – let's say sometimes you've got one man and that man some time can have many relations behind your back so you end up catching the disease from that person because you – that person is not faithful to you but is pretending to be good so you end up having the disease.

Some interviewees spoke of their regret at the ignorance of others with one suggesting that religious leaders could help communicate accurate information about transmission. Two, who had acquired HIV in a higher prevalence and poorly resourced country, spoke of searching their history to know more clearly how they

came to have HIV. The inadequate and unhygienic hospital care they had received years earlier, perhaps the blood used in transfusion or the unsterilised needles used in other procedures, was regarded by them as the source of their infection. One person saw their contracting HIV simply in terms of 'bad luck and ignorance'.

Another related HIV transmission to the Catholic Church's position on condom use and the UK government's slow response in providing information when the first HIV infections were identified. Exposure to the western world was cited as increasing transmission among African people and someone spoke of the cultural diversity of Leicester and the wider range of transmission routes which that would, in his opinion, foster. Another referred to 'different sex'.

Sources of HIV information

Few *questionnaire respondents* referred to sources of HIV information, a number declaring that there had been no need and others not anticipating any need. There were references to the necessity for any information and communication of it to be expressed in religious terms.

I would wish [information] to respect our teaching ... and acknowledge that people choose to live by it and that it is a healthy and safe choice.

One respondent did display a poster with contact telephone numbers for members of the congregation with concerns about HIV. And a small number of respondents acknowledged their own role as (potential) sources of information, one noting 'I had a lack of understanding about a whole group of people who face challenges'; and another stating

Better informed I am the more effective pastorally to those affected and to help others learn about real issues.

One commented that 'public health information was sparse'.

Group participants drew information about HIV from a number of sources. There were references to TV news and soaps, magazines, posters, health clinics and charity

magazines. Some recalled the early mass publicity campaign with leaflets featuring tombstones but said they encountered few contemporary references to HIV. One person had been a school teacher when information about HIV was first circulated.

I mean when – when I was working in school, I think it was in the 1980s was it when the first explosion hit? Endless staff meetings talking about this but we were led to believe then that it was all – it was just same sex sex sort of thing. There were no heterosexuals. Nobody thought it came from that at all ... you sort of got these visions now of Diana, now she's been dead ten years hasn't she, going around hospitals talking to these AIDS patients And have we moved on in the twenty years really?

Several people referred to having seen no information in Leicester. How far this opinion was due not so much to the absence of any awareness-raising material or more to its appropriation and application may be a legitimate focus for further enquiry (Denscombe 2010: 315) since one group noted the focus appearing to be the prevention of pregnancy rather than sexually transmitted infections. Young people, they thought, prioritised oral contraception without recognising that the pill would not protect against STDs.

Um, and I think - many people — most people would know someone or hear of someone who may be, you know, pregn — teenage pregnancy. Again it's like N said, we've never heard of anyone contracting HIV. We don't know anyone. And that makes it very — or it could happen to everyone there but it may not happen to me. I think it's that type of attitude.

One group noted a direct correlation between their heightened awareness and understanding of HIV, their close association with a person living with HIV and there being members of their congregation affected by HIV.

Another group member acknowledged the inadequacy of her and her community's knowledge of HIV.

I'd just like to reiterate that I do think it's important to understand how it is prevented because I may have learnt what I learnt from the soaps, but that may not be an accurate picture. I may not have the whole picture. And there may — I'm sure there's a lot at the minute I don't understand or I don't know. Um, and I think there needs to be general awareness because it may not, you know, in my — amongst my friends it may not have happened, amongst my parents, um, generation but there is a lot more unprotected sex and sex outside marriage within Muslims occurring more and more you know. I think it's increasing rather than anything, you know.

Religio-cultural tensions were expressed also in other groups.

... you've got people who are desperately holding on to their roots and refuse to believe any ... refuse to learn anything new ... and then you've got the people who adopt to new ways and are now exploring everything are willing to learn and accept everything that comes with living in a westernized country and educating themselves and therefore educating their children as well. So their children, if they ever did have AIDS – like if I had AIDS, I'd be able – I'd be open to talk to my Mum and Dad, um, as opposed to some of my friends who would never tell their parents about it.

Some references were made to sex education programmes in schools during which similar tensions often surfaced. The main issues concerned parents withdrawing their children from lessons and the consequent access or otherwise of young people to sexual and reproductive health information, the challenge to parental responsibility and the early age at which group participants understood children begin sex education lessons in school. These issues are given further consideration in a section below (from pages 157-164) on sex education in schools.

There was a reference to the HIV training a participant had undertaken in her professional life. One asked the group not to blame Africa or 'the monkey', pointing out that businessmen, tourists and sailors traveled the world 'and you know they didn't have their wives with them so they had good times everywhere and that's how it spread.'

An African woman held that being very thin was an indicator of HIV/AIDS and another, also African, told of a young woman with HIV putting her blood in the family's food and infecting them with the virus. It was made clear in this account that the young woman was of a different nationality from the family. In the same group questions were asked about the risks associated with mosquito bites, touching, sharing toothbrushes and chewing tobacco.

A dawning realization among the group that their knowledge about HIV was limited led to a request for information sessions and a regular drop-in to be established with local specialist agencies for women in the community. Another group noted a similar need in their community and began to discuss how appropriate the religious meeting place would be as a venue. Something of a consensus emerged. 'It's a safe house'.

Since diagnosis *interviewees with HIV*, of course, were well informed about transmission routes given the need to continue to protect themselves and avoid infecting others. Information would have been communicated during post-test counseling and in subsequent meetings with doctors and other health and social care professionals.

Some remarks during the interviews suggested pre-diagnosis difficulties in cognitively relating risk information to their own life style and identity.

Someone who had been at school during the major UK campaign in the 1980s remarked

... we had all the adverts on television that, you know, 'AIDS is going to kill you', sort of thing and I think even at that point we were sort of 'It's going to happen to somebody else. It's not going to happen to us'. We're – even when I got my diagnosis my friend came with me to get the diagnosis and she said 'It doesn't happen to people like us'.

Chiming with established health belief theorizing and health promotion models (Davies and Macdowall, 2009), others spoke of this unwillingness or incapacity of people today to connect behaviours and lifestyle with risk knowledge whatever the source of information.

Reference was made to ignorance and to a refusal on the part of many to take seriously any suggestion that HIV could be an issue in their life. One interviewee noted that although everybody, in her view, now knows about HIV many don't believe they can get it. Another spoke of people knowing about the need to use a condom but refusing to do so because 'we don't get the pleasure'. Several interviewees asserted the need for pastors in churches to educate their congregations but then acknowledged 'some people listen, some don't'. Although agreed by some group participants to be an effective component of HIV education, few people with HIV speak openly of their diagnosis and their life as a person with the virus because they fear discrimination will follow. One man told of a cousin in India dying with HIV illness and no-one attending the funeral. One person spoke of the Christian teaching she had seen on the internet referring to AIDS as a punishment from God. Another, although feeling unable to disclose her HIV status in her own church, did make the case for people with HIV finding the confidence to speak out.

Silence is going to kill the whole world.

The education of children and young people was urged.

Throughout the course of this study a number of barriers - for example those defined by religious beliefs, culture, gender relations, sexual identity, socioeconomic circumstances, education, communication skills and stigma - are presented as limits to effective appropriation and application of sexual health information. The following account of the beliefs about HIV transmission offers additional perspectives by which those barriers and their impact can be conceptualised.

Beliefs about transmission

The religious leaders or representatives who responded to the questionnaire set out those teachings and or principles which shape their approaches to and understandings of HIV. Together with the contributions from the small groups and the interviewees, their responses have been categorised here as 'beliefs about transmission' but, in broader terms, as can be seen in Table 14 at page 120, they inform the responses to most if not all of the questions. It is anticipated that as the data are reported and

subjected to preliminary scrutiny issues of identity and authority will present and elements of coherence and dissonance begin to emerge.

The main positions described, whether using theological language or not, relate to the paradox at the heart of much religious experience and personal history: the human need, at one and the same time, to flourish both in relation and as autonomous individual when the interests and the perceived realities of the one may be in conflict with the interests and perceived realities of the other. It is the paradox with which every social grouping and individual grapples, not least the religions and the religious of the world and a paradox which neither (as this researcher will argue later) public health strategies nor theologies can address adequately as they relate to the provision of HIV prevention and care. The need for coherent believing and knowing confronts the need for consistent health messages when the required respect for religious views collides with necessary protections for sexual minorities and the furthering of gender equality (Hunt 2004).

The tensions described above are represented in the *questionnaire responses* in various ways but captured most concisely in the familiar maxim, at least in Christian circles, '*Hate the sin, love the sinner*'. These tensions, generally understood to characterize theologically conservative approaches to religious believing, surface in various forms a number of times in the data.

- Deep sympathy and concern + overt hostility," they deserve it".
- Christian values or Victorian values hardwired into people: some condemn, others full of compassion and care; concern to educate.

That there are few responses which are either fully condemnatory or fulsomely supportive will be discussed in the following chapter. Examples of the first include:

- Low moral standards lack of care for the other poor direction from the church.
- Conduct contrary to biblical teachings on hygiene and sex.

- Abstinence from sex before marriage. Marriage for life as per Bible pattern, Christ's teaching.

And of the second

- Poverty, lack access to info/condoms, misogyny + homophobia; lack access to medical care; drugs.
- How got it should be immaterial to love who need to be loved, served etc.

 Guess we probably mostly draw conclusion about how person got it and maybe act differently; depends.
- Love responsibly, treat others as beloved and respected children of God, not your personal property. Learn to see as Christ sees.

Notions of 'innocence' and 'guilt' continue to influence responses.

- ... Not all people who have HIV are responsible for their predicament eg children of infected parents, those who have unfaithful partners, but many have committed sinful behaviour. Nevertheless as Christians we should offer them compassion and practical support whenever and wherever we can.
- An illness (not a punishment); an illness that can be contracted through unprotected (and often promiscuous) sex may be innocent victim eg blood transfusion or living with result of own actions or actions of partner.

Those in the **small groups** spoke of their beliefs in similar ways. As one person put it, echoing the Christian clergy response:

The sin is frowned upon rather than the sinner itself and the sinner is therefore viewed with compassion and um – and – love – and um – encouraged to, you know, make his way towards God or God consciousness of whatever faith that person might be, the person who's actually got AIDS or HIV ...

Distinctions between innocent and guilty were noted as familiar and valid underpinnings to their religion's and their community's responses to HIV.

... there is still a sense, as it were, innocent or less innocent contractors of this disease ...

One small group participant reflected

... as a perfectly innocent individual you have this disease because it's been passed on to you and that's another sort of theological questions isn't it ... how do we understand that and how does that person deal with that?

And in an example of the self-interrogation which the discussions often generated

I mean if you said "well this was an innocent or uninnocent person who got malaria", I mean that doesn't make sense does it? I mean ... that is still the terms in which ... you both find yourself thinking about this or you're aware that people do think about it.

Mother to child transmission receives some attention in 'innocent victim' terms but, by and large, beliefs about transmission focus on and opprobrium is reserved for those who have sexual relationships outside marriage.

The Catholic Church's position on the use of condoms raised questions for some.

- ... at the level of the Vatican and the official teaching they would not condone condoms. They would say it shouldn't be even to prevent AIDS ... is that right?'
- 'That's the official view.

Someone in the group went on to point out that that some religious took a different view and some priests, they thought, also. This questioning of Church authority was justified in the religion's calls to be compassionate and just.

- ... I hope that's one of the best things about Catholicism that people are compassionate towards other people.
- ... there's teachings in the Church about God which, yes, you should accept if you want to be Catholic, but certain things you should decide perhaps for yourself ... poor people they tend to be very much more in obedience to the Church than we are in the west I think.

Another group spoke also of the influence of social differences.

... so it's sort of like the lower class disease, um, because all the Black in Africa were the servants around the house. So ... they associate it with the lower class as well.

There is reference to conspiracy theories, to the virus being a punishment from God for wrong behaviour and to it carrying apocalyptic and eschatological messages.

...there are a lot of people that seem to think that HIV is man made. I mean there's a few conspiracy theories flying around like that... I've read a lot about HIV how it tends to mutate itself very quickly therefore bypassing any treatments that can be created for it. And as far as I know there aren't many other viruses in nature that can do that or do it as stealthily or as quickly as HIV can. So that has made me think, you know, maybe there is maybe a little bit of man made genetic modification to an existing virus to make it into the HIV virus, maybe that kind of notion exists, but you'd have to be one hell of an evil so-and-so to come up with that as a means of population control. But that's what it is evidently, isn't it, population control.

... there are references made to diseases that will appear towards the end of time that mankind has never seen before, never experienced before, and is completely new and completely alien to what we've been used to for the previous millennia and I think HIV falls into that category.

Characterized by their struggle to make sense of what is happening to them and to their relationships and providing examples of both tentative and forthright, diffident and confident approaches to their various religio-cultural constructs, *interviewees* spoke of their beliefs about transmission and accounted for their HIV infection in a number of ways.

One person held that different beliefs will generate different responses to HIV. Noting the limited capacity of Church pastors to prevent transmission of HIV she questioned how 'pastors and the other leaders' could

'follow up to every household, "Are you doing this?" It's not according to the religion it's according to the beliefs. It's up to the person who makes his or her own decision ...'

and then reflected on her partner's conviction that he will not contract HIV:

... "I don't get HIV from you". His cultural beliefs ... It's according to what he thinks ... Well maybe there will be other beliefs rather than going to Church or to believe in God then he's got other beliefs ... like I was saying that my partner just say "Ah, I'm OK" ...

In a similar vein another pointed to the diversity of Leicester and the various beliefs and behaviours which, in different ways, may put people at risk.

... there is so many people from different kinds of walks of life, different countries, different cultures, all staying together, so that it is bound to influence maybe what we do in day-to-day living and how we are associated, so I think it becomes a bit more wider on how it is transmitted in this society we live in now.

Lifestyles came under scrutiny. One referred to the impact of alcohol.

Several spoke of the silence, the blame and the shame associated with HIV and the impact it had on their life.

- They won't speak at all ... I can count there are certain people that are affected but they won't come out because they feel that Oh, if we'll say that we are HIV ... nobody will marry our children. Nobody will call. We'll be out of the community... Your social life will be ruined, everything. Because people feel that if you are HIV and if you go to that person's house, if you shake hands or if you drink at that person's house or things like that you might get infected.
- HIV is getting spread but some people think that it is a shame ... and we don't touch these people and we don't talk to these people. When I was admitted in hospital ... all of the relatives ... they were not sitting beside me.

One expressed concern at being thought of as a prostitute, another at the assumptions made about her having several sexual partners. A participant saw on the internet 'AIDS is a punishment from God'.

During the interviews several participants spoke at length about their personal circumstances and the life changing impact of an HIV diagnosis, reflecting for some a process of deep self-examination. Their stories can be described as quests for coherent meaning and understanding as they struggled to draw together the facts of their experience and known religio-cultural teachings and responses. Clearly for some the outcomes were built or building on an empowering autonomy; for others the barriers of self condemnation remained firmly in place (Yip 2005, Jaspal and Cinnirella 2010, Yip et al 2011).

The struggle involved identifying and naming the source of their infection. While some interviewees were aware that their sexual partner had been the one with HIV and put the fact of infection down to ignorance and their respective failure to avoid transmission of the virus, one participant was explicit in describing her infection as the result of a trust betrayed. Some were certain they had acquired HIV through medical interventions. One person was particularly aggrieved at her inability to bring to justice those health professionals whose incompetence, as she saw it, had resulted in her contracting the virus. Her diagnosis had brought significant emotional and

mental health problems. For another, infection by a similar route had led to the breakdown of a marriage and the loss of home and income. One person referred to HIV as a specific intervention by God or by Satan. For another the route of infection was disputed within the family.

'She thinks that it is my fault. I give – give her brother, but I didn't. If I did then my brother also complain to my husband that you kill my sister.'

One spoke of 'good HIV and bad HIV', a reference to the hierarchic construct of responses to HIV which insist on referring to the 'guilty' and the 'innocent victims':

'Like good HIV is ... when it's been not your fault ... let's say a blood transfusion ... and then it could be it's in Africa because they don't have the money to deal with it and then it's drug users ... and then you've got dirty queers at the bottom of it ...'

Responses to questions about participants' HIV prevention and care messages to their faith groups and local communities could be expected to reflect also the expressed beliefs about and knowledge of HIV.

Prevention and care messages

A number of *questionnaire respondents* called for everyone to practice safe sex. One advocated the use of condoms, two, more obliquely, advised 'protection' and another 'prevention methods'. But for many respondents, strategies for HIV prevention and notions of safer sex reflected a religion-informed moral approach couched in terms of chastity and fidelity. Examples include

- To follow commands of Allah and in all aspects to abstain from what is forbidden.
- Faith groups ... should stand up for traditional principles and age-old taboos which have protected societies in the past.

Abstinence from sex before marriage. Marriage for life as Bible pattern (Christ's teaching) Gospel recipe for us all Isaiah 53.6, Tim 1.¹⁵

Some, however, took what may be described as a more liberal line and proposed more openness, greater honesty about the presence of HIV within communities and the sexual lives of community members. One person, in a call for faithfulness in relationships, included 'hetero or homo' and another wrote of abstinence being 'a counter-productive message'. Any relationship between prevention and social justice barely figured. There was one reference to the need for the empowerment of women and another for 'support to get out of poverty.'

The tone of the responses in most of the **small groups** was less absolutist and more compassionate than those of the questionnaire respondents. Calls for more awareness and an appreciation of the complexity of lifestyles and relationships informed a notably tentative approach when the realities of and responses to sexual morality and personal responsibility were addressed. This sense that transition not tradition was in charge can be detected in a number of responses, reflecting some of the tensions relating to intimacy's place in contexts of secular and religious diversity and change described by Sylvia Walby in terms of complex inequalities (Walby, 2009).

One group member referred to knowing of a drug using mother giving birth to a child with HIV and drug dependency.

...But we can't sit here and sanctimoniously tell her to behave herself and not to take any more drugs. You can only do the best you can, can't you? I couldn't think of – I couldn't think of anything feasible to say that wouldn't sound sanctimonious.

And the participant advocating 'Protection, protection, protection' added '...The Church might say that's not really the kind of life you should be leading anyway but if you're going to lead that kind of life then it's about protection.'

¹⁵ Isaiah 53.61: 'All we like sheep have gone astray; we have all turned to our own way, and the Lord has laid on him the iniquity of us all' (NRSV 1989). Timothy 1. This reference applies to an entire chapter of fifteen verses encouraging faithfulness to the gospel of Jesus Christ. This is the researcher's interpretation and emphasis and may not have been that of the respondent.

Noting that the main route of transmission was sexual, one person posited a 'Stick to the person you married' rule. Others pointed to the differences in their community between the generations. And in a similar vein:

I think you know a softly-softly approach to it in educating specifically youngsters. As again the older generation, parents, grandparents, I don't think they would particularly pay attention to it even if they did hear about it. But I think ... young people, they're more aware of it. They are aware that it does concern them.

With their responses deeply embedded in their religious philosophy another group saw their practice of compassion towards all life, 'becoming perfect examples of compassion', as the key to assuaging suffering in all its forms including that associated with HIV. It was held that with increased compassion levels of 'greed, pride and envy' would diminish. The goal was always union with God and HIV 'like any other disease was a hurdle on the path back to Godhead'.

The personal experiences of *interviewees* and their reflections upon them clearly influenced responses to questions about HIV prevention and care. Religious and cultural dimensions surfaced more as barriers to rather than generators of prevention and care.

One person spoke of the patronizing attitude of the church, another of the Pope's suggestion that HIV can pass through a condom. Acknowledging that not everyone will listen, others called for the religious leaders to break their silence about HIV and become instrumental in raising awareness in their communities of HIV and creating the environments in which HIV could be discussed more openly.

Churches are not speaking. Maybe some, but from where I've been there's nothing like that.

Prayers referring to people affected by HIV while welcomed were not thought to be an adequate response.

We just pray, pray, no education ... It's affecting everyone whether black, white, pink, yellow. It's affecting them. So it's an issue which should be, you know, put on the table.

Others referred to the diverse nature of beliefs and how some people believed they were safe from disease in accord with religio-cultural traditions of protection or healing. One person questioned the integrity of those pastors who told their congregations prayer would rid them of their HIV infection.

I think in the churches, you know, they've got to encourage people to seek medical advice ... We don't want them to say to their members 'We can pray'...They can pray to give moral support, but they can't get rid of the disease just by saying all right, you go back tomorrow and you'll be negative. That's not right. They should encourage their — anybody else to seek medical advice. At this stage we are, because as far as I understand there's no cure at the moment.

Another interviewee referred to their pastor's use of biblical accounts of the end of the world and the coming of diseases with no cure. Congregants were persuaded that HIV was just such a disease and they must, therefore, be faithful to one another. Another interviewee spoke of the practice in their church of couples being encouraged to have HIV tests before they married.

Stories of past betrayal drove calls for more openness and honesty between partners, testing prior to marriage and 'that you don't do the things to harm someone'. Others acknowledged the educational value of people living with HIV speaking out, but at the same time fearing to do so, uncertain not only of the consequences to themselves but also to their family members particularly their children.

I think we all need to stand up and say I'm positive. When I went to the World AIDS prayer meeting ... there was a fantastic man who said we need to stand up and we need to tell people. And I came out of that meeting saying that's it. I'm going to work and we're going to tell everybody at work ... and then when

you get like 24 hours down the line you're thinking ... maybe I'm not quite that brave. But I understand what he means. I'm not going to, you know, contaminate you just by touching you ... there are a lot more of us out there than you realize and I think there needs to be a lot more awareness and a lot more people need to get tested to sort of stop, stop the spread, because it's getting a bit rife.

Other suggestions urged safer sex, protection and condom use. For one it meant 'free condoms' and 'more sexual education'. For another

I just wish that those people who are infected they protect themselves so that they don't spread it all over so that it can be reduced or be finished, that there will be a year where they will be saying that there is no more HIV in the world.

One had decided to have no more sexual partners. Another referred to the religion's tendency to judge

I think if they really believe that the church is more about loving one another they will take every person as a human being even if someone has got a disease or even if someone is HIV, just also still a human. They're not supposed to judge that person of that HIV because they don't know how God is taking that person because sometimes God has already forgiven that person even if that person is a sinner, so they don't have to judge people. They don't know exactly where is God, God has put that person.

After urging the use of condoms and care when injecting drugs another went on to call for acceptance of people with HIV.

Don't neglect your health. Health is wealth. And try to accept those people who are infected. I mean they are just like you, ordinary human being. Try to accept them.

The following section sets out the responses of participants to sex education in schools. Questions continue to surface as to how far the personal experience and reflections of interviewees with HIV, this essential situated-ness, finds voice and validity and is permitted to lend authority to their suggestions and ideas (see Basset and Stickley, 2010) over against those of traditional authority figures, including religious leaders and medical experts. (How many priests have consulted with people affected by HIV before making religious pronouncements?) How far, also, is the one with HIV deemed authoritative in quests for coherence and in calls to break the stigmatizing silence around HIV?

Sexual Health Education for children and young people

The questionnaire requested a brief outline of respondents' views on sexual health and relationships education in schools. Many were positive and supportive referring variously to the need to build young peoples' self esteem, for teaching to take an open and honest approach to 'the realities of under-age sexual relationships and homosexuality' and for time to be spent not only on the delivery of facts but also on discussing emotions and relationships. Others called for an emphasis on placing information in a moral context: 'facts and moral questions and saying No';' teach sex in marriage bond'; 'promote faithfulness to one partner'; 'open and frank within value-laden context in favour of stable relationships'. Some stressed the need for content to be age-appropriate, meaning, for some, starting at a younger age and for others older: 'educate early before sexually active'; 'allow children to be children'; 'discussing at young age pernicious and anti social'; 'too much given too soon'; 'after age of sixteen'; information when they can respond maturely'. There was reference to the view that giving young people information about sex will lead to experimentation. One respondent expressed concern about condoms being available in schools: 'seems to give permission for indiscriminate sexual activity'. Several placed themselves in the 'don't know' category and another expressed the view that sex education is 'Best by parents. Best in loving home'.

Teachings on intimate relationships

The 'sex education in schools' question drew no explicit references to religious beliefs and teachings, texts or traditions in support of *questionnaire respondents'* views. However, if responses to questions about their religion's teachings on intimate

relationships are included in the analysis a different picture emerges: one in which religious beliefs inform both concept and conduct of right relationships and for a small number of respondents also the condemnation of those which they class as 'wrong'.

- We follow the Bible precept: Marriage is honourable in all and the bed undefiled; but whoremongers and adulterers God will judge. (Heb 13:4).
- Intimate relationships belong within marriage. There is no Biblical justification for approving other sexual acts but sinners are forgiven if they repent.

Many respondents describe the 'formal' teaching of their religion, often in absolutist terms, but add a qualification which seeks to accommodate the realities of many contemporary relationships.

- Intimate relationships should be conducted in context of respect and commitment normally this means within marriage.
- Sex for marriage, enshrined formally. Many marriages conducted in ... between cohabiting couples. Homosexuality celebrated but second class.

One person acknowledged the desire for exegetical certainties in the following terms:

People like to think Bible v clear but truth is it is v confused esp re sex outside marriage, re male homosexuality. Shld be taught as life affirming + joyful, but not good at being honest about it.

Connections between the traditional teachings and the prevention of HIV were made by two respondents but with differing emphases.

Although HIV/AIDS can afflict innocent victims the principal safeguards are chastity before marriage, total fidelity in marriage, abstinence from any homosexual relations, avoidance of illegal drugs and reverence for the body.

Marriage is one of God's greatest blessings & we are called to exercise absolute chastity outside marriage and absolute fidelity within it. HIV/AIDS has undoubtedly spread due to failure to observe these standards, but faced with the present situation we must continue to support all measures to stop the spread of HIV/AIDS eg education programmes, distribution of condoms etc.

The responses deliver a range of views, as one respondent put it

There is a large range of teaching and belief from the very liberal to v. conservative, from compassion to judgment, from concern to neglect.

But all draw on religious beliefs and teachings to formulate and express them.

Furthermore, when *questionnaire respondents* were asked whether those in their faith group conducted their intimate relationships according to their religion's teachings many were persuaded that they do. Others presented a mixed picture often attributed by respondents to cultural and peer pressures driving young people into multiple partnerships and sex before marriage.

These various appropriations of beliefs and the authority they are accorded over life choices must raise questions as to whether or how far the religious beliefs of respondents impact their conceptualization of and, potentially, the design of and access to key social policy issues, for example the delivery of sex education in schools and HIV prevention programmes in the community.

Many of the *group responses* to questions about their religion's teachings on intimate relationships held the 'no sexual relationships outside marriage' line but at the same time advocated a non-judgemental attitude towards those who chose a different way. The 'westernisation' of young people in minority groups was mentioned.

- Sexual relationships are to occur between a man and a woman but not before marriage. Is that the teaching or is –

It's still there, but the young generation are changing now ... I think they've become more westernised ...

This group went on to note the impact of living in a diverse society.

...you become more westernized when you grew up in a country which is nothing like your home country should I say, so the culture and the people that you're surrounded by are of so many diverse backgrounds and cultures that you're ... you have a diverse view as well of how everything is and you have a merged view as opposed to just one narrow way of living because everyone around you is different.

Specific religious teachings were alluded to by some:

- Karma was mentioned in relation to those behaviours deemed to be in breach of the religious teaching. This reference was followed immediately by a call to make no judgements but to look on those who have disobeyed with immense compassion. A similar point was made by another group when a comparison was being made between Christian and Hindu teachings:
 - I've got a few friends who are Christians and they say the same thing that even in the Bible it's very similar to what we say in the Hindu religion. Like no sex before marriage but then if you do it's a sin. So it's very similar to Ours doesn't count as a sin though. Ours counts as Karma.
- Young girls are held to be 'the light of God'; 'God's incarnation before we start our periods'.
- The Virgin Mary was associated with Catholic teaching on birth control and the use of condoms. 'The sanctity of womanhood was defiled by the use of a condom ... the Virgin would be treated with respect and dignity and that using a condom is defiling that. So that's how I think. We don't all hold that view'. Others thought condoms were important to HIV prevention.
- Islamic permissions for men to have several wives.
- Homosexuality and anal sex being forbidden. 'N are a nomadic people and anal sex is not part of N experience'.

One person remarked 'The Catholic Church – I feel it's only had one sin and that is sexual. In contrast I find the Church of England amazingly liberating.'

In their references to religious teachings on intimate relationships, *interviewees* with HIV made several references to anomalies and ambiguities attaching to the teachings and the communication of them. The predominant religious message is one of fidelity within marriage between a man and a woman, but interviewees' reflections often drew attention to the realities of complex lifestyles and relationships which the religious traditions often, it was reported, failed to acknowledge.

Several women spoke of their religion consigning to them a subordinate role in relationships, of an HIV diagnosis being evidence of misbehaviour, of being regarded as a feminist or a prostitute, of being untrustworthy, dirty and out of control.

After marriage your husband has only the rights and you should just obey your husband They don't teach you anything at all even for the hygiene of the woman ...they won't say it except when you are — when the four day periods time, you are not supposed to enter the Temple they're told. They said that those four days you are not clean. You are unpure. That is what we will have been told. But we have never been told that these things are — or how to build the relationship with the husband ...

And the same interviewee added

Even if you have been raped or things like that they would say that it was your fault.

She wanted the religious leaders to engage with efforts to speak more openly about sexual relationships and HIV prevention and help members of the faith group understand that an HIV diagnosis should not be construed in terms of *Karma*, as condemnatory rather than compassionate responses to a person affected appeared to be the norm. This constitutes a necessary interpretative task, in her view, before any realistic approach to the prevention of sexually transmitted infections, unintended

pregnancies, abuse or violence could be addressed within her community. The present silence on such issues was not an option.

Others spoke also of the silence. One said there was nothing in their religion. 'It's just about Christ. There are no teachings'. Some spoke of the supportive impact of religious attitudes to their circumstances. One interviewee whose relationship had broken down held up the support and help she received from her church group.

Another referred to the leader encouraging members to be tested for HIV. A woman spoke of her church group as 'quite liberal'. 'You wouldn't be condemned for living in sin or having, you know, been sexually active or anything like that'. A gay man spoke appreciatively of an understanding minister when, as a teenager, he was struggling to come to terms with his sexuality. This confidential help, as unexpected and as welcome as it was, was not enough to ease the impact of the wider church's and society's condemnation: '... but it wasn't OK for me then because then, as I said, I went on to get aversion treatment. I did put myself through some punishment'.

Most participants with HIV spoke positively and supportively about sexual health education for children and young people. One person declares '... the children, if they don't understand, then they do the mistake', following this with an account of her own mother's instruction to her,

'Be careful. Don't talk to any – any boy on the way. If they stop you and tell you to come over here don't go. Don't trust anyone. Don't talk to stranger'.

By and large the feeling was that more factual information and at a younger age was preferable with additional emphasis on the emotional aspects of relationships.

Fewer than half the questionnaire respondents, that is, the religious leaders and representatives, expressed support for more sex education in schools. There were calls for factual information to be provided at an earlier age but alongside enhanced exploration of relational and moral issues.

Participants in the small groups were largely supportive, often noting specific and practical justifications. There was a recognition that for some teachers the delivery of sex education lessons could be particularly difficult and a suggestion that local health professionals be invited to supplement resources. In one group a person spoke of visiting a country where there were posters everywhere about AIDS. She noted information declaring that the ages most at risk were those between five and fifteen years followed by those between the ages of forty five and seventy five years. This led her to call for sex education at a very early age, but this was queried by another member of the group

To be open about these issues, yes, that's good. How that's done is – is a matter of method, not the sex education at schools, Yes or No. It depends how it's done'.

Others expressed clear disapproval of sex education being delivered to primary school children, preferring the subject to be taught at secondary level only. Indeed, 'age-appropriate' concerns and calls for careful discernment in determining the right age surfaced several times. In another group a participant noted what she regarded in her community as increasing numbers of young people having unprotected and extramarital sex and advocated greater awareness of health risks. Another group participant placed her arguments for more sexual health information and education firmly in the contemporary context of the social and commercial sexualisation of young people. Others added that same sex relationships must be on the agenda, myths broken down and consequences considered. That 'no-one is saving themselves for marriage... ', and 'the life and death' nature, as a group member saw it, of the risks associated with ignorance and HIV, also generated support for sex education in schools with the UK's high rate of teenage pregnancy used in the same group as an illustration of need.

It is a mixed response, with a diversity of religious views influencing responses in a variety of ways. It is not possible for this study to assess how far these religion-informed opinions about sex education differ from or concur with the views of the wider community or influence the access of young people to information. Many studies and organisations support the provision from primary level (4-5 years in the UK) of age-appropriate evidence-based high quality sexual health and relationships

education in schools. But there are those who do not (Leicestershire County Council 2010: 8-9). As the religion-informed views of people with HIV appear in this study to support a more open approach than those of the religious leaders and the group members, it may be legitimate to encourage and sustain regular community-wide, as well as school-specific, conversations on the content and delivery of sexual health and relationships education in schools. Indeed, the shifting variabilities of demographic and sexual health profiles of diverse communities and the intersecting realities of multiple inequalities, not least those of gender and sexuality, require the continual reviewing, renewing and strengthening of partnerships between parents, the wider community and professionals and experts from various agencies to resource adequate and appropriate Sex and Relationships Education (SRE) for children and young people (Department for Education, 2008).

Such dialogical approaches and the associated tensions between the potentially conflicting need to deliver a curriculum to all children and the constraints placed on doing so in some situations by cultural and religious norms are not unfamiliar to the design and implementation of Leicester's and the neighbouring county's policies (Moat Community College 2011, Leicester City Council 2010, Leicestershire County Council 2010). Efforts to bridge gaps in knowledge and build consensus about content and delivery through partnership and dialogue could benefit also from the contributions of those directly affected by HIV. In a 2011 national survey by the Sex Education Forum one in four young people said they had received no HIV information at school (Sex Education Forum, 17 May 2011). This was echoed in an audit of Leicester's young people in their experience of SRE (Leicester City Council 2010)

Talking about HIV and sexual health raised further issues also for the research participants.

Talking about HIV

Faith group talking about HIV

More than half the *questionnaire respondents* do not believe their congregants talk about HIV (56 per cent). Various reasons were offered:

• not an issue for their faith group;

- a taboo subject;
- the associations with forbidden behaviours;
- cultural sensitivities:
- regarded as an issue for developing countries;
- not a priority;
- unless in the news;
- reluctant to talk about sex :
- ignorance and lack of confidence;
- anxiety about appearing to be 'liberal' and 'non-moral';
- refusal to target specific groups: 'All have sinned. Christ died for all';

Those who declared their members do talk to one another about HIV referred to

- marking World AIDS Day;
- inviting a speaker from 'Third World country';
- parents' need to raise children's awareness of HIV;
- wanting to care;
- needing to talk of someone they know with HIV;

One respondent did qualify their 'Yes' with

We rarely talk about sex at all - homosexuality especially is a very controversial issue with regard to Anglican Communion at the moment and we don't like to have arguments!

Another added a note about the tendency to prefer talking in theoretical terms rather than about the realities of peoples' lives. Another made the same point in a slightly different way

Gen we don't like to talk about sex, think bec so oft out of kilter with our teaching. As partly STD – seen as taboo.

These tensions, expressed in different ways, surfaced among a number of responses. The fear of the faith group passing judgement on each other's opinions was regarded as a hindrance to speaking of the virus. Another respondent noted the capacity of HIV and other sexuality issues to confound a congregation's desire to be more open and accepting. Another detected similar room for contradiction between the congregants' religious belief and their work place policies on diversity and equality.

Issues of tension and confusion were raised also when the participants in the **small groups** turned to questions of talking about HIV. Several group conversations opened a sometimes new and unfolding awareness of dissonance between the status quo of the believing community and the presenting realities of HIV.

Many in the groups reported silence in their faith community, but the question tended to prompt extensive discussion as group members considered some of the issues raised and the inconsistencies exposed and went on to explore ways by which they could be explained and reconciled. The following extracts from three of the transcripts offer clear examples of the type of conversations held.

In the first example, their silence is questioned. As the conversation progressed someone prompted the group to think about the risks of contagion and the anxieties a shared communion cup will raise for some. The fear of sharing the communion wine is then connected by the group to their first introduction to HIV: the government's first awareness raising campaign in the 1980s which was graphically illustrated with tombstones and contained explicit references to sex and death. All this and the fear it generated is recalled by the group members. They then connect this fear with the reluctance of people with HIV to speak of their condition, concluding that this is due to an anxiety about being judged and rejected. Someone spoke of a member of their family having TB years ago and wanting to keep it hidden. They acknowledged they knew something of HIV in Africa but nothing about HIV in their own area.

- But I think to our shame we don't discuss it as a church do we?
- You know we don't actually. When it's World AIDS Day we never actually have anything up in the church do we?
- But why not? But we could, couldn't we?
- Why can't we?
- Perhaps we ought to.

- I don't know why not.
- ...One of us here could have it.
- And how would we know?

And then the story of the communion cup.

- ... I'm sure there are people in our church that do it that way [intinction] for the fear of catching something ... I'm sure it's probably not AIDS but who knows, but they still have this fear of catching something by drinking out the same cup ... I mean my point is regards taking ... Holy Communion, it's you know, so long as you receive it I don't think God would mind whether you dipped it in or took it one way or another. I mean, years ago they didn't have a silver cup for Jesus ... but our vicar was saying we must stick to the doctrine ... But thinking about people's worries, fears, anxieties, maybe we should be addressing why they want to do it that way and what is it they're frightened of?
- ... It's just that people are frightened of catching things even whether it be a cold or HIV or anything else ...
- I've never thought of that before.

And here the recalling of the early publicity campaign.

- It was very scary really wasn't it?
- You don't get those same adverts now do you?
- I was only jolted this Comic Relief with the tragedy of these children.
- I'm totally ignorant of what's going on around here.
- Why wouldn't they tell people?
- Is it because of their fear of being judged by the people, the fear of being rejected? What would be the barrier?
- Well, I think it's an embarrassment that you've got it ... that people will begin to say Well how did they get it then?
- I had TB in our family and I didn't dare tell anybody in my grammar school's form because I felt dirty. You know I couldn't tell anybody.
- ... it's being transmitted here as well.

- ... the only images I've got and it sounds like you as well, is in Africa are all these tragic cases where it spreads like a pyramid.
- Nobody sees a programme on what's happening in Leicester do they?
- Perhaps that's what we ought to do.

The following extracts from a group transcript relate to a different religio-cultural context.

- If you've got AIDS then perhaps you'll be branded as someone who's had sexual relations. If you're unmarried especially and you are found to have AIDS then people might question all sorts about your purity and your decency and your morals and especially if you come from perhaps a religious background, a Hindu background or an Indian culture where it's not widely accepted to have sex before marriage. Um, in that case it'd be frowned upon. So it may be hidden. You can't hide it from your family for so long, but from the general public you could say they've got a general illness.
- ... the younger generation, they understand ... about HIV but the older generation they won't especially in India like in villages and places like that where they come from, HIV is like swept under the carpet ... I think people should open up now and start talking about it because it's one of the most serious infections you can get at the moment and it's life and death isn't it?
- I think it's easier to discuss diabetes, high blood pressure and other -
- Alcohol.
- ... I think everybody needs to learn about this HIV. Like you said people will talk about diabetes and heart problems and this ...
- It's easy to talk about that.
- ... So because of our Indian culture and the respect for our parents there are certain boundaries we don't cross ...
- I think we got to balance as well, then, people who come from Africa are more liberal, more tolerant about things like this, but in India they don't talk about this. But in Africa those people who've been brought up there and been over here, you'll find them that they are more flexible in everything.
- They've seen it already in Africa.

- They've seen it so they'll talk about it. They're more open. Where in India the people there are more conservative in a sense.
- Also ... in India there is none of this in the education system at all ... it's never been highlighted in their life. So it's always been covered up.

But, as one participant pointed out, in Kenya

- ... in schools they discuss. Boys they go to a different class. Girls they go to a different class.
- Was it like open? Could you talk ...?
- Yeah, the teachers were ladies so they just talk openly ... because in Africa it's such a big issue ... as opposed to India.

Someone noted it was easier in the cities to be open about HIV than in the villages and the discussion continued.

- Respect as well. Mutual respect. How can I talk to them?
- ... it depends on which sort of family you come from because if you come from a more liberal family where you talk about things as a family...
- Need to understand the Hindu community in Leicester. Most of them are Gujarati. Gujarat's a massive state and even in Gujarat there's urban and rural areas. Cities... have more sex education than perhaps little villages, so perhaps it's not reached down, hasn't filtered all the way down, but within Leicester we've got a whole cross section of everyone from Gujarat ... But you've got also from Africa the growing Gujarati Africans. But you can't really generalize if it's the village or if it's an urban thing. It just comes ... down to an individual themselves. Like ... I could speak to my mum about something, but I couldn't speak to my aunt about the same subject. So it depends on the individual.
- I think the older generation ... whether they would just ignore it but I think they wouldn't ... say no if it was marketed to them in the correct way, I don't think ... they would um ignore it. Turn their heads away.
- The reason it works well is because the setting we are in. We are in the

 Temple so people would not be afraid to come to the Temple. They know that

people in here are devotees of the Temple, but although it's a taboo subject outside the Temple, within the Temple the doors have opened to discuss these issues. So although they wouldn't go to speak to a priest about it directly, but it's a safe house. It's a safe house.

- Like there are ten of us today, next time if we have some discussion like this there'd be about twenty and once the word spreads people will start coming in, especially younger generation will come in and chat about it and then they can go back and take leaflets and whatever and then pass it on to the older generation. You know, a learning process.
- ... to get in the Asian community, to get the older community involved ... like our grandparents or parents involved in teaching their kids. Something like this would work well because they feel even if their kids was taking them by the hand here, they know that it's a good thing. They'd have somebody else teaching their children as opposed to them being there and them doing it. They'll still be able to be in on it as well.

Out of their participation in the study and an emerging concern for their community's engagement, or lack of engagement, with HIV the group offered a culturally and religiously appropriate model for awareness raising within which key generational sensitivities could be affirmed while at the same time addressing the realities of a significant but stigmatizing health issue.

The next extract from a group transcript refers to an Islamic approach to talking about HIV.

- In all honesty, it's not something that's been discussed in mosques or in Islamic circles that I've ever attended personally. In fact, I've never discussed it in the religious context. It's only been in the social context and it's usually watching soaps or it might lead to a discussion amongst my friends, but never in from a faith context.
- It's never spoken about within like Muslims within Muslims not because of a taboo subject because it's just something I myself have never ... been in a position to discuss. Again, it's not known. If it comes up or ... if it's on Eastenders or Coronation Street ... it's sort of like educating you to a certain

degree about other people's prejudices and it makes you realize ... whether its films or soaps it's made me realize 'Oh, OK, well they're humans and they've been treated, you know, like ... you can't share the same drink with them and that's how people treat them ... And that sort of like shows you that ... that's not how you treat people. So if I did come across somebody with HIV I think I would be more cautious to treat someone in that manner ... But ... like I say it's – I don't think it's – um, not discussed with Muslims. Even my non-Muslim friends have never really discussed it.

- Not at university. Not at college. It's a topic that's never come up.
- ...I think ... for example if you have a group of Muslim women it's not a taboo subject within a group of Muslim women to talk about it. It's just that there's no need. It's just never come up. It's just one of those things that's never come up. It's just not a concern, not a community concern ... there's no barriers. Even today there wasn't no-one actually said ... 'I don't want to come because it's about HIV' ... the response I got was 'Oh I don't know what to say' because they'd never discussed it or talked about it so they just felt that they didn't have anything to offer HIV information.
- But it wasn't a taboo subject. It wasn't like 'Oh my God, I can't talk about it'.

A participant then returned to her account of a relative's friend who was awaiting the results of tests after a needle stick injury.

- Now if she had contracted HIV through sexual means it's very likely that I wouldn't be sitting here giving her as an example because I wouldn't know about it ...

And if the Imam were to talk of HIV

- I think the Imam would get a mixed response ... Um, I think some people may think this is not a concern of our community. Why are you talking about it? It doesn't affect our community.
- Why did you talk to us about that for? We don't know anyone. It doesn't affect our community. Um, I think you'd get a mixed response.
- I think they'd be more open to it.

- Those who've gone through education in this country. Especially this generation. I think they are more open to it. I think if somebody could just ask the question to a religious leader and I think it would depend on the religious leader ... of what age they are. So maybe the religious leader might not be comfortable speaking about it.
- Middle-aged forty-plus male I don't think they'd be open to talk ... whereas the younger generation might.

Some *interviewees with HIV* recalled that prayers said in their church included an occasional reference to people affected by HIV. One spoke of the religious leader who linked safer sex messages with his teaching of the need for faithful relationships and avoiding harm to one's partner. Pastors who called on people with HIV in the congregation to present for healing were mentioned, and although silence was the more common experience where HIV is concerned, for one interviewee talking of HIV in her faith group was a positive and regular occurrence. For her this practice was embedded in her own and her group's strong belief in the healing power of prayer. Another was confident that church members would give help and support to someone who is ill with HIV but then declared that she would not speak of her situation in her present faith group as 'they are less welcoming here and so I am not able to start to talk to them about it'. Others, also, were firm about not speaking of it in their faith group or to their religious leader citing anxieties about confidentiality and exclusion as the foremost barriers.

So you find not so many people are open about it and discuss it freely with anybody ... I can go to my pastor and say maybe 'I have got stomach problems'. But what's the cause?...I won't be open enough to say I've got AIDS ... If I just say I'm HIV positive, well it depends but all eyes are on you ... Everybody looks at you ... What kind of person? How did they get it? What is he doing now? And all that kind of perception.

In a similar vein, one interviewee described seeing people from her church in the hospital clinic and of their never being able to refer to those encounters for fear of identifying one another as an individual with HIV to the faith group or the wider community. Two people pointed to the silencing roles played by cultural sensitivities

and tribal identities. And although a known and trusted religious leader may be safe to confide in, speaking of HIV in the wider faith community by either the religious leader or the interviewee with HIV would not happen due to the stigmatizing risks involved.

The above extracts, particularly those from the groups, not only help contextualize aspects of the silence and confusion around HIV but also demonstrate the potential for resolution. The group members themselves to a larger or lesser degree were able through the course of the discussion to acknowledge the community's need to speak of HIV and to find ways of responding to that need within the paradigms and values set by the religio-cultural milieu.

Faith leaders talking about HIV

Clearly, for some, the barriers to effecting HIV-related conversations and an associated raising of awareness among community members were more dense than for others. Some of the *religious leaders who responded to the questionnaire* saw the removing of such barriers as a particular responsibility with specific reference to the religion's calls for compassion and the avoidance of scapegoating and judging providing a framework for a number of responses.

- It's an important issue that we should talk about not least to dispel the myths.
- Set the tone as one of being an open and accepting community.
- Believe any kind of scapegoating is counter to Jesus' teachings so wld use HIV as an example
- I campaigned for condoms to be freely distributed to students.

But for others, in line with the numerical information above at pages 129 to 130, talking about HIV was neither a necessity nor relevant. One respondent thought most in the congregation would see it as 'inappropriate & perhaps even offensive'. And another responded

Only discussed with medical staff and religion prohibits illicit relationships therefore would not be discussed with rel leader.

Initiating discussion

As suggested by the discussion in the small groups, the mobilization of support among a few open individuals may generate change. Indeed, a few questionnaire respondents had clearly initiated some discussion about HIV or responded pastorally to the needs of someone who had come to them for help. And some people with HIV thought the appropriate person to initiate a raising of awareness would, indeed, be the religious leader, although some advised the need for them to further any discussion on the basis of accurate information and empathetic understanding.

An *interviewee* made reference to a pastor urging couples planning marriage to go for an HIV test. This seemed to be an accepted and supported practice within that particular community. Another interviewee, speaking of the silence in her home country, wanted leaders to teach the children in the Sunday Schools and others thought someone should go into churches to try to educate the people. One participant with HIV had given careful thought to speaking out herself but barriers appeared insurmountable.

I wouldn't mind how people react ... but the issue is how do I raise the issue? How do I start it? You see? How? ... I have been silent for a long time. I need to do something. We are sitting back. If us, we don't stand up who is going to do it? No one. We have to. Because we have to raise awareness to everyone and stop the stigma. We want it to stop... but how do I start it? I don't know. Maybe you have an idea. Sitting back is not going to help anything. Silence is not going to help anything. It will never stop if we sit back, sit back and feel ashamed of ourself. No, no, no. Hope is the first thing we have to find then shame is the last. There's no shame.

One interviewee referred to the inhibitions which deter men and women engaging with sexual health issues: to the responses of people to those who speak openly.

If you talk about it they'll say 'Oh, she's a bad person ... She's talking openly about these things.' They won't understand why that person is trying to teach

or tell the truth. They will just tell you that 'Oh, she is a really rough character person' and things like that.'

And to the tendency to resort to traditional remedies rather than experience the discomfort of explaining in detail, that is if the appropriate language is known, an intimate health concern to a GP, particularly a GP of the opposite sex. For her the priest, an open and understanding priest, is key to a community's HIV education.

I think they should organize every month or something like that a seminar. We should call all the people. It should be open for the public and first the priest should be told that 'No, this is not an issue where your bad karmas or whatever you have done in your pre-birth is coming up. The priest should understand and he should try and educate the people because I know that a priest's voice will be listened ... because if I will be standing up and speaking they won't listen. But because priest is ... we say that 'Oh, he's a high rank person and if he starts understanding things ... I know that things can go really in the right way.

Others took an alternative view with anxieties about the religious leaders' extent of knowledge and grasp of the issues. A former Catholic with a partner who had suffered abuse by a priest was adamant, 'No, definitely not the priest'.

Even in the *group discussions*, although at times there were clear indications that the group members themselves were moved to initiate some HIV awareness – one participant announced that because of the group discussion he now felt able to talk with his parents about HIV, how it is and is not transmitted – barriers, personal and cultural if not overtly religious, were noted.

... we're kind of, you know, wanting to sort of do the right things about this, we're aware of all these sort of hang-ups and fears about this and what ... what will we be doing if we do this and what will people think we're doing if we do this? And, you know, all this – this stuff which is basically about our perception of ourselves and other peoples' perceptions of ourselves and all the

rest of it ... I mean that's not helping anyone with HIV. That's just about us isn't it?

Another group, expressing an initial eagerness to design and develop a model for awareness-raising in their community which involved the religious leader were cautioned by one person in the group to take account of the potential for wider implications.

With a priest, he is usually quite old ... they're religious ... so you respect him on religious grounds and then you respect them on the age grounds ... then there's a respect boundary because you don't want to talk about certain things in front of them because you know there are certain expectations and you don't want them to know about your personal life. There are so many boundaries ... it's about losing face in front of them. It's a good thing that they'd accept it but you'd worry about whether it would have a direct impact on Hindu society as well, how people are perceiving things because then it could blow out of all proportion. It could become a bit too open.

Such insights into the psycho-social resonances of responding to HIV, particularly those which reflect anxieties about exclusion are scattered throughout the data and will be explored more fully as issues relating to the nature and impact of stigma are discussed.

Talking to health professionals

Most respondents and group participants were positive about speaking with health professionals for advice and information. Few religious leaders had made such an approach, regarding it as unnecessary, but some had done so in order to be better informed about HIV and more pastorally competent should someone approach them for support. The only religious reservations cited concerned doctors' sensitivity to the patient's beliefs. One respondent hoped any information would 'respect religious teaching and acknowledge that people choose to live by it and that it is a healthy and safe choice'. One group participant shared a similar anxiety describing her own experience as a young woman.

... there have been times in my life when I have been chary of trying to approach the health service or a health counseling service about issues relating to human sexuality because I didn't think they would take seriously the fact that I had these quite traditional beliefs ... I would say sometimes you ... as a young British Christian, you might think I don't want to go to the doctor and try and talk about this because the doctor will say 'Why is this an issue? Get yourself a packet of condoms and start having sex, girl'...and, for example, our Church members from India, they clearly have a very strong feeling that the – the good name of the Church and their Church membership is apparent in every aspect of their life

Another acknowledged that some would find it a struggle talking to doctors but for her personally it would not be a problem. Approaching a health professional was the more likely option.

Few in the small groups would have chosen to go to their religious leader.

- But I think things like HIV isn't something that is in any of the Islamic texts or something that an Imam would have actually studied, so it'd be whoever's the best person for that subject.
- I would go to a doctor or a counselor
- To a GP or a health centre.
- Yes, someone who's got knowledge.
- And the trust, you know, confidentiality.

In another group

He says here you would feel confident with the doctor. If there is something wrong with your body you've got to go to the doctor. He's seen people suffer from AIDS before. They deteriorate and you melt like an ice cube.

Not surprisingly, the *interviewees with HIV* spoke in support of seeking the advice of health professionals. Some saw the potential for cultural difficulties and another pointed out that belief in prayer was important for some. But most advised seeing a

health professional for advice or information about HIV and identified no religious barriers to doing so.

You have to speak with your doctor so that they can show what to do for you. When you don't speak you are going to die.

Talking to religious leader

Two **people with HIV** had told their local religious leader of their HIV diagnosis. For one this appeared to be linked to the fact that the participant knew and respected the father of the priest. Another talked over the telephone to a former leader who was living in their country of origin. One other thought 'pastors they can keep secrets' so it was safer to talk with them than to other members of the faith group. Most declared they had not confided in a religious leader and some felt it unlikely they would do so. One participant, a gay man with HIV, was adamant at first about not approaching the priest, but after some reflection decided

If there was a Catholic priest who was up to date on all the facts and knew everything, yeah, I probably would feel confident. But I don't think – I don't think that's likely to happen.

There were occasional references by the *questionnaire respondents*, that is, the religious leaders or representatives, to the view that people in their faith group would not speak to them about HIV due to shame and embarrassment. Forbidden sexual behaviours, clearly perceived as the only relevant routes of infection, being in their view, the cause of the guilt. Some, however, had been approached by a person with HIV, either in their present post or in another location. Others expressed a hope that individuals would feel able to contact them or another appropriately qualified person in the faith group should a need for care and support arise. And there were those who had never considered HIV infection as a matter of concern within their community.

Participants in the **small groups** thought, by and large, that it would depend on the leader – how much knowledge the leader had about contemporary issues, whether or not he or she was personally known to the individual with a concern about HIV. The education, age and gender of the leader may be issues as perhaps would be an

assurance of confidentiality. Doubts about the security of any information disclosed were placed in the context of Asian caste structures by one group member; and by another in the perceived low priority given to pastoral support by community leaders. Another group saw the encounter with the priest in the sacrament of reconciliation as the safe and appropriate moment for speaking of HIV.

Clearly, as the responses above and the numerical information at pages 129 to 130 indicate there is work to be done before the religious leaders' own perceptions about their accessibility and openness to people in their faith communities who may wish to talk to them about HIV match the support decisions of those living with HIV and the views of other community members. An emerging correlation between knowledge about HIV, knowing someone with HIV and an ability to integrate that awareness with the realities of a community's life and faith may be made more visible as the following section unfolds in detail the study's focus on participants' knowing people with HIV.

Knowing people with HIV

Knows person with HIV

Describing them variously as friends, as people in the faith community or neighbourhood or as people introduced through church projects supporting people affected by HIV, fourteen of the *questionnaire respondents* knew someone with HIV.

A few **people in the groups** knew or knew of people with HIV. None appeared to be close friends or acquaintances. One person had visited a hospital in Africa a few years ago.

I found it deeply disturbing that humans were allowed to exist in those conditions and they were actually dying. Deeply disturbing ... if you believe what the World Health Organisation reports say that 23 per cent of the population on the coast is HIV positive. You know, in an environment like that I would have thought there would be a little more compassion, but there isn't.

One person spoke of knowing two young people in her professional life who had died. Another group member had been told of someone who was awaiting the results of tests after a needlestick injury. One spoke of knowing an affected family in the community but they had moved away.

Each *participant with HIV* knew or had known another person or persons with HIV. For some it was a partner or another relative, for others it was through a support group. Some did not know others directly but suspected a person had HIV from their appearance or health problems or because of the occasional encounter in a hospital setting. One interviewee met someone at their church. He became so anxious about the risk of disclosure both to himself and to the interviewee that he left the town. One person knew no other people with HIV other than his partner and others he thought had HIV because of the community's behaviour at the funerals. Anxieties about disclosure exercised some of the interviewees from minority cultures. One person had a relative with HIV.

Who knows? Telling someone you have HIV

The same anxieties about confidentiality surfaced yet again when **people with HIV** spoke of telling someone of their status. Clearly, for most the decisions about disclosure are made with great care. For several the care cautions disclosure to even immediate family. One person had not told a close relative. 'I am just waiting for the time where I'm thinking can I tell her.' She spoke also of hearing the same relative say she would want nothing to do with a person with AIDS. She values the friendship and support which her church provides but has not spoken to anyone there of having HIV. Another interviewee has not told his brother, a preacher known to hold conservative religious views. One person felt able to disclose to a small number of trusted individuals, including her pastor, but not to her mother. Fearful of a changed relationship, another has chosen not to disclose his HIV status to his most immediate family. Parents are particularly cautious about telling anyone because of the impact disclosure may have on their children.

No, I haven't disclosed because the thing is I know that it will affect my children's life. It will affect my social life and things like that... They think that after my partner's death they might think that I have gone outside and slept

with someone ... people will start pointing my children that 'Look, the mother was really a rough character and she was going out and these children are not in a good family people'.

Another parent described it this way.

Everybody I've told has been supportive and wanted to ask questions, wanted to know what they could do ...But I think within church, um, more openness ... I mean I could quite happily stand up and say I'm HIV positive, let's talk about this. That wouldn't be an issue at all but I think it's just – I'd worry about the children ... so I think more openness and free condoms.

Several had spoken with a small number of trusted individuals. For one interviewee these included 'our Jesus'.

Some they know but they don't speak of it. When you like you can talk to someone but when you don't like you can talk to our Jesus, tell him.

Anxieties about the prejudice which may be encountered upon disclosure are issues for many. A man and his wife have not told anyone about their diagnoses but suspect that some people may have guessed. Others are less fearful about the consequences of disclosure.

I just thank God that ... I am still living because when I got it I thought the following year I wouldn't be there already, so now I've learned that I've got to accept that I've got it.

But, for some, reservations remained. Commenting on the charity work one interviewee undertook for an organization supporting people affected by HIV a church member asked

'Do you know anybody who's personally been, you know, affected?' And I said 'Oh yeah, I've got a friend'. And she went on, 'Is it a man?' And it was like – and part of me wanted to say 'No, it's me. No, it's me'. But I knew she'd

just – the pity in her eyes was just too much and I thought I can't, you know, I'm quite happy. I think the HIV is part of my life, but it's not a massive part of my life ... It's there and ... as sort of a family we deal with it, but we don't talk about it every single day.

One interviewee took a particularly positive approach.

It doesn't matter how you got it, but it's how you live with it. That's the most important thing is how you live ... It's how you live with HIV is the most important thing. That's my opinion.

A *member of a group* drew attention to a paradox in the phenomenon of HIV disclosure and religion. The context in which a person would expect generally to find greatest comfort and solace in times of need has become the place where, for many people affected by HIV, fear of disclosure's consequences is greatest (Chinouya and O'Keefe 2005, Dodds 2006, Anderson et al 2008, Ridge et al 2008). Most of the time, she pointed out, people who belong to a church, particularly long time members, want to talk about their troubles and their illnesses.

You know, in a church context, if somebody has got to have some ghastly operation or they've got some particular form of this disease or that disease, you know, you can sit there in the vestry and the vestry steward is describing to you, you know, her – the state of her bowels and things.

But, of course, HIV is different.

... people might be within a church context feeling that they would want to disclose and that they wanted people to know and they wanted people to be aware, you know, so they could pray for them, so they could visit them, so they could act appropriately.

And disclosure is not the norm. As most of the participants with HIV said, neither their religious leader nor the people at their place of worship are the ones to whom they would choose to disclose. Some people with HIV referred explicitly to valuing

the support they received or could expect to receive in times of illness but even in those circumstances the fact of their HIV infection may not be made explicit.

Knowing person with HIV in faith group

A small number of *questionnaire respondents* know people living with HIV in their faith group.

In the *groups* two spoke of knowing an individual with HIV. Another referred to the realization in the congregation after the funeral of a church member that for the African members of the church HIV can be a significant presence in their lives.

At one level this raised awareness may be perceived as positive and helpful in terms of fostering mutual understanding, sympathy and congregational solidarity. However, at another, in pointing to the potential of HIV to undermine pastorally charged and fellowship driven if not psychologically or emotionally secured relationships, it exposed the enduring barriers generated by the stigma attaching to HIV.

Reporting that a person from Africa had told her that people at the church seemed hesitant about 'building up a relationship with them' the group member wondered whether, each time a person from Africa joined the congregation, existing members would be wondering whether that person also has HIV and keep their distance. The group member noted also that without that direct encounter with individuals from Africa with HIV her own awareness may have been drawn from gossip and speculation about gay colleagues and their episodes of ill health.

An *interviewee with HIV*, active in her church and whose HIV status is known to a small number of members there (though not the leader), also illustrated the stigmatizing influence of HIV. Reflecting on the response she could expect if she disclosed to the entire congregation, there would be, she thought, a 'backlash for a time', 'meetings and discussions' resulting in the congregation being split. But then added 'Or people might be hurt that I've not said anything.'

In one way or another the person with HIV, in this participant's understanding and experience of her church (and she adds that this is 'all theory and hypothetical'), will

be made responsible for the difficulties others face in addressing their reactions to HIV and people affected by it.

Introduced by an outline of the main religious themes reported by respondents as influencing attitudes to people with HIV, the following section looks in more detail at the nature of support provided to and experienced by people with HIV.

Support for people with HIV

Responding to people with HIV

When *questionnaire respondents* were asked to make specific reference to the influence of religious teachings and beliefs in describing their faith community's response to people with HIV the split between condemnation and compassion was apparent with most recording tendencies to both judge and forgive – the familiar 'hate the sin, love the sinner' theology. A number of respondents engaged in this dichotomous approach to people with HIV with differing degrees of emphasis. For example

- ... analogy of VD and leprosy and 'wrath of God' frequently seen as valid. Att of our Lord to those thought ritually unclean is model for imitation.
- Total support and acceptance. Forgiveness if a person feels guilt from their past. Faith for a measure or even complete healing through prayer. As with all sickness, pain and suffering it is part of the judgement allowed by God on a fallen earth ruled essentially by the Prince of Darkness. As Christians we await a new heaven and earth where sorrow and sickness will flee away.

Some leaders acknowledged the need for more teaching to foster, as one person put it, 'a healthy view'. One noted that the faith group held more conservative views than the leader and another, echoing the responses of many, the assumption 'that people may have brought it on themselves like smokers and lung cancer'.

This is not to say, however, that neither fully compassionate nor fully condemnatory responses were absent. Examples of both were expressed.

- ... they feel loved & affirmed by Christ & offer the same.
- To visit, assist, care for the sick and infirm is a virteous [sic] act, encouraged in Islam.
- OT att die hard HIV as God wrath, even those who suffer see it this way

Of those faith leaders who responded there was general agreement that appropriate responses to people with HIV would and should involve acceptance, compassion and friendship with an avoidance of prejudice and judgement. Some, though, as indicated above, expressed uncertainty about their faith group's collective desire to be either supportive or non-judgemental in an encounter with someone affected by HIV, with signposting to health professionals and specialist agencies expected to be the extent of their support.

Some respondents referred to the faith group's capacity to respond appropriately by drawing on the resources of those members with appropriate skills – counselling, listening and pastoral care in particular. Several mentioned the need to ensure the full inclusion of people with HIV by raising awareness of the issues impacting the life of a person affected and help break down any barriers to inclusion harboured by the wider congregation. One respondent identified the need to 'press for adequate treatment and care' and another called for the congregation to be 'a compassionate community, break down marginalization of others and fear in ourselves'. There were some references also to the building of hope. And with one of the few explicit references to the theological ground upon which their responses were based, one respondent wrote

Many affected will be thinking of God and praying or asking questions.

Although moral questions may be involved we should not be judgemental but offer God's love, grace and above all hope to sufferers.

Two others suggested the best support for people with HIV involved urging them to repent and seek God's forgiveness.

Signposting to other agencies was suggested, sometimes as a way of augmenting the support offered by the local faith group or as an alternative. One respondent mentioned the local HIV chaplaincy service and another, the 'correct authorities'. For some respondents referral to health professionals constituted appropriate support. For others the suggestion that anyone with HIV would approach the faith leader or group for help could not be contemplated. Medical help was the only appropriate channel. These suggestions may indicate reluctance on the part of the faith group to engage in supporting a person with HIV. Or it may be a failure to appreciate that in the UK and with an early enough diagnosis, access to any necessary treatments and the capacity to follow adherence schedules, most people with HIV for most of the time will be physically well. With adequate social and emotional support they will be contributing members of society, perhaps with jobs and families. It may also be the case (although this was not in the questionnaire) that those affected as partners, relatives, friends or colleagues, in their anxiety and concern for the one with HIV, may approach a faith leader and the faith group for support. Only two respondents referred to the support needs of partners and families.

Religio cultural justification for condemnation and for compassion became the focus of much reflection in the *small groups*. Most participants set out religious teachings and cultural norms which gave authority to prejudicial and judgmental attitudes towards people with HIV. However, after some searching discussions, and apart from one person who opted for a different reality, the majority of participants called for a compassionate response to people with HIV and identified religious reasons for doing so. The exception was the group member who felt there was no denying that some people with the virus would have engaged in behaviours which the religious teaching, and she herself, would undoubtedly condemn. Although feeling uncomfortable expressing her reservations, for her the 'guilty' or 'innocent' question was precisely the way to construe one's level of support for those with HIV.

- HIV/AIDS is the leprosy of our era.
- Yes, certainly, we can't condemn people.

I think that's an idealistic way and if it works I used to go thoroughly with that, but now –

- Yeah, the teachings is one thing but what people think may not necessarily be the same thing.
- It might be an ideal but what's the reality?
- Well, I mean Christ's teaching, love God and love your neighbour.
 I think the bottom line is people would be compassionate wouldn't they?
- Precisely. Yes.
- Do all in their power to help them if they needed it, I suppose.
- I don't quite see it like that ... I feel a bit guilty that I don't, but um, I think the other illnesses you can't help getting, but I would think there must be some reason why have they got it. But I probably would wonder.

Other groups, while not supporting such views outright, noted their existence within their faith groups and communities. Some thought that older people would find it more difficult to be compassionate than younger people. Others referred to some of the ways cultural beliefs and traditions can be confused with religious practices and actively fuel division and exclusion and, potentially, increase vulnerability to HIV. Due to the tendency to see AIDS as an African issue and because there were those in the community who had known African people as servants, HIV was 'associated with the lower class as well'. There was clearly some concern the moment it was uttered about how such a comment could be construed as prejudicial. It was immediately pointed out that Asian people from African countries were more liberal in their attitudes than those who had come from India.

They've seen it so they'll talk about it. They're more open. Where in India the people there are more conservative in a sense.

One group member spoke of the divided lives some young people live – going out in the morning to school or university or pretending to be at school or work, and returning to strict parents who will not allow them to go out in the evening. There was reference also to the 'impurity' assigned to a female when she is menstruating; her being unable to enter the Temple or the kitchen at home. A girl known to one of the participants had to eat from paper plates.

In some of my friends' houses, if a girl's on her period she's not allowed in the kitchen. One of my friends has to eat out of paper plates, this is today, she was born in England. This is their belief that the woman is impure if she's on her period, right? And so that's a cultural belief. It's not a religious belief.

(Researcher - Is the notice forbidding menstruating women to enter the Temple still standing on the stairs to the Jain Temple in Leicester?) All this was used to help illustrate what the group saw as a need for more education – more general education and more education about HIV.

The *interviewees with HIV* experienced or anticipated a range of responses by family, faith group and community to people with HIV.

For the majority of interviewees support was available to them as members of a faith group in accord with the congregation's usual practice of caring for one another, without there being any known HIV-specific need. A majority of interviewees took the view that people in their faith group would hold discriminatory views about a person with HIV and the need for trust was paramount before a disclosure of status would be volunteered. A small number had revealed their HIV diagnosis either to the religious leader or to other members of the congregation and had valued the support of prayer and guidance. One person spoke of receiving a great deal of help.

Even me, I will stay there sometimes I'm not feeling well, come and take me and spend one week there. They take me to hospital. Then I don't have food, even me, supporting me a lot, loving me a lot.

This contrasted with her experience of the pastor from her home country who preached 'Love one another', as she put it, but had not contacted her when he was in the UK although they had been very close. Another interviewee spoke also of the discrimination associated with HIV and the assumptions made about a person's sexual behaviour and the route by which HIV has been contracted.

A number of interviewees, particularly those from African countries, in speaking of discrimination and prejudice referred to the prevalence of gossiping. One reflected on the harm inflicted by gossip and in doing so made a connection between an earlier practice in her culture of setting the sick person outside the village.

Well Zimbabwe long ago when someone gets worse when he is ill then it is not really okay. In our country ... that person would be taken – they used to make a hut for him outside the village, but I couldn't hear somebody gossiping. But for our age, oh it's a real big gossip. We would be gossiping, gossiping.

This was no longer the practice (although the researcher had encountered the practice of placing the person with HIV in a small hut at a distance from the main house during a visit to Tanzania in 2000), but it provides an interesting analogy. Was the interviewee suggesting that, echoing Goffman's theory of spoiled identity (Goffman, 1963), the exclusion, the casting out, of the diseased, the stigmatized, the 'spoiled', and securing, as it may have been perceived, the community's safety, was today effected by gossiping and the fear of the one who may gossip?

Another interviewee makes a similar association when speaking of 'good AIDS' and 'bad AIDS'. And another commented

the Catholic Church always makes you feel guilty about everything. You can imagine if you tell them they'll look down on you like you've been wicked. You know, it's like the plague almost ... you've brought it on yourself type thing. I mean that's how the Catholic Church works.

Others noted the silence and the determination to regard HIV as someone else's problem. 'It's not happening here. It's happening there, so it's not really'

Ignorance about the risks of transmission during everyday social contact and the idea that '...we don't touch these people and we don't talk to these people' was also an issue.

Some interviewees made direct connections between their situation and their religious beliefs. One likened herself to Job.

'I am like Job...Satan asks God about Job and God gives Satan Job, but he never kills Job. That's what I was only thinking staying indoors.

Making sense of her situation in a different way, another referred to the claim of some that HIV was a punishment from God. One interviewee wondered whether 'Maybe God trying to teach his children'.

There were differing experiences of family support. Some interviewees extolled the support of their family members.

Everyone in my family was supportive. They went and read about it, you know, and educate themselves and they accepted who we were. I thank God for that ... You could think of killing yourself but nothing like that happened. I was very lucky ... very lucky. I had so much support.

Another observed

They said 'Oh, if you are like that, you are not part of the family' ... I have seen people kicked out.

A sense of resignation was not untypical. One participant noted that people are kind but 'some of them have got little bit low understanding' and another took the view that '... they think it's my fault. And that's it'. These and other comments suggest a powerlessness and an internalization of blame and a loss of identity which their contributing to the work of the faith group could help resolve. A small number of interviewees spoke positively of their involvement in the activities of the group, its capacity to foster a sense of belonging and self-worth.

One person cooked food for people in church celebrating special occasions. She used to do much more and cleaning too, but others have now taken it on.

So my pastor say ... 'Let us help you because you are doing too much'. So now I stopped to do my things but in a good way'.

Another helps with food when there is all-night prayer. Before arriving in Leicester an interviewee had been very involved in the activities of her church, an involvement which increased after her diagnosis with HIV. Another reported 'Sometimes I play bells and singing songs'. One former church member, now turning towards another faith, recalled being a Sunday School teacher.

It's the whole family thing that I quite liked you know, of belonging and the community ... I can remember writing plays and the kids putting plays on and stuff like that'.

Two interviewees held a formal position in their church, and for one this involvement was a large part of life. For the other the role appeared to hold little significance reflecting, perhaps, her personal history and the complexities of her life as a person with HIV.

Support of faith group

For those *interviewees* who had been open in their faith group about their diagnosis prayer was a major form of support. Access to the processes and practices of the faith group's prayers for healing was important to the few interviewees who had disclosed their HIV status.

For one person there was a belief that even though she was taking medication 'sometimes it doesn't work out because you have got ... different things in your blood or in your mind'. It appeared as if for her confidence in biomedical prescriptions was either faltering or non existent and that she turned to prayer to boost the efficacy of the medication or actively to express her trust in the healing power of God. It was as if she was caught between obeying the instruction of the doctor and the teachings of her religion. She sought to describe them in coherent terms.

Sometimes the medication can even fail to work for you because you've put a lot of – if – you need to be supported by prayers as well. God will need to heal you again, but not a hundred per cent healing, but he's got the power to heal ... if you believe that God has got the power to heal me ... not the lay leader or

the leader of the church, but you yourself you have to give permission that God will heal me.

The religion's influence over an individual's decision making and autonomous thinking was illustrated by another interviewee's description of her church's support for people with HIV. Although the person believed her faith group would be very supportive if a person said 'I have HIV', she herself had not spoken of her own HIV status. She appeared to acknowledge both the importance of individual agency but also the reality of religious authority.

You know everyone has his own heart. And everyone has his own thinking. I don't know what is inside – what he sees. I don't know how it feels ... When you speak of it you feel that you are now free. You are free. Set free from God.

Other interviewees spoke of the love and care they could expect from their faith group especially if they became very ill. Apart from the practical help again there was reference to the significance of prayer and the value of belonging 'as if you are just like anybody at the church'. One person had been asked specifically about whether or not they wished the disclosure of their HIV status to be kept confidential or not.

Two participants, from different faith communities, spoke of members of the faith group in their home countries refusing to provide the traditional rituals and services at the funerals of people who had died with HIV. Another had always found what he regarded as s tendency of the church to take a patronizing approach to care and support. "'Oh, let me help you', instead of having an attitude 'Let me help you help yourselves'". A former Catholic recalled approvingly a drop-in centre he visited many years ago in London. It had been run by a Christian organization and he had valued its informal and relaxing atmosphere.

For those who had not disclosed their HIV status the support of their faith group was generally valued and appreciated. Prayer, pastoral visits and practical support, whether delivered by the religious leader or by other members of the faith group, were important. Another feels guilty if she does not attend church and another goes 'just to pray and feel that I'm in the house of the Lord at present, you know'. One interviewee

spoke of the happiness he feels when he attends his place of worship and another of the security and sense of belonging her church and faith provide. And one person, in not disclosing she has HIV, spoke of feeling she did not have HIV when 'they make you to be part of the church so you become just like anybody at the church. That experience of inclusion was important to her.

Some less positive comments about the support of faith groups reflected interviewees' questions about the nature of God. For one interviewee it involved the bogus claims, as he saw them, of some religious leaders to cure people of HIV by the power of faith and prayer. And for another, who now described himself as an atheist, it involved some accounting for the diverse ways in which beliefs are appropriated: from acknowledging the strength and comfort many receive from their faith, 'Please help me in this troubled time' and the attributing by others of blame to God, 'Why didn't you stop me having HIV?' and 'Why are you doing it? You know, decimating parts of Africa for instance?' He went on to express the view that spiritual health will affect emotional, social and physical health and, with specific reference to HIV, suggested that general health could be rooted in spiritual health, that 'faith health or whatever you want to call it really has a knock-on effect to people with HIV's general health, you know, so'.

Although, throughout, references were made to the problems of disclosure, one person felt the tendency to be judgmental was outweighed by the good that the congregation accomplishes.

The expectations of those **group members** who spoke of this aspect of support for people with HIV focused on the caring tradition of their faith community and the general and mutual concern to meet need in as appropriate a way as possible.

Acknowledging a realism about 'respectability' one participant reasoned 'We're the people who are members of the church in that place'. Another imagined her church would be very supportive if she had cancer but was unsure about their response to her having HIV – if she were to tell them, that is.

Recalling the help older members with alcohol problems in the past had received, help which might involve spiritual reflection and guidance, a group spoke of the warmth of

support a person with HIV could expect. One person spoke of going away with members of the community and meeting someone with HIV, a *charismatic* and *supportive* individual, who was, with an understanding on the part of community members that HIV cannot normally be transmitted through everyday social contact, also loved and supported. However, in another group limits on expressions of support were anticipated.

The guidance is absolute, no discussion. People will respond in different ways to people with HIV. Some will be judgmental, others will be tolerant. Some would respect and support, others would not. Idea that is 'their fault' would override call to compassion. I would like the community to respond more positively.

During their discussions some participants noted similarities between attitudes towards people with HIV and people with mental health problems or disabilities, 'not everybody will accept them'. Education and information was identified as a key to change. One group spoke of the complexities in the life of congregation members and how everyone is familiar with a range of needs one of which could be due to having HIV. Hope was expressed that a person with HIV would receive what is made available to any other member but added 'People feel it's some sort of tainted thing ... I think perceptively that's still quite a hard thing to shake'. Disclosure, it was thought, may create problems for some individuals in the congregation. One group, not seeing HIV as a matter for the faith community, 'I don't think the religion comes into something like this ... I think that's like one of the reasons it hasn't come up', wondered whether a person with HIV from their community would prefer to approach a specialist agency for support, hoping at the same time that the support available would relate to their particular faith community.

The tensions between the desire to offer unconditional support and care and the perceived need to bind compassion to religious rules of conduct surfaced in all the groups.

According to the *questionnaire responses* the majority of respondents and their congregations would provide pastoral care as part of their religious practice. One

person referred to the support already given to the partner of someone who had died with an HIV-related illness. Many mentioned the availability of listening, visiting, practical help and the importance of friendship and acceptance to people affected by HIV – indeed the same support which anyone in any need could expect to find. There were offers of affirmation and safety and recognition of the need to provide information about local specialist support including the project with a Chaplain who manages that service. A small number of respondents referred directly to the religious roots of their approach to support – to the *Jesus who would not make outcasts of people*, for example.

The faith leaders would also make available largely compassionate and sensitive support to people who disclosed their HIV status. Although there was a general expectation that people with HIV would experience friendly acceptance, a small number of respondents expressed reservations and wondered how non-judgmental the congregation would in fact be faced with the support needs of a person with HIV.

Some respondents thought education was needed with posters and information leaflets providing useful resources for the congregation, for the leader him/herself or for the person with HIV. One leader made explicit reference to the signals that the displaying of such materials can communicate to anyone venturing to access support within a religious context. Some respondents referred to particular religious support. Prayer featured many times. For one 'sacramental ministry and pastoral visits' were important. With the view that the 'greatest sickness is separation from God', one respondent held that the prime task was 'to meet spiritual need'. For another it was 'Faith in a loving God' and for another 'Salvation through Christ Jesus'. A model for the nature of any approach to people affected by HIV was presented by one respondent as 'att of our Lord to those thought ritually unclean', that is, an inclusive and caring approach, echoed also in the following, 'In Christianity there shld be no outsiders because for Jesus Christ there were none', and also in 'Christ-like love'.

While moral support was important for two respondents another insisted on a 'no moral high ground stance'. Aware that resources in Africa were scarce, one respondent thought HIV should be 'pushed up the agenda'. However, another described the congregation's support for 'childcare in Africa, a hospice in Asia + two

medics'. Some referred to holding services for World AIDS Day and the local Chaplain for people affected by HIV was regarded also as a useful resource. For a small number of leaders the provision of support would consist of referral to specialist agencies and health professionals.

Support of other agencies and wider community

For some *interviewees* the network of support which existed beyond their faith group played a critical role in their life. One person made the distinction between being supported as a church member and being supported as a person with HIV.

... the point is that you didn't come open to them that you've got HIV ... they support you as a member of the church but not that you've got HIV because they don't know and you didn't tell them you have got HIV ... the support they give you it's okay because they don't know the situations of your life history.

At the hospital and other agencies her HIV status is known and she can speak openly of her support needs. Other interviewees valued education and health services. One called for HIV education to be extended to Sunday Schools and another described the difference the UK's health service had made to her life.

'...when I didn't come to UK I think I was already died because I didn't know that ... I have HIV but when I came here when they checked my blood and they said that I have that disease ... so I started to go to the hospital'. They gave me the medicine and now I'm all right. So it's good. It's good. God is good.

One contrasted the realities of biomedical responses to HIV with the claims of various pastors and evangelists to cure HIV by prayer. He questioned the motives of those who offered such a service – were they looking for fame and fortune rather than a person's good health? – but noted that some people would choose to trust their claims rather than visit a doctor.

One person pointed out that HIV services in the UK have improved a great deal over the years. He had been diagnosed in the 1980s and, with no follow-up counseling, recalled being told by his GP 'You are going to die'. Anxieties about transmission

meant being separated from other patients and patient notes and files had details of his diagnosis prominently displayed.

Another interviewee saw support in terms of wider society's attitudes. A gay man with HIV, he had met with prejudice and with violence at times but his own church, he recalled, had been open, 'accepting people as they were', so he did not believe it was only a religious issue. Indeed, he went so far as to suggest that making it a religious issue, blaming religion for the ills of society, for the prejudice towards people with HIV, would be harmful to those for whom religious belonging was important to their well-being. There was a need for all of society, he argued, to be able to talk about and accept people affected by HIV.

Concerns about confidentiality limited the access of some people with HIV to services. The problem lay not with health or social care staff but with other service users.

They don't want to come to the drop-in because they know they will meet other people in there and people will get to know that they've got HIV. They don't want people – so many people to know so they just – know them, they come and collect their food vouchers they'll come and collect and go for their support for their food and all those things.

Others spoke appreciatively of the support and care available, one person contrasting it with that in her home country. They are dying for hunger. They are dying for that situation because of no money, no water. Two interviewees referred to the extent of the changes in health they had experienced when a diagnosis had been made and medication became available. One spoke of being 'reborn again', of being 'given a new life'.

Opportunities for mutual support in groups, the outings, the drop-ins, the food vouchers, the chaplain's hospital visit, advice at times of difficulty and help with accessing financial support – all these were mentioned in positive and appreciative terms. Hospital services were spoken of warmly. There were a small number of participants who enjoyed the support of family and/or friends and had little or no need

at present, to receive other than clinical care. One interviewee, however, valued the availability of other services should the need arise.

Most *questionnaire respondents* saw their religion's teachings having little if any impact on wider society's response to and provision for people affected by HIV. People outside the faith groups, a number of respondents stated, would ignore religious approaches to HIV outright or see them as hostile, judgemental and homophobic. One person noted a tendency to use dogmatic teachings to beat one's self and others: 'Oft as stick for own fear & guilt'.

There were several expressions of concern at the perceived irrelevance of religious views, but there were those who regarded the attitudes outside the faith group as more open and accepting. And although largely regarded as inconsequential in terms of attitudes towards and support for people with HIV outside the faith groups, some saw religious influences in the compassionate approaches of wider society and the, perhaps faith-based, expressions of 'professional/vocational engagement'. Similar connections were not made, it appears, when another respondent declared that Princess Diana had more influence on responses to people with HIV than religious teachings or beliefs. And one respondent wrote a "General attitude to the majority of HIV/AIDS sufferers appears to be 'they brought it on themselves'".

Suggestions and comments concerning the provision of HIV support by other agencies and organizations in Leicester suggest some, though limited, recognition of the existing support services. Respondents noted the value of local support groups and drop-ins, access to a specialist worker, the displaying and distribution of information resources. One person, already aware of local provision, advocated 'working together as a good way to spot gaps'.

Little was said in the **small groups** about support provision beyond their respective faith communities. One person thought

The right response from the church could improve responses from the general population; equally, the wrong response could produce the wrong response,

for me preaching from the pulpit hellfire and brimstone and they've only gotten what they deserve.

Another saw the need for more awareness in the wider faith community but could not see how this would be accomplished in her own community. One person spoke of an assumption that everyone in the city would receive a positive and supportive response. Another anticipated being able to go to an 'HIV-charity, an HIV-specific place' should the need arise, but would prefer to seek the support of friends rather than approach a local priest.

The extent of support for people affected by HIV is largely unknown and hidden. In some respects this invisibility is helpful in that access can be confidential, but in other ways it reinforces the barriers of prejudice and stigma which continue to blight the lives of many of those affected by HIV and limit the access by the wider community to information about HIV.

How far attitudes, whether prejudicial and stigmatizing or affirming and compassionate, may be shaped by the appropriations of religious beliefs is explored in the following section.

Appropriations of beliefs and teachings

As discussed at 'Beliefs about transmission' (page 145), distinctions are discernable between the few who draw on religious teachings, foundational texts or other traditions of the faith to judge outright and make distinctions between 'innocent' and 'guilty' and between those who gild condemnation with calls for repentance and good works in order for the forgiven, the 'sinners', to be worthy members of the community and deserving recipients of compassionate care.

We all sin and sin has its natural results, promiscuous sexual intercourse is wrong. Ideally hate the sin LOVE the sinner.

Those dichotomous tensions (not the sole preserve of the religious) governing the conduct of many human relationships, justifying inequalities and exclusions and reflecting and risking internalized self hatred are expressed in various forms by many of the respondents. All too rarely, though, are such differences and tensions questioned, explored and understood even though these are not uncommon traits in the appropriations of beliefs and the constructions of meaning (Hull 1991, Fowler 1981). Islamic, Hindu and Christian religious traditions sanction and facilitate such belief structures in coherent and authoritative if not authoritarian terms.

Christianity & marriage to promote Biblical values. Personal & corporate responsibility + sin thro' abuse, immorality, ignorance. Not always individual's fault. Hate the sin, love the sinner, offer acceptance, love, healing. Biblical guidelines re chastity & loving rel for wider good of whole community as well as individuals. Christian rules the ideal. Worried Biblical teaching fuelled fear used to condemn people with HIV.

Other respondents construed their beliefs in a fully compassionate framework, omitting any reference to innocent or guilty, judgment or sin other than to express regret for their presence in parts of their own or in other religious traditions. One referred to religious teaching validating 'people's blind prejudices'. Others wrote of their own understandings and attitudes differing from people in their congregation or from the religion's 'official line' on, for example, same sex relationships.

- Judgemental attitudes and fear have been caused by wrong interpretation of the Bible and bad theology.
- Ch needs to be compassionate community, break down marginalization of others & fear in ourselves.
- Sadly not found coherent voice to say anything useful or constructive yet.

 Beloved children of God shld be treated no differently from others. If it says anything else I wld disregard what it says. People like to think Bible v clear but truth is it is v confused esp re sex outside marrge re male homosexuality. Shld be taught as life affirming + joyful but not good at being honest about.

Confusion described affects evry aspect of ch's att to everything to do with sexuality ... still v bigoted people in my ch despite reg exposure to reality. perceived biblical sexual ethics can be excuse for non-Christians also to be judgemental & unforgiving.

The belief patterns of respondents present as largely coherent, with responses to HIV having been considered within the wider context of religio-cultural authority. That the religion provides in its core narratives the means by which dissonance and ambiguities, perhaps unacknowledged (Rosenfeld 2010: 513), can be masked or held in tension, keeping integrity breakdown at bay, is discernable if not explicit in the responses. And this coherently plausible cover for failure to examine and engage deeply with personal and institutional responses to the other among us and within us does appear to rest at times on misunderstandings or distortions about the nature and impact of HIV and assumptions about the routes of transmission. For example, respondents expressing a more doctrinaire approach assume a person with HIV will have engaged in sexual behaviours contrary to the religion's teachings – usually outside faithful heterosexual married relationships - in which case they have 'brought it on themselves' and are 'guilty' rather than 'innocent' 'victims' of the 'disease'. And there are expectations implicit in many responses that a person with HIV will always be ill and therefore 'deserving' of charity.

Those respondents who report divergence between their own openness towards and acceptance of people with HIV and the still conservative position of their congregants may be suggesting a movement on the respondent's part in which individual agency has risen above an alternative, closed authority. The following diagrams offer a representation of the two main response processes indicated by the Questionnaire data. The first (Figure 5) suggests an 'external locus of control', or 'institutional religious authority', terms coined by Stephens, Jordens et al (2010) in their discussion of religious perspectives on abortion. Again, taking Stephens' typology and its attempt to differentiate 'religions according to how they position the faithful', the second diagram (Figure 6) below illustrates an 'internal locus' of authority, that is, one shaped by individual agency or self expression.

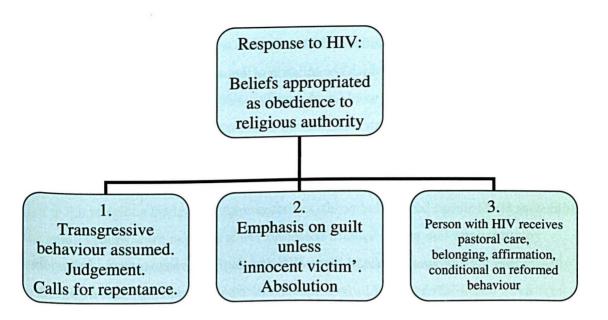


Figure 5. 'External locus of control' (Stephens, Jordens et al, 2010)

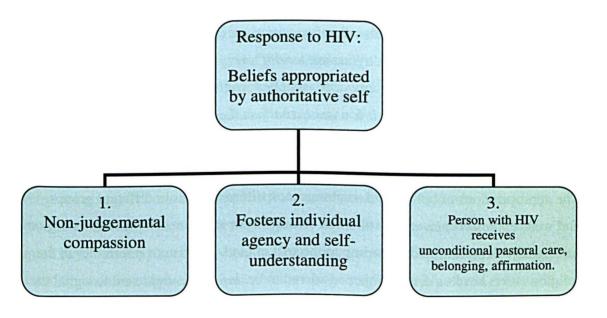


Figure 6. Questionnaire respondents' positioning of people with HIV modeled on a typology 'Internal locus of authority' set out by Stephens, Jordens et al in their paper 'Religious Perspectives on Abortion and a Secular Response' (2010)

The tensions described above and associated with beliefs which subscribe to notions of salvation resting in processes of retribution and redemption are exposed more fully in the discussions held by the **small groups**. Responses were faltering and less confident when some of the realities of HIV infection were drawn into the conversations. The resources which the religion offers and which in generalist terms and in more familiar situations would customarily satisfy, were found wanting at times as group members, through their various contributions, raised new questions and articulated various opinions and insights. In one group such a discussion was generated by a participant's account of a visit abroad where she met a mother and a child with HIV.

...and his wife and child now have HIV and they are what you would consider to be innocent victims of ... by somebody else's actions being — of having sex without protection and then therefore spreading it to what you would consider innocent victims. So I was discussing this idea that 'Well, how could a child be born with AIDS and, you know, what's their role in that?' And again we were, I was discussing this role of Karma and the acceptance that we are spirit entities and that, you know, through maybe past life ... you know deeds that actually this is what — what happens to us, but when you actually see it, it's very difficult and on a humane level it's very difficult to accept when you see a young child or an innocent, what you would call an innocent person suffering. So um I think it is a quite a subject that, you know, is talked about, um, I mean within — within my friends definitely, I would say, definitely.

The appropriations of beliefs and teachings took different turns in different groups and were expressed in a variety of ways. According to someone from another religion having HIV is predestined according to the will of God. HIV is not referred to in the religious texts but as a disease it is considered to be one of the signs said to signal the end of the world. As long as this view was held and taught the participant thought people with HIV would be despised and rejected. In another group taking a non-judgemental position was advocated by one member but challenged by another.

But that's what it says doesn't it ... the woman shall leave her family and cleave to her husband and if you literally read the Bible it does say that

doesn't it, you know, that if they're together then they should be married and that is – that is almost a Christian viewpoint, really, except that society's changed and - and as a Christian, do you – it's very difficult then isn't it as a Christian to say Right ... am I so fundamental that I'm going along with what it says in the Old Testament and the New Testament to a certain extent or do I say Times have changed and have I the right to judge? You know, should I be saying to everybody 'Right, you should all marry?

In contrast with the expressions of belief reported by the Questionnaire respondents, that is the religious leaders or representatives, those beliefs and opinions expressed in the small groups were exposed if not subjected to questioning and opposition by others. Pre-existing appropriations of belief could be, and at times were, challenged and group consensus fractured and a dissonance would surface. This may have been the experience if religious leaders had been invited to meet in groups and engage in discussion. (That earlier methodological argument for not inviting religious leaders to discuss their responses to the questionnaire in groups is exposed here. At that stage the impact of group discussion to this aspect of responses was not acknowledged. Perhaps a method for further research?) However, it may be the case also that those with leadership roles have and require a more well-defined belief system which they will describe more clearly and guard more resolutely. Is it in considering the fact of HIV and the person with HIV that challenges to any prior belief equilibrium are more readily appropriated and incorporated into a new coherence by 'lay' people than by many of those 'guardians' of religious authority, the leaders? Is it in education and openness to an experience of and immersion in socio-cultural shifts which drive religious change? Or do those interests of the religious institution which reside in resistance to change exert the levels of power and influence to maintain the status quo? Psychotherapy's model of group counseling may offer a process through which such dimensions of believing and knowing can be explored with others, either with other religious leaders or with people from a range of backgrounds.

These questions of authority and coherence dance around the theory of cognitive dissonance described by and given narrative exemplification by Festinger, Riecken and Schachter in their book 'When Prophecy Fails' (2008, first edition 1956) and given further application to religious believing by Richard Rubenstein in his work

'After Auschwitz' in which, while positing European Christian discomfiture with the presence of those whose claims rivaled their own, he reminds readers 'that one of the most important roles of theologians is dissonance reduction' (Rubenstein 1992: 92) and that the motivationary thrust of dissonance reduction could result in extreme measures. Rubenstein does not advance cognitive dissonance as a 'total explanation' of the Holocaust but he does posit dissonance as a way of 'enlarging' understanding (1992: 83 ff). ¹⁶

That dispute between a priest and member of the congregation (recorded above at page 167) suggests a contingent, shifting place for religious authority in the appropriation of belief. It will be recalled that some congregants preferred intinction, that is dipping the wafer of bread into the wine and then consuming, rather than each communicant drinking from the same cup according to the tradition. The priest had pointed out that the silver chalice and the alcoholic content of the wine are deemed to create a safe and hygienic way to share from the single cup without risk of infection. The participant's drawing attention to the imposition of such a rule when fear of infections, a fear that is not always irrational, overrides, or threatens to override religious tradition was useful as an illustration of the potential for rational and irrational, intellectual and psychological responses to HIV and the various combinations of each to inform religious responses to HIV. That these differing realities drive the construction of differing religious responses, both coherent and dissonant, suggests a further factor influencing the appropriations of beliefs: the access of individual and group to the religio-cultural means by which identity and belonging can be authorized and secured. For the priest the tradition and the doctrine governing the practice were central. For some congregants the fear of disease trumped all.

For another group the relationship between religious authority, personal belief and group identity were presented as inseparable and incontrovertible. They agreed that HIV is a punishment for disobeying God's laws and that a person with HIV would

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¹⁶ According to Greenwald and Ronis (1978) Festinger's original theory (Festinger 1957) evolved through the years following to become one characterised primarily by 'ego defense' or the preservation of self-esteem 'rather than a need to maintain logic-like consistency among cognitions'. This shift, while not casting Festinger as redundant, does enable a subtlety of application more appropriate to the micro narratives of individuals and to the macro narratives of religious groups and institutions.

feel shame and not speak of having HIV. A reference to anal sex brought grimaces to the faces of those in the group and, from one person present, the information that, although it may be known in urban centres and the coastlands of their country of origin and on the European mainland where participants had lived before coming to the UK, they are a nomadic people and anal sex is not part of their experience. For this group such notions appeared to be fully supported and acceptable to all, compatible as they were with individual appropriations of belief and the expressed commitment of the community to religious obedience.

In a similar way another group spoke of parents pointing out that in their heritage country where the religious teachings and beliefs were deemed to be more strictly observed there were no pregnancies outside marriage and no sexually transmitted infections including HIV.

And when you do go to places such as — to other Muslim countries that are predominantly Muslim, you don't see those ... you don't see um people with STDs of ... not just HIV, any sort of STD ... either that or it's not talked about. It's a taboo subject. Or you don't see teenage pregnancies and I think especially my parents' generation they will compare it ... They'll be like 'Well you don't see it there and you know here in this country where people are more sexually active and there is more sex ... 'They will say ... 'what do you expect when this is what's going on and this is how people are behaving?'

Largely regarded as a generational position with older people described as contrasting the wider, stricter moral conventions of the country of origin with those in the country of settlement, the 'West', nevertheless, such views, according to those reporting them, appeared to carry some weight and legitimacy within communities although it was acknowledged that changes are occurring.

...if condoms do prevent AIDS spreading then yes they should be used, no question, but on the other hand using family planning has enabled people to be promiscuous and adulterous because ... the fact there might be a child was a deterrent wasn't it for most people ... So in a way it's a bad thing but it's here now and if ... better to ... keep true to one partner and everything but it

doesn't – that's not life is it ... divorce is another things the church doesn't believe but there is still divorce within the church.

Another group also made inter generational comparisons noting severe impacts of ignorance and social disapproval.

- Years ago to have children out of wedlock was very ...
- Well you got put into an asylum actually. There were people at N asylum who'd had babies out of wedlock.
- ... I know my mother told me she didn't even know where the baby was coming from when she was expecting.

The process raised many questions both within the groups and for those individuals unable or unwilling to participate in groups. The resulting exposure of tensions and complexities, if not practical and moral failings, extant in the application of traditional teachings and beliefs to HIV, to the acknowledged realities of many peoples' lives and their various needs in terms of identity and belonging, were clearly unexpected and previously unaddressed in the ontological or teleological reflections of most group participants.

The challenges were forcefully illustrated by one group member's story. She spoke of attending an HIV awareness raising event organized by the chaplaincy when she was a student at university. They were asked to reflect first on the image of the Body of Christ with TB, then on the Body of Christ with AIDS. The first presented little difficulty but the second image created consternation; '... after the service it was the one thing that people were talking about and how shocking this was and how Jesus couldn't possible have AIDS because – 'But it became clear to her that theologically and biblically it was a sound position to take.

But it was a shocking thing to do ... and yet that has to be what the truth is. If our church members have this disease, Jesus has this disease, as it were, and you know that has to be the reality of it.

The religio-cultural components of coherent believing which are used to affirm individual identity and relationships and give meaning to life and death are rooted in the historic and recent experiences, the narratives, of human society. The data above set out some of the key components in that process which the religious leaders and the group participants described as their responses to people with HIV. Tensions between judgment and compassion, and disputes concerning the weight to be given to the one or the other, characterized the process for many. For most of the individuals living with HIV, the interviewees, their HIV diagnosis generated a similar struggle: how to incorporate the realities of life with HIV into beliefs and teachings which had hitherto served needs for belonging and meaning but which now demanded to be redrawn or reinforced. Faith in the confused, bifurcating or absolutist interpretations of religious leaders may not be justified when 'self reflection and a tolerance for ambiguity' are the route to coherence and wellbeing (Rosenfeld 2010: 513; Hull 1991).

For *the person with HIV*, particularly the religious person with HIV, earlier appropriations of beliefs and teachings were subjected to re-appraisal as life with HIV raised challenges to existing structures of identity and belonging. In managing their own self-knowing they were required now to address those pronouncements, both positive and negative, issuing from the religious leaders, community members and their own families about people with HIV. For most of the interviewees the process involved significant effort to avoid, accommodate or transform to one degree or another the self-condemnatory, depressive risks involved in internalizing negative attitudes towards people with HIV – and, by and large, it was the negative that was heard and felt, not the positive.

The journeys were never simple.

There are those who are struggling to understand why God would inflict such hardship. Is it really God's will? 'Maybe God is trying to teach his children'. The story of how one participant believes she contracted HIV is one of heartbreak and powerlessness in the face of bad practice by health professionals.

That is the question every time I ask myself when I cry every time cry Why Lord? Why Lord? But there is no answer, ever ... I will just die asking Why?

With failed pregnancies and the breakdown of her relationship she has depended on 'my own strength' and the support of family members, for which she thanks God. She attends church services and draws comfort from prayer but will not disclose her HIV status there. Struggling to turn her life around after so much difficulty she is determined to make a new start. So far, though, she has felt unable to speak of her struggles and achievements as a person with HIV in the place and with the people, it could be argued, she could expect to be most open and most accepted (Chinouya and O'Keefe 2005, Ridge et al 2008)

Others seek to assert the difference between themselves and those who engage in irresponsible behaviours, behaviours which are in breech of the religious teachings. There are those who look to distance themselves from and challenge the religious charges of infection with HIV being God's punishment for bad behaviour and the common identification of HIV with prostitution.

What will be the reason for punishment? Especially if I know I wasn't a prostitute. Because if it's a punishment that person who will be doing prostitution is the one who is supposed to be punished, but it's not like a punishment because anyone can just have it ... sometimes besides sex so it's different.

Another participant set out at length his concern at the claims made by many pastors, that they can heal, that is, cure, a person of HIV by prayer. He saw value in the moral and spiritual support which religious leaders could offer but was clearly troubled by the claims to cure and the potential risks to prevention, testing and adherence to treatment messages. The life changing impact of medication on his own health clearly influenced his views. Other interviewees, however, believed emphatically in the power of God to heal through prayer and faithful obedience, beliefs which had persuaded one interviewee that she should refuse medication, a decision she reversed after intervention by her church group. Another, describing extensive healing in her church group - of TB and HIV - believes it is necessary to declare her HIV status in order for the prayers to be effective.

The phenomenon of HIV was attributed variously to the works or will of God or the devil, to the arrival of incurable diseases foretold in scripture, to punishment for bad behaviours, to the fulfilment of God's purposes and to the inappropriate teachings and practices of religion.

Obedience to religious authority, in whatever form that authority is understood to reside and express itself - whether in the 'word' of God communicated by the instruction and interpretations of religious representatives, in the religious texts, in liturgical practice, in dreams or private devotion, in direct communications between the supernatural and the individual, in presenting for forgiveness and being 'good' – is discernable in participants' descriptions of their beliefs and the place those beliefs occupy in their life as people with HIV. Whatever the level of control and influence the religious authority assumes or is accorded most of the interviewees depict their beliefs, the religious group and their religious identity as a major source of support and affirmation, irrespective of HIV disclosure. Those who have set aside the beliefs and religious belonging of their upbringing and take a critical, highly critical in one instance, view of some mainstream religious positions as they see their impact on prevention programmes and the lives of people with HIV (teachings on same sex relationships and condoms, for example) nevertheless, have a sense of their value to others if not to themselves. One person spoke with bitterness and anger of the abuse by a priest his partner had suffered and of the church's failure to respond appropriately. Forbidding, as it was seen, the use of condoms in an age of HIV also drew criticism.

Interviewees had clearly reflected at length on how life with HIV could best accommodate and be accommodated by religious believing and practice. Several took positions which challenged traditional orthodoxy: the influence of Karma on Hindu and other responses to HIV (one interviewee called on religious leaders to explain how Karma can be appropriated if it is to be useful in furthering HIV prevention and care); the tendency to blame and make judgments (interviewee pointing out that she is not a prostitute and another that no-one can know whether or not God has already forgiven the person). Some identified directly with scriptural characters, stories and incidents. One spoke at length of her tradition's myths and practices which she applied directly to her own situation and from which she sought to give meaning and

understanding to her life as a woman with HIV. Gender relations also surfaced occasionally mainly in reference to the subordinate status of a wife and the tendency of some men to betray their partner.

...I was just trusting my partner since we are both Christians. I didn't know whether he have got some girlfriends outside or where he got that.

Some resolved the challenges which their HIV diagnosis and the response of their faith group, whether HIV was disclosed or not, had raised for their beliefs by placing more value on their own thinking and decision making, on articulating a critique and deploying personal agency. Most remained within their tradition. Two had left, but one made it clear that he had not left the religion of his upbringing so much on account of the attitudes towards same sex relationships or HIV, but more in the wake of a youthful questioning. Now exploring another religious path, he pointed to the ambiguities that certain religious believing can harbour, the ways people find strength in times of need and the charging of God with blame when things go wrong.

Other interviewees faced the future by securing themselves more deeply in absolutist believing and religious authoritarianism. There were also, of course, positions across that spectrum, but for all interviewees the appropriation of religious believing was a key process in the construction of meaning for a life with HIV.

Making meaning

That participants' appropriations of religious teachings and beliefs become the lens through which constructs of meaning in response to HIV are perceived and conceptualized will not in itself surprise. For some, meaning is clear, incontrovertible truth. For others truth is elusive, wanting, perceptions blurred by complexity and difference. This section introduces participants' references to wider influences on responses to HIV and their potential for clarifying and obscuring truths. First, *questionnaire respondents*.

For many of the religious leaders participating in the study the truths which undergirded their responses to HIV were described in terms of either 'them' or 'us'. In other words there were those who did not identify with someone who has HIV even

if the one with HIV is an individual of the same religion. Assumptions were often made about behaviours having deviated from the religious norms and religious beliefs and authority were drawn upon to justify both the judgements made and the subsequent insider/outsider divisions set up. Religious truths were often clear and any shifts deemed to invite trouble. In other words the teachings are there to protect and 'People do not pay attention to teachings'. Put another way 'Chastity and marriage to promote Biblical values'; and 'Christian rules the ideal'.

On the other hand there were those who could and did empathise with people affected by HIV and who distanced themselves from religious opinion which judged and discriminated.

- Still v bigoted people in my church despite reg exposure to reality
- Worried Biblical teaching fuelled fear used to condemn people with HIV
- Bible not clear re sex very confused. Shld be taught as life affirming and joyful but not good at being honest about.

There were those who held together the condemnation and the duty to care, but apart from a small number who refused to take other than an inclusive approach, even when members of their congregation and their religious authorities are taking a different view - 'Judgemental attitudes and fear have been caused by wrong interpretation of the Bible and bad theology' - most Questionnaire respondents 'othered' the person with HIV either without compromise or with an offer of inclusion contingent upon repentance for wrong behaviour or the good will of the religious.

- Many make lifestyle choices contr to kingdom values. We live with consequences & all need supp & healing
- General attitude to the majority of HIV/AIDS sufferers appears to be 'They brought it on themselves'.

- My religion tells us that it is a great sin to commit unlawful sexual activity.

This unlawful sexual activity is the root cause of HIV/AIDS...

So, taking the responses of the religious leaders, in relation to HIV the world was divided between those who are prejudiced against those affected by HIV and those who are accepting; that is between those who see a world or community with HIV as 'our' world and 'our' community and those affected by the virus as 'us',

Conservative line – sex for hetero marriage relationships BUT social awareness, inclusive core values allow for & recognize diversity and other 'behaviours'.

and those who see a world and community with HIV as 'their' world and 'their' community and those affected by the virus as 'them'. The 'others' and the routes by which respondents' distance themselves from them are variously identified in terms of lifestyle, 'western' secular influence, shifting cultural norms, modernity's sexual freedoms and the declining influence of religion.

Similar issues exercised the discussions in the *groups*, but there appeared to be a looser attachment to religious authority, a greater willingness to acknowledge ambivalence and diversity and a readiness to include the person with HIV and respect individual choice. The discussions themselves ranged far and wide with participants, in many cases, raising, identifying and going on to explore the challenges HIV presented to existing, and that would usually mean traditional, constructs of meaning with varying degrees of agreement. While there were those who would attribute prejudice to their wider religious group/community there were few who identified themselves with this 'othering' of the person with HIV. Although there was concern that in some communities blaming the person with HIV for his or her own infection would override any calls to compassion, by and large, HIV education was seen as the recipe for increased levels of understanding and acceptance.

The need for inclusion was not only seen as necessary in terms of religious duty but also in terms of it being the most humane response and the one most relevant in breaking down barriers to the access of resources for prevention and care. It may be

significant that the group most recently settled in the city expressed the most exclusivist views; views which, nevertheless, generated a few questions about traditional practices and cultural morès, suggesting an emerging anxiety about the accuracy of the information which shaped those views and the capacity of the individuals in the group to assert any need to re-appraise them in terms of risks to health. For example, reference to the practice of polygyny alerted the women to the fact that the sexual history of the partners may not be known to all those involved and any risks of transmitting HIV would remain hidden; questions were raised about access to information, to testing facilities, to a female doctor, to interpretation services. (This dimension of their own exclusion and marginality as female members of a recently settled minority group with specific religio-cultural needs was not articulated or protested using the language of inequalities.)

Others spoke of the 'sanctity of womanhood' being 'defiled by the use of a condom', in that the teachings intended to protect women from sexual exploitation were being ignored. This led to a recognition by most in the group, '...we don't all hold that view', that the Vatican's prohibition of condoms in HIV prevention was a mistake (see Footnote 14 at page 137). Issues of gender were raised again in another group. How girls were regarded as 'the light of God' until menstruation began. One group member described how no menstruating girls or women would be permitted entrance to the Temple.

'... the woman is impure if she's on her period, right. So that a cultural belief. It's not a religious belief'.

Another described a friend who was not permitted to enter the kitchen, who ate from paper plates during her period. In the same group the view was expressed that men travelling on business and sailors having 'good times everywhere' were responsible for the spread of HIV.

Men always go for the business in his own way. Yeah, he go India and Hong Kong and here and there and then he enjoys his life there. That's why they pass it to each other.

Others were of the opinion that African men were unfaithful to their wives. Grandmothers were bringing up orphans. There was a reference to Muslim girls being removed from sex education classes in school, and a recollection that, not so many years ago women, who 'had children out of wedlock' would be admitted to an institution. The 'othering' of those with HIV can be characterized by gender as well as by sexuality, religion, race and ethnicity and at both inter- and intra-group levels.

Diversity's influences on making meaning also came into play. One person spoke of the challenge generated by a preacher from another tradition challenging the religion of her upbringing.

Catholics, how can they possibly go to heaven they all worship Our Lady.

That was the first time in my life that I'd ever actually thought someone thinks we're not right.

Others described the tensions created by efforts to maintain a cultural identity when it is constantly challenged by a new social milieu.

When our parents came over from Africa or India they tried so hard to hold on to our culture in England and so they were especially with the first child of the family they were overprotective because if you see us deviating away from our culture they over-reacted to bring them back. It would also make them rebel ... A lot of kids, young adults, they live two lives.

One group noted the differing ways of thinking and talking about HIV. From a congregation with very diverse backgrounds including people directly affected by HIV a participant wondered about coming together and talking of it:

I don't know what the barriers are for each of us. We'd have to be quite careful if we wanted to have say a sort of multi-group, multi-racial group ...

Concern was expressed about those who are diagnosed, the questions they have to address and how difficult it is for them especially when 'membership' of a faith group

has historically conferred a degree of respectability, a respectability which is deemed to have been compromised by having HIV. And when the 'other' is a member of the group it is then that religion's capacity for enabling its members to avoid or overcome dissonance is most severely tested (Festinger et al 2008: 141 ff, Rubenstein 1992: 93, Hull 1991:188 ff).

For interviewees the key tasks in constructing meaning revolved around the need to counter the 'othering' of others. Prejudice and discrimination raised their consciousness of being 'other' and the assertion of identity and belonging were significant strategies in limiting the impact and fear of exclusion. For some, though, quests for both identity and belonging were cast in ambiguity and uncertainty particularly in those for whom identity involves multiple streams of prejudice above and beyond that of being a person with HIV. There were those interviewees who experienced marginalization on account of their sexuality, their gender, their ethnicity, their race, their immigration status, their low income, their limited communication skills or a combination of several of these. For most an attachment to and involvement with a religious group helped secure a stronger sense of identity and belonging. This was not the case for the gay interviewees, both of whom had left the church of their upbringing, one taking a highly critical and angry approach to his former church's Position on sexuality and HIV and the other leaving, not on account of any response to his identity as a gay man, but as a consequence of his own questioning and the desire to explore alternative belief systems. Many interviewees recalled difficult and distressing situations – the death of family members, the breakdown of relationships. the betrayal of hitherto trusted partners or friends, the loss of work and income.

The circumstances of their diagnosis and its impact on their life and the questions it raised about earlier experiences generated a good deal of reflection. Although some could point to life changing benefits in their HIV diagnosis - access to medication, heightened faith, increased involvement with a religious group and more discernment in relationships and lifestyle choices - for others the betrayals of those they trusted, the knowledge of infecting a partner, the fear of speaking out, the grief, the separation from family, the financial worries and anxieties about disclosure loaded the costs of integrity and well-being with an exposure too far. Their efforts to confer meaning on these messy narratives without succumbing to the outsider status which family and

society insisted on attaching to them as people with HIV were often channeled through religious beliefs and places of worship. Religious identity and belonging mattered to several - but without, for most, the disclosure of their HIV status. And without disclosure the 'other' was rendered powerless in any challenge to the 'othering' of the religious group echoing Ackermann's assertion that stigma is 'deployed by social actors', in this instance religious authorities, 'who seek to legitimize their own dominant status' (Ackermann 2007: 114).

Disclosure

Anxieties about confidentiality and reaction govern decisions about disclosure of HIV status for *interviewees*. No-one reported an easy time, though everyone had spoken to someone. For some the chosen *confident* proved untrustworthy, causing unlooked for distress. Others had spoken with family members, partners and friends and found in one or another welcome care and support. Few had chosen to speak with their religious leader. One interviewee put it in the following way:

... It's quite difficult to say like - to tell like your members of the church or your - your leader. It's quite like you say this is private. This is like confidential. No, you can't even tell your partner. But that when you really wholeheartedly that 'I must say it now' ... but then it's really very difficult because you don't know maybe that person he won't keep it private. So that's why you feel sometimes you doubt to tell the pastor or the leader that ... is your condition ... he is a human being.

Another took a different view believing pastors 'they keep secrets'. For one person an acceptance of her situation and a thankfulness to be still living had brought a new perspective and reduced anxiety about disclosure. Others were fearful of hurtful reactions not so much for themselves but for other members of their family. One person was afraid that disclosure would create insurmountable barriers between himself and those he loved. There was recognition on the part of some that their silence was complicit in bolstering the prejudice and the stigma which drove caution about disclosure.

... I have been silent for a long time ... If we don't stand up who is going to do it? No-one. We have to. Because we have to raise awareness to everyone to stop the stigma ... but how do I start it? I don't know ... Silence is not going to help anything.

And yet the perceived risks were too great. There was reference to a relative with HIV who was asked to complete a form for his employer. The form included a question about HIV. The relative, fearful of dismissal, decided against declaring his HIV status.

Speaking to a health professional created fewer difficulties for most interviewees. By and large there is an understanding that confidentiality will be respected and that it is in their interests to be as open as possible so that diagnosis can be made as early as possible and access to any necessary treatments and services put in place. However, it was clear that for several the visit to the GP or hospital had not occurred until there was a recognizable deterioration in health or particular symptoms which required attention. One person had concluded 'When you don't speak you are going to die'. When he was asked by doctors to consider an HIV test he and his wife agreed and 'that's how we managed to move on'.

Disclosing one's HIV status to a religious leader was regarded as a safe option for only three interviewees. At one end of a spectrum of views was the person who had been open in her church group and was receiving a great deal of support and care, both practical and spiritual. At the other end was a former catholic.

Well, I mean, I'm saying if you were a young lad and you went to a catholic priest and he just started spouting the evils of this and that, you wouldn't come away feeling too good, would you?

Most had spoken of their situation to only a few close friends or relatives. But these choices varied according to levels of trust or the type of response to be anticipated or both. One person had not told a close relative because she had expressed what the interviewee regarded as highly prejudicial views in the past about people with HIV. Already estranged on account of a relative's conservative religious views another

participant had not disclosed to him his HIV status. Anxiety about exclusion from and the well-being of the family circle were also issues which came under consideration. One person who had acquired HIV from her husband spoke of the family response, illustrating the widespread tendency to ascribe blame and create a distance between self and virus.

It is a distancing which is echoed in some, and only some, of the leaders' responses to disclosure for most anticipate or can attest to an open and accepting encounter between a person with HIV and the religious leader or other members of the congregation.

The majority of *questionnaire respondents* described a supportive and accepting environment within which they expected or hoped that people affected by HIV would feel able to disclose their HIV status.

- I would hope we have enough respect and trust for/in one another to discuss such a topic.
- I hope they would feel we cared and respected them.
- This happens where there is an atmosphere of love, understanding and faith. A two way flow is important where everyone shares their needs and fears. This can be very emotionally freeing and healing.
- Is something that can happen in total anonymity or when someone feels they can totally trust you. Role is to inspire trust for the time it's tested

A small number identified the embarrassment and anxiety of the person with HIV and a lack of understanding within the faith group as barriers to openness and religious contexts of support.

- Fear, lack of understanding in some people would create silence.
- I think it depends who they choose to talk to some more comfortable than others.
- No. They feel guilty.

The extent of the compassionate response anticipated by the majority of questionnaire respondents to an approach by a person with HIV wishing to disclose to their religious leader or a member of the congregation is not matched by the perceptions and practice of the participants with HIV, most of whom expressed a reluctance to speak to their religious leader or to someone in the group in a way which would involve the disclosure of their living with HIV. The people with HIV are not hearing or choosing not to hear the accepting and caring tones of the religious leaders' message about the safety of disclosure.

In those *groups* where issues concerning the disclosure of an HIV status were imagined there was a recognition that a person with HIV would be reluctant to speak of their situation to others in their faith group unless fully assured of confidentiality (unless explicit permission was given to share the information with others) and an accepting and caring response. Apart from an acknowledgement on the part of a minority that such a sharing of information would be treated by some leaders and members with utmost respect and sensitivity, most group participants suggested such assurance could not be guaranteed. There were references to there being certain leaders with whom the information could be shared but an expectation that for most people with HIV anxieties about the response would persuade them to approach health professionals or specialist agencies for their support needs. In a Muslim group a member asked herself the question:

Would someone with HIV – I mean if someone were with cancer they may say 'Oh, I've got cancer. Could you pray for me?' Someone with HIV, would they say they've got HIV? I don't know. It's a very difficult, difficult – I couldn't answer that. Um, I could only speak for myself ... I would go to a doctor or a counselor.

That the care and support offered in those secular contexts may be purposively different from that which a person with HIV could hope for from their faith group was missed.

Another participant reflected on the support she was certain she would receive if she were ill with cancer and then imagined herself as a person with HIV.

I suppose if I had cancer and was undergoing chemotherapy I know I could definitely count on the support of my church group. I know they would be around looking after me and making sure everything was going OK. They'd probably do the same if I had HIV but I don't know I'd give them the chance. That says more about me than about them.

And it is that last comment which exposes a further tension in responses to HIV: the role of the person with HIV in determining the response of a religious milieu characterized variously as both place of comfort and the place of disgrace, as both the place of belonging and safety and the place of isolation and danger. Is the person with HIV responsible for the faith community's positioning of itself in the face of HIV and people affected by it? Is the person with HIV an independent agent in shaping the response of the faith community towards him or her or merely a silent player in someone else's story?

Efforts to remove from the congregation any responsibility for attitudes towards people living with HIV surface again in the group discussions. In one person's view it is not anxiety about the response which prevents disclosure within the faith group but a personal reluctance to disclose. The issues were those of the individual with HIV not those of the faith group. The participant was adamant that her faith group would be welcoming and supportive. For her any barriers to disclosure by someone of their HIV status were not religious but personal to the individual with HIV. In a similar vein one person saw HIV as one of many health topics that people would hesitate to speak of. Mental illness, depression, alcoholism, irritable bowel syndrome and tuberculosis were mentioned. 'It's just another illness as far as I'm concerned'. But a member of another Christian group felt there was something distinctive about HIV and disclosing one's status.

'HIV is still a different case because ... when it comes to sort of almost any other disease you can imagine people might be within a church context very feeling that they want to disclose and that they wanted people to be aware ... so that they could pray for them, so they could visit them so they could act appropriately.

She went on to reflect

I don't know what the reaction of everyone in our congregation would be if people felt they wanted to disclose their status. I don't know whether that would actually make problems for some members of our congregation.

Hearing that as well as ... what it would be like to say that.

Several expressed the view that an individual would be too ashamed or feel too guilty to approach their religious leader or disclose their HIV status to members of the faith community. In one group, while comparing past responses to TB with present day attitudes towards HIV, the point was made that with greater knowledge and understanding shame no longer attaches to a diagnosis of TB and that a similar process of advancing awareness will remove such obstacles to the disclosure of an HIV status. A participant in a Hindu group referred to the traditional respect accorded to elders and the difficulties that would pose for those with HIV wishing to speak out. The reflections of one participant turned towards the religion's identification of promiscuity and same sex relationships, '... obviously not something that goes down with the support of any church really...,' with lifestyles which may put individuals at greater risk of infection. She went on to say there is no place for judgment and that 'all we can do is react as Christians or as good people to meet their needs' But non judgmental approaches to need are notoriously difficult to express and effect without taking a patronizing tone. She continued '... and you can do that without endorsing what got them to that stage or without endorsing the way they live'. The right response, in other words, requires an individual to summon the effort to set aside judgement and engage dignity.

The route of transmission or speculation and assumptions about it may govern the response, but one way or another the person with HIV is being charged with some responsibility for the response of the faith groups, for their silence and prejudice and for any acceptance and support all of which impact decisions about disclosure of HIV status.

An examination of how far the religious teachings are drawn upon by participants to support their opinions follows.

Religious teachings

When asked to describe their religion's teachings and beliefs about HIV and people who have the virus most *questionnaire respondents* described in one way or another their tradition's calls for sexual discipline, that is no sex except within a marriage between a man and a woman. This was regarded as the moral foundation for intimate relationships, the raising of children and the building blocks for good family life through which individuals and society at large would flourish. Celibacy also was noted as a legitimate choice for some Christians. Failure to follow the religious teaching would be seen as sinful and, for some, the very presence of HIV as well as its transmission was explained by contemporary, and for some 'western', disregard for the religious teachings. As one respondent put it 'Islam forbids sex outside of marriage and unnatural relationships to protect society and prevent diseases'. People with HIV were seen as those who have disobeyed the religious rules and could be legitimately described as personally responsible for their situation. For Christian respondents taking this line a repentant person with HIV would receive forgiveness, compassion would flow and inclusion within the community would be restored. Hate the sin, love the sinner. The Vedas' calls for chastity were noted by a Hindu respondent and reinforced by an opinion that 'Hindus should not have HIV'. Several referred to religious texts and theologies to support their view. The Fall was cited as was 'Not the Fall'. Isaiah was quoted and the Our'an referred to. There were those who drew on notions of God's judgement and punishment inflicted for sins committed to describe the relevant teachings.

Other respondents cited religious teachings conceptually defined by compassion and inclusion. The all-embracing love of God and the example of Jesus towards outcasts were mentioned. Some, while acknowledging their religion's formal requirement for heterosexual rectitude, drew attention to the diversity of relationships within a community and an increased acceptance that couples often live together prior to marriage. The reality of same sex relationships was also noted, usually as forbidden, but, by the minority of respondents who preferred to focus on loving commitment and

fidelity irrespective of the couples' sexuality, homosexual relationships were regarded as acceptable expressions of human love and intimacy.

A tension between the religion's formal teaching and the informal or personal approach of the local minister was described in several responses

A biblical relationship is exclusive, faithful, loving, life-giving – personally this can be seen in same sex relationships as well as marriage.

Similar tensions surfaced in the *small groups* where the characteristic confusions and ambiguities of debates about sexuality found expression, not least when the religious teachings appeared to be incompatible not only with rights-based requirements to be inclusive and non-discriminatory but also with those religious calls to compassion and welcome. It is a dichotomy which has presented at various stages of the data-gathering process within all three participant groups and which resides also in the design and delivery of public service policy not least public health approaches to HIV prevention and care. The multi-sectoral approach needed to take account of social determinants of health and eliminate health inequalities advocates partnership working with local authorities and the third sector (Marmot 2010, World Health Organisation 2011a). This level of engagement will encounter those religiocultural responses to sexual and gender identities prone to furthering prejudice and discrimination towards LGBT people and women and girls.

The question again arises as to whether the use of religious beliefs and narratives (eg predestination, Karma, penal substitution: God as agent of judgement, wrath and punishment and also of mercy, justice, love and compassion) to both generate and resolve the quandary represents a psychologically integrative process to growth and agency or an accommodation, if not affirmation, of dissonance and prevention of maturation (Hull 1991: 201 ff, Rosenfeld 2010).

The religious teachings with sexual rectitude as their primary theme were articulated in absolutist terms by many in the small groups but that strong line was clearly uncomfortable at times and the religion's offer of compassion and care for those who are ill was presented to dispel the tension.

- Sex is to be within marriage but that is not to say that HIV only affects homosexuals ... we separate the sin from the sinner ... there is a tremendous amount of compassion.
- A Christian has got to say what she believes is the proper way to, to live but at the same time have compassion for those who don't live that way.

There was sometimes the sense that the religion drew individuals to repentance and/or compassion with the promise of reward in this life or the next. Visiting the sick is deemed credit worthy. Acquiring HIV is seen as punishment for breaching religious rules.

... maybe you're paying the price for whatever you did bad in your past life and that's why you've got AIDS now...

A Christian group recalled the plight of women caught in breach of traditional teachings. If pregnant and unmarried they would be sent away and perhaps disowned by family and friends. Some women were known to have been admitted to a local mental institution.

A small number of participants expressed a fully inclusive view.

- I think about what Jesus would have done. We can't condemn people.
- Everybody equal in Methodism and loved by God.

One person saw HIV as a modern disease and 'not one that I particularly link with church teaching'

There was some recognition that the religious teachings were inadequate in the face of modernity's norms. The debate within the Catholic Church on condoms drew differing responses with one participant reiterating the official position that condoms 'defile the sanctity of womanhood' and promote adultery and promiscuity. Another

announced 'I think the catholic teaching is very clear. I don't personally necessarily agree with it all'. Promiscuity and adultery were known to be prohibited but there was also an acknowledgement of marriage breakdown among Catholics. This discussion acknowledged the political and social relevance of catholic teaching on condoms both for limiting fertility and the prevention of sexually transmitted disease and included a reference to the church being an authoritarian hierarchic institution. 'It comes from the top downwards. We're not a church that goes from the bottom upwards'. Others saw injustice in the requirement for the teachings on condom use to be followed especially in the case of developing countries where 'poor people they tend to be much more in obedience to the church than we are'.

I think there's teachings in the church about God which, yes, you should accept if you want to be a catholic, but certain things you should decide for yourself perhaps.

Islamic permissions for men to take more than one wife collided with descriptions of the religious teachings as being monogamous marriage. With qualification this injunction became sex within marriage but it was clear that among the Muslim women participants the vulnerability of wives in such polygynous marriages had not previously been considered. The diversity of the community and society were also understood to challenge traditional teachings and practice.

By and large, the formal religious teachings were known and understood by the group participants but, in contrast with the majority of the questionnaire respondents, they were questioned, reinterpreted or rejected as inapplicable to contexts of contemporary experience and the realities of modern life.

People have this difficulty with, you know, a party line and their conscience.

Similar challenges are presented in the responses of participants with HIV.

When asked about their religion's teachings on HIV *interviewees* referred in various ways to marriage between husband and wife as the only legitimate context for sexual relationships and anyone deemed to have disobeyed the rules could anticipate

some degree of condemnation. Only one interviewee spoke of her sense that there would be no outright condemnation of someone 'living in sin or having, you know, been sexually active or anything like that ... we're quite liberal'. Some described the assumptions made about infidelity and 'going outside' when a person was known to have HIV. Two women spoke of teachings which branded a person with HIV a prostitute. Others spoke of the infection as a punishment from God for bad behaviour. There was reference to teachings which drew on scriptural accounts of an incurable disease to be sent by God. HIV was understood by the leaders to be that disease. Some noted claims to possess the power to cure individuals who presented for healing. Those who had heard the association made by the religion between HIV and prostitution questioned strongly the judgements made about their behaviour.

Sometimes they can talk about it as if it's a disease which was just put on earth to discipline people who are prostitutes... it makes me unhappy sometimes because I can say what will be the reason for punishment especially if I know I wasn't a prostitute.

Another interviewee challenged the authenticity of the claims made by pastors who offered a cure. A Hindu woman called on the priests to challenge the traditional silence which put community members at risk of infection through ignorance. Speaking and teaching about HIV and people affected by it, she argued, needs to find a way of avoiding the condemnatory appropriation of Karma to justify the present blanket judgement made on every incidence of HIV infection.

Although some interviewees valued their religious involvement for the prayerful and caring support it provided, the religious teachings, in their view, did not communicate an assurance that disclosure of their HIV status would be received without prejudice and condemnation. Some acknowledged the value of their own speaking out to the raising of awareness and the breaking down of discriminatory barriers, but would not do so because of the risk to the safety and well-being of themselves and/or family members.

A significant task awaits religious leaders who attempt to deliver an unconditionally compassionate message to a world with HIV. Even though a number of the leaders

who responded to the questionnaire declared an open non-judgmental and caring approach to people affected by HIV it is clear from the interviewees that rarely are those compassionate responses either anticipated or heard. This study is not able to assess, only record and propose, whether this is due to an internalization of judgemental positions, actual or perceived, taken by many, including religious, authorities - I must be guilty, N says so - or - I cannot belong, people like me are not wanted. Neither was this study designed to measure any projection of fears about HIV and the consequences for stigmatizing attitudes (Herek 2002, Hamra et al 2005, 2006), but there are distinct echoes of Goffman's presentation of stigma as spoiled identity (1963) in the interviewees' and other participants' accounts of HIV's relationships with religious beliefs and teachings. All were engaged at some level in negotiating the stigmatising influence of religion and wider society on their life as persons living with HIV. There were those who protested their 'innocence', those who declared an alternative reality - 'it is an illness' - and those who sought affirmation and comfort in other appropriations or contexts of belief. Most conducted this negotiation and search for integrity alone and in silence.

Much of the data presented above signals something of the stigmatizing nature of the religious teachings and beliefs described by participants. Their influence in informing responses to HIV and people affected by it can be neither denied nor ignored. The following section attends to key aspects of participants' accounts of what may be described as religion-related stigma in engagement with HIV.

Stigma

The exclusionary thrust of stigma impacts the life of *participants with HIV* in numerous ways. Every category of their relationships from the formal institutional to the most intimate has to be negotiated with HIV-related stigma in mind. The fact of an HIV diagnosis and its associated exclusions and taboos intrude into many aspects of their life. Interviewees refer to anxieties surrounding the access to services from local authorities, institutions and agencies. Others speak of the realities and the fear of rejection by employers, colleagues, friends, family members and partners. Others tell of the silence and denial which characterize religio-cultural norms and the consequent defining of individual and community approaches to HIV. There were those who note and regret their collusion with stigma's silencing power: their failure to speak out;

their fears of disclosure's impact on their own well-being and that of their children; the need to identify as 'innocent' victim. This 'felt stigma', that which 'motivates individuals with a stigmatized condition to attempt to pass as members of the non-stigmatised majority' or as 'normals' as Goffman names them (Herek 2002: 595), is described by Graham Scambler (1989: 56-57), though in the context of epilepsy, another condition which implies non-conformity and threat to the status quo. Scambler distinguishes between 'felt' and 'enacted' stigma. Enacted stigma is that which relates to instances of discrimination or violence generated by those characteristics which are perceived by 'normals' to flout social and religo-cultural norms. Anxiety about enacted stigma will persuade some people to hide the realities of their situation from others. Persistent felt and internalized stigma can exacerbate vulnerabilities and limit any opportunities for change for as long as any perceived threats of enacted stigma remain (Herek 2002: 595, Scambler 1989: 60).

Some people with HIV experience multiple contexts of prejudice: being gay, being female, being a parent especially a single parent, being black, being disabled, being older, being an immigrant, a newcomer, a stranger, being unemployed, being poor, having few communication skills. Stigma in all its diversity, then, weaves a web of cross cutting threads moving in different directions tying individuals with HIV in knots of anxiety where the resources and opportunities with which to bridge the distance between exclusion and belonging are inconsistent even non-existent.

That religion fuels stigmatizing influences is acknowledged by a number of the *questionnaire respondents*. One respondent recognized that religious teachings often 'validate blind prejudices' and another worried that 'Biblical teaching fuelled the fear used to condemn people with HIV'. Other leaders ascribed to themselves compassion and openness but to their congregations bigotry, condemnation and fear. One wished their church to be a place of safety and welcome but recognizes that this may not be 'true as I want it to be' in the case of HIV. Others advocated the authority of teachings which demand 'chastity outside marriage and absolute fidelity within it' claiming that the emergence and the spread of HIV are due to failures to observe these prescribed standards.

In the **small groups** the links between religious teachings and attitudes to people affected by HIV surfaced in most discussions. Associations between HIV, taboo, shame and denial and connections between such exclusionary concepts and the religious and cultural beliefs and teachings which accorded them some authority were made in most groups.

The impact of religio-cultural influences on the stigma affecting people with HIV is pervasive. There is little expressed appreciation from the questionnaire respondents that religious teachings and beliefs can fuel the stigma attaching to HIV and in so doing endorse exclusionary attitudes to people affected by HIV with a peculiar authority making the barriers to inclusion more dense and the anxieties about difference and diversity more present. Obedience to the religion's rules governing the conduct of sexual relationships protect the individual and society. A 'good' Christian, Hindu or Muslim will not have HIV. The implications of such approaches for the well-being of individuals with HIV and their families is barely noted by respondents and the potential impact on public health prevention and care strategies does not register.

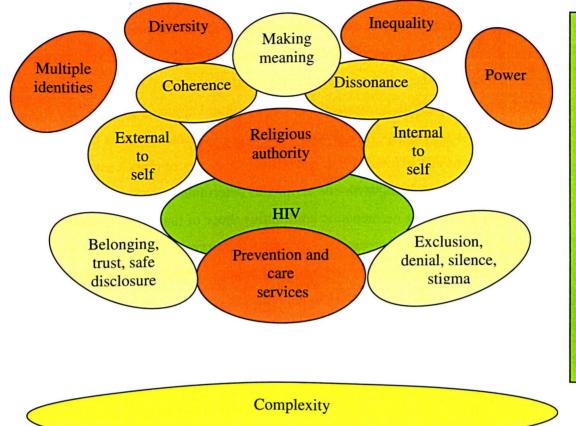
This collusion of religious groups in the wider stigmatization of HIV and people living with it appears to receive little if any attention at grass roots levels by most faith groups. There have been occasional international and national initiatives which have drawn together representatives from various faiths. Joint statements of commitment to compassion and care and the rejection of prejudice and discrimination will be issued at the close (UNGASS 2001b, 2011b; African Religious Leaders 2002; Interfaith AIDS Conference Bangkok 2003; South Asia Inter-religious Council 2004; Cairo Declaration, 2004). Data from Leicester suggests that for local religious leaders and congregations these statements and commitments have minimal grass roots impact. It may be particularly difficult to generate interest and initiatives at local levels in extensively diverse communities where the risks to a community's standing, perhaps especially the standing of a religious community, of associating itself with a stigmatized and stigmatizing health condition, a community dimension of the 'felt'stigma described by Scambler (1989) will be a step many are unwilling to take. The shifting nature of religious leadership and membership may also militate against serious and regular engagement. Furthermore, public health policies and, in this case,

HIV prevention and care strategies, which are required to respect religio-cultural beliefs can expect to make little impact while stepping softly around this religion-related sensitivity and, albeit inadvertently, colluding with the status quo.

Synthesis

The data provided by local participants have exposed tensions between Leicester's public health approaches to HIV prevention and care and those of some religioninformed responses. Evidence has emerged of conservative traditional approaches to sexuality and gender risking the communication of inaccurate information, the generation of confusion, silence, denial and stigma and the perpetuation of mixed messages for HIV. However, it has been shown also that religion provides security, comfort, identity and belonging for those with HIV, even though very few will disclose their HIV status in their religious 'home'. For most participants, safety to disclose their identity as a person concerned about or affected by HIV could be assured only in the environments of health and social care agencies. As it evidences even limited compatibilities between characteristics of 'faith' and 'health', can this study begin to advocate more confidently routine co-operation between public health practitioners and, initially, those religious individuals and contexts where compassionate and non-judgemental approaches to people with HIV do and may prevail? In the context of this investigation evident compatibilities in the local data between the dialogical principles informing public health policy and practice for HIV and an emancipatory action-based practical theology are notable and not irrelevant to the findings and recommendations of this work, as will be demonstrated in the closing chapters.

Although the theoretical landscape remains fundamentally similar to that shaped by the coding categorizations and the early identification of themes (Table 14 page 120), further significant dimensions were exposed as the process continued. 'Making meaning' and aspects of 'agency', presenting to a far greater degree than was anticipated, take their place in a revised model below.



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Figure 7. Revised thematic clusters showing inter relational nature of the theoretical discourses

Figure 7 sets out those data streams, largely inter-related, to be explored in the following chapter. Broadly in line with the model above, the discussion at Chapter Six will draw on the discourses of sociology, anthropology and (social) psychology and refer as it does so to international and local sources. The theoretical format of complexity will continue to inform the framing of a more effective response to HIV needs and develop the already alluded-to potential for integration between religion-informed and public health responses to HIV.

CHAPTER SIX

Discussion and further analysis

Emergent themes

The global and the national, the local and the personal realities of HIV explored in the primary and secondary data position the investigation in diversity's paradigm of interdisciplinarity. With biomedical and socio-cultural approaches to health; with conservative and progressive appropriations of political and religious believing; with gender relations and expressions of sexuality, hierarchies of class, caste, education and economic status vying with one another as determinants of identity and agency; with a self referencing hermeneutic confronting those of family, community or God, hegemonic tensions and interactions characterise responses to HIV. Globalisation's exposure of multiple identities and modes of belonging both extends and limits the profile of hermeneutical choice. In widely diverse communities individuals and groups, not least hidden and new minority communities, hermeneutical choice and associated quests for coherent believing and self understanding are confused by a multiplicity of authorities. The dominant or chosen hermeneutic may prioritise 'respectability', an acknowledged and valued contribution to civil society and access to civic representation and power over any association with, or consideration of, a stigmatising disease, deeming any such association or consideration as detrimental to their wider aspirations and a threat to community and personal integrity and standing. These religio-cultural and socio-political influences and the multiple and widely differing positionings towards HIV they inform will shape engagement with, and access to, public health HIV information and care and any consideration of the religious responses involved.

In seeking to illuminate discourse, policy and practice at the interface between religious and public health approaches to HIV prevention and care, the following discussion will focus on the substantial theoretical ideations and argue thereafter that in their characterisation they offer evidence and support for an appropriation of complexity theory in reaching an adequate analysis and improved understanding of HIV's capacity to expose different needs and competing realities in both public health and religious responses to HIV.

The key classification clusters (see Figure 7 in the previous chapter at page 232) have been theoretically streamed and are set out below.

THEORETICAL CLUSTERS	STREAMS OF INTEREST
Diversity	
Multiple identities	Globalisation, migration
Belonging	Cultural norms, particularising,
	relativising
Exclusion	Challenge social norms
Silence, stigma	Controlling social norms; self
	condemnation
Prevention and care services	Uniformity preferred
D.	
Power	Minorities, gender etc
Inequalities Diversity	Difference
	Negotiating difference – redefining
Multiple identities	identity in pursuit of power and
	meaning; reconciling contradictory
	dimensions eg sexual and religious
Power relations	In or out, just/unjust – complex interpla
ower returners	of dominant knowledge and local
	traditions with socio-cultural layers of
	power and authority
Exclusion	Outsider, no voice
Du	
Religious authority	Moral codes, cultural norms
Making meaning	
Coherence, dissonance	Conscientisation – reconstruction of
	religious orthodoxies, negotiated coherence
Agency- external, internal to self	Hermeneutic/hegemonic authority
Diversity	Globalisation – challenges of
Diversity	secularisation, human rights, civil
	liberties, homogeneity
Belonging	Diaspora
Identity	Gender roles
HIV Prevention and care services	
Disclosure- safe, unsafe	Implications for transmission to
	partners, for access to information,

Silence Prejudice

Denial Belonging

Trust Inclusion support, treatment and care

} Safe disclosure - self appreciation

} Stigma

Stigma	
Exclusion	
Denial	
Silence	} 'Other' (and self?) in breach of religio cultural norms and moral codes
Prejudice	
Discrimination	} Exclusion
Difference	
Power relations	Defining, protecting, controlling socio- religious norms. Challenging guardians of tradition
Multiple identities	'Felt' stigma. Several stigmatised identities

Table 21. Theoretical clusters; streams of interest

First a marrying of the theoretical streams emerging from this study's primary data set out above at Chapters Four (page 116 ff) and Five (page 136 ff) and with the key classifications identified in the literature review.

Diversity

Experience of and responses to diversity impact responses to HIV world-wide. Globalisation's exposure of and to diversity bring greater exposure of and to difference and inequalities (Walby 2009: 2). The impacts of these exposures are experienced and known in material, relational and conceptual terms at both individual and collective levels. Responses to HIV are not immune from these social and philosophical movements, but few localised studies investigate the impact of the complexities of a multi-religious environment on the responses to and delivery of HIV prevention and care.

A globalisation-induced confusion out of which ethical decision-making is influenced by an ever increasing range of historic, continuous, novel and unknown complexities, responses to which are at least as emotional as intellectual is noted by Strassberg (2003). She explores how a conceptual framework for that which she has described as an 'ethics of complexity, chaos and contingency' (Strassberg 2003: 170) in a complex, chaotic and contingent environment can be applied practically to the challenges of HIV.

Strassberg argues that ethical decision making is made on the basis of moral literacy, a literacy which can be limited by the power of beliefs, including religious beliefs and an absence of scientific information. Moral literacy is to be informed by the appropriations of accumulated knowledge from a variety of scientific and socioreligio-cultural contexts. In the absence of the high levels of moral literacy, moral competence is deficient and ethical decision making will fail to generate the environment necessary for human flourishing. Strassberg is advocating a sophisticated moral literacy to deliver the moral competence necessary in any response to HIV. She expresses the hope that in complex interdependent global and local contexts inter faith dialogue on HIV could transform existing ideological divisions and develop a collaborative approach to cultural, social and political consciousness in order to secure moral competence. But, as pointed out in the literature review at Chapter Two (page 39 ff), too little account is taken of globalisation's agency in exposing difference and discontents in increasingly diverse religious contexts and the ways in which that very 'chaos and complexity' can generate both 'contingency's' retreats from and engagements with dialogue. And although religio-political dialogue is not renowned for generating consensus. particularly on issues of gender and sexuality, at either the global or the local levels, Strassberg's support for deep engagement with interdisciplinary and dialogical approaches to ethical transformations and moral decision-making in a world with HIV will inform the recommendations which will close this study. First, though, a return to those realities of division and dialogue which diversity can deliver.

Strassberg is not the only advocate of institutional, organizational and individual partnering (including the religious) in the anticipation that inter- and multi-religious and inter- and multi-agency collaboration might address more adequately ethically agreed global needs. Katherine Marshall, noting that in contexts of extensive diversity (Marshall, 2004) a lack of mutual trust has been identified as a major inhibitor, also argues that greater investment in inter-sectoral and inter-religious dialogue is necessary if sustainable co-operation between religious groups and other sectors is to succeed. She, however, starts with a claim that a rights-based approach to

development will incorporate principles which underpin any historic religious ethic¹⁷. This, Marshall suggests, will help draw religions away from those approaches to need which rely on charity and short term relief towards a sustainability approach which looks to long term creative partnership and mutuality for results. Perhaps extensive agreement could be expected but how far it would translate into strategic implementation in the field of HIV/AIDS where distinct and diverse views on gender relations and sexual ethics could be expected is more uncertain. Religious antipathy to the development human rights agenda, particularly in respect of gender and reproduction, remains a key issue and in part underpins recent religious emphases on the secular-religious divide. The tensions of increasing globalisation, not least those between parallel influences pressing at one and the same time for relativist and absolutist perceptions of reality as well as particularist and universalist notions of need, become impossible to ignore. Marshall recognises that any hope for a solution to seemingly intractable global problems like poverty, and, some would add, HIV/AIDS, requires multi-sectoral participation and collaboration at international and local levels on an unprecedented scale. The absence of such collaborations to the extent required suggests, following Strassberg (2003), that ethical decision making is governed by the 'knowing' and the interests of a few, secular and religious. Then, taking too little account of difference and inequality and systemic increases in marginalisations, inconsistent HIV prevention messages and a confusion if not incompatibility between public health approaches to HIV and religious teaching become the norm at international and local levels.

Globalisation's diversity and associated notions of difference and inequalities touch responses to HIV in internationally defined and local contexts. For public health institutions, the range of sometimes subtle but significant differences among religious groups are not always recognised by policy makers in their efforts to involve or take practical and strategic account of religion in responses to HIV. All institutions then, whether religious or secular, become themselves both agents and objects of the new diversity, both participants in and reflectors of its nuances and multiplicities. How far the religious groups of Leicester recognise the need to engage more completely with globalisation's impacts is open to question.

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¹⁷ Marshall refers to Hans Küng whose work on a global ethic has taken the form of a Declaration of the Religious for a Global Ethic and was endorsed by the Parliament of the World's Religions in 1993.

In communities world wide an African diasporic presence cannot be denied. In Leicester the increase in and presence of African-led Independent Churches with often nationality- and/or ethnicity-specific and/or language-specific congregations and leaders is barely noted among hosting mainstream Christian inter-denominational representations. Catholic and Orthodox congregations for immigrants from Eastern European countries may be able to access connections with local host churches and clergy, particularly in the case of Catholic-identified groups, but by and large they remain marginal to mainstream church structures. Similar divisions, principally those between Asian, Middle Eastern and African Muslims, Sunni, Shia and Sufi have been noted in Islamic groups. The continuing appeal and practice of traditional religiocultural beliefs add further, often hidden, dimensions of diversity, including those of multiple identities, to the scene of analysis and theory. Flights from chaos, conflict and economic crisis add further layers of difference and inequality. Pfeiffer (2002) argues that it is in those places where social reconciliation and healing can be effected - he has in mind religio-cultural community groups - that the realities of communal crisis, social, economic and moral disintegration and vulnerability will be discerned.

Thomas Tweed's work (1997, 2006) also describes the tendency of diaspora to draw together tightly defined groups where the recovery or restating of identity, meaning, history and purpose are paramount. Whether the realities of an HIV crisis would be readily exposed in such circumstances is debatable. The evidence from the participants with HIV in this study suggests HIV would remain hidden unless specific well-informed initiatives by religious and community leaders were undertaken. Furthermore, the tension between the stated aim of the religious groups to respond compassionately to people with HIV and their need not to compromise religious teaching on sex and sexuality and, in some cases, condom use is implicated not only in the invisibility of HIV but also in the wider reinforcement and impact of stigma.

In Leicester resources have been directed recently at identifying the pastors of African Independent Churches, inviting them for training in HIV awareness and enabling them to communicate information to their congregations. The interest was generated by the visit of an African priest living with HIV. This visit and the event at which the priest would speak was facilitated by LASS, a local voluntary HIV support

organization, in collaboration with its various networks, its service users and staff. Early evaluations suggest the initiative is proving something of a breakthrough in dissolving previously dense barriers of silence around HIV in local religious groups. The more difficult assessment will be that of appraising whether the information about HIV has been integrated by both leaders and congregants, including those with HIV, into existing belief systems with a sustained stigma-reducing impact, or whether, to effect such an integration would require too substantial a change to the supposedly coherent theological framework and scriptural interpretations in present use (Hull 1991: 182).

The need to preserve the status quo, that is the comfort-inducing theologies which define the insiders and the outsiders, and its place in the avoidance of dissonance and any associated disruption to an equilibrium dependent on religion's role as a bridge between the turmoil of life - including, perhaps, an HIV diagnosis - and the reassurance of the traditional and the known, may vie with the introduction of an unfamiliar stress on the needs of people affected by HIV. The disclosure by a visiting priest of his HIV diagnosis is one thing, as is the demonstration by the resident clergy of local rapid result testing facilities, but a definitive shift in the theological appropriations of teachings and beliefs may be another. Such a shift would require a religious leader and his or her congregation to relinquish a degree of authority when defining the membership of the group. With training and speaking to one another about HIV are the barriers of stigma breaking down in the wake of this initiative? Will a person with HIV, fearful of prejudice and rejection, now trust their leader and the group with information about their situation? Or will the initiative generate unanticipated and unarticulated anxieties? Will more members of the group be wondering if there are those among them with HIV? Can a person with HIV belong here? Who will decide? As demonstrated in the data analysis, issues of power and authority in the appropriations of religious teachings and beliefs are relevant in shaping moral decision making and in defining criteria of identity and belonging. Although there are no guarantees, the project staff in Leicester are trusting that their ostensibly user led community development model for HIV prevention will effect long-term change.

A similar model, presented in community development health promotion terms, (Campbell 2003a, 2003b, Campbell and Jovchelovitch 2000) and brought to attention in the Literature Review at page 53 following is given a further reading below in the context of power relations

Power

The distribution and exercising of power in various biomedical, socio-cultural and behavioural dimensions are reflected in responses to HIV. Democratic and 'multistakeholder partnerships' (Campbell 2003a, 2003b) at grass roots and public policy levels tend to be regarded as the necessarily innovative and extraordinary response to an extraordinary situation. Drawing substantially on Paulo Freire's advocacy of conscientisation (Freire 1972), Campbell points to a 'social psychology of participation' calling for community development approaches to HIV prevention and care, but as she shows (2003a), even the most carefully designed initiatives can fail. Her own multi-stakeholder project set up in a South African community failed, in her assessment, due to the dominance of biomedical approaches and the very diversity of the democratic model. She noted the resistance to unfamiliar ways of thinking and working; the dominance of medical over social responses to prevention; the impact of denial and fatalistic attitudes; lack of commitment on the part of some stakeholders to the implementation of agreed strategies; low levels of organizational and managerial expertise; the failure to enable participation of traditional healers although it was known that substantial numbers consulted them; the inability to resolve political and personal conflicts and a failure to understand the potential for disagreement in the stress making, stigmatised context of HIV. This attempt to ensure sustainable extensive collaboration was unable to secure conceptual alignment and practical agreement.

A few years before the failure of the South African mining community initiative, Campbell with Jovchelovitch (2000) had argued for the need to address the vulnerabilities of marginalisation in all its global and local complexities and call for democratic and dialogical approaches to inform local initiatives (2000: 258).

With its own efforts to empower the local in identifying and designing responses to HIV prevention and care, it is to be hoped that Leicester's participatory initiatives will

both widen the scope of HIV prevention and sow seeds of wider democratisation and religio-cultural change. Referring to social psychology's discourses on social identity, social representation and power, Campbell and Jovchelovitch had set out to offer a more robust theoretical construct of participation in order to further its practical application to community development's contribution to health. Of particular significance to contexts of HIV prevention and care are the authors' warnings about idealising local knowledge (and, Strassberg [2003] might add, moral competency) and the need to allow for and be alert to differing if not competing realities and representations. And it is with similar notes of caution that religio-cultural responses to HIV are to be approached. Religious authorities and individuals occupy a privileged, often legally protected, place in the life of many societies and communities. In the UK religious freedoms and respect for religious beliefs extends to providers taking account of religious sensitivities in facilitating access to and provision of services. Religious authorities may hold quasi-representative positions of influence in national and local life, for example, the 'established' nature of the Church of England, the bishops' bench in the House of Lords and local Councils of Faiths.

Working within the diversity of Leicester much has been achieved by religious representatives and the local authorities together contributing to what is generally agreed to be a high level of community cohesion. And although a similar model of participation and dialogue can be seen in early and continuing public health and social care provision for people affected by HIV, the visibility and the voice volume of senior religious representation stand in stark contrast to the exclusion and the silence of people affected by HIV in the religious contexts of the community. Inter religious and wide inter institutional dialogue is strongly commended and well supported in Leicester but, as noted in the data gathered from the community's people with HIV, their anxieties about raising their voice remains a reality. It becomes clear that Campbell's and Jovchelovitch's warning about the idealising of local knowledge is particularly potent when religions meet HIV (and perhaps when religions meet advocates of biomedical approaches to HIV as in the South African mining community approach [Campbell 2003a]). Even conscientisation's empowering thrust may not be adequate in the face of HIV-related stigma. Prioritising a Freire-like approach to stigma reduction, that is, an education and awareness based challenge to oppression and exclusion, may deliver change. Indeed, there were hints in this study's interviews with people with HIV and in the group discussions that talking about HIV, entering into an experience of HIV, can move individuals into a place of dissonance and inclination to change. In the search for a restored coherence oppressions and injustice can be identified and perhaps articulated and challenged. But for people with HIV the question remains as to whether the power exercised by oppression-bound appropriations of personal histories and by religio-cultural meta narratives can be transformed on the scale required without first a transformed social milieu, one committed to justice and equality and to the moral literacy advocated by Strassberg (2003).

This trapping of the oppressed and the stigmatised in a circular reality and the charging of them with responsibility not only for internalising their own exclusion but also for those stigmatising attitudes of others became evident in the data and is characteristic of stigma's force (Goffman 1963, 1984)

Campbell and Jovchelovitch argue that the participation of communities of the marginalised in conscientisation initiatives increases the potential for a reduction in health inequalities. However, in this researcher's experience the formation of communities of activists with HIV in low prevalence settings, particularly conservative and religious settings, is notoriously difficult to achieve. Even strong well-informed advocates, as evidenced in the responses within this study of participants with HIV, can be silenced.

The relationships between diversity and power cannot be ignored whatever the context but responses to HIV expose their significance in sometimes startling ways. The face of HIV in a world with HIV is that of an African woman. The face of HIV in Leicester is that of an African woman. This suggests a significant failure in implementing both human rights and associated community development approaches to HIV. The multiple diversities and the power sets they generate and the struggles they trigger reach into all parts of global and local community life including those of religions.

Religious Authority

Religious beliefs and the authorities from which they are deemed to derive can help individuals and groups cope with the anxieties and uncertainties of change, particularly change which is rapid and alienating. Sundkler (1961) refers to the 'cognitive bridge' which beliefs and practices provide for those who look to having their attachment and dependency needs met amid the turmoil of psychosocial and material disruption. This is seen in the popularity of traditional religio-cultural environments of 'belonging' in migrant communities throughout the world. In the UK the larger African Independent Churches assume a particularly significant role in securing a community's identity and stability and supporting individuals as they seek a new equilibrium and settle in their adopted community. In some religious contexts such reconciling beliefs and practices are expressed in ways which have particular resonance in identifying the norms and parameters of physical and mental health. These issues were raised by some of the study's participants with HIV. Traditional healing and treatment beliefs and practices were referred to. Although by no means confined to African settings, such issues surface in a number of Africa- based studies. Pfeiffer (2002) and Agadjanian (2005), for example, note a complex web of anxieties about witchcraft and spirit possession and their perceived role in causing misfortune and ill health, particularly reproductive ill health. In an African environment women are more likely to seek a church than visit the traditional healers. Men tend to favour traditional healers where women may be accused of infidelity or be blamed for the presence of malign and avenging spirits (Pfeiffer 2002: 177). (Interviewees in this study noted that a partner set more store by traditional practices and treatments than by the medical advice and testing for HIV accessible through health and social care professionals in the UK [pages 150, 155]).

Characteristically, the African Independent Churches' emphasis on Pentecostal-style faith healing which draws on belief in the interventions of the Holy Spirit chimes with reliance on the powers of traditional local healers. Many individuals, including Hindu, Christians both indigenous and migrant, and Islamic people with HIV whether in their country of origin or in the UK often believe that illnesses derive from spiritual/supernatural sources and it is through their responses to those sources that the religious leaders and the traditional healers offer help. Reliance on both, and the relationships, whether syncretistic or conflictual, between them, may speak of historic

convictions and a reluctance to sever relations with familiar patterns of meaning. This may have an impact on access to HIV information and care for it has been argued (Agadjanian, 2001) that it is the degree of diversity within the socio-economic and cultural networks and backgrounds of congregation members and not the teaching and beliefs of the religious contexts *per se* which influence openness to innovation and change.

This was echoed by this study's participants who referred to the strong allegiances of their parents and grandparents, first and second generation immigrants, to the religiocultural norms of their heritage country. Their children and grandchildren, engaging more fully with the diversity of Leicester, acknowledged these tensions and the high level of identity preserving and affirming participation, characteristic of ex-patriate communities (Agadjanian 2001, Tweed 1997, 2006). The potential barriers such differences can create may deliver inconsistent if not opposing effects on appropriations of information, changed practice and behaviours due to limited access to wider social and mainstream religious networks. Agadjanian is noting diversity's and religion's paradoxical influence in their capacities to both foster access to HIV prevention and care and also to constrain it.

Similar tensions, that is, those between religious (in this case, Christian) expressions and lived realities (those of 'non-heterosexuals' and women) are addressed in a UK context by Andrew Yip (2005) and Kristin Aune (2006). Variously they find that for some individuals cognitive constructs and personal preference ultimately supercede biblical and ecclesial authority, and in so doing inform the appropriation of a more coherent believing and living. Like Yip and Aune, Miller (2007) also introduces wider questions of theological and socio-political and social psychological interest. He notes the various responses of Black American churches to HIV/AIDS. Miller makes explicit the highly negative impact of homophobia and heterosexism on the effective participation by Black American gay men in and access to HIV prevention and care. The inconsistency, or dissonance, Miller identifies between religious calls for justice and the frequent denunciations of gay people and their relationships is reflected in some of the comments made by participants in this author's study and described through Chapter Five.

A majority of the studies cited relate to Christian contexts. Some work has been conducted in Islamic contexts (Gibney et al 1999, Ghalib and Peralta 2002, Maoulidi 2003, Gatrad and Sheikh 2004, Gray 2004, Esack et al 2004, Gańczak et al 2007, Esack and Chiddy 2009, Loue, 2011). Only one study with a Hindu-specific (as opposed to 'Indian', of which there are many) focus was found. This was Gray's et al's paper 'Knowledge, attitudes and beliefs about HIV/AIDS among Hindu students from a government women's college of South India' (Gray et al 1999), which recruited a Hindu majority sample of female students. The study's findings centred on the religio-cultural milieu and influences on their sexual behaviours, their HIV knowledge and attitudes and reported widespread pre-marital sex and belief that HIV would not affect them. Religio-cultural barriers to accurate information were noted (Gray et al 1999: 210). Although not HIV-specific, Iyer's work on fertility and development in India and in a context of religious pluralism engages with Islamic and Hindu beliefs and advocates the interdisciplinary integration of religious perspectives, including local interpretations, into economic and development policy setting (Iyer, 2003). In so doing Iyer points to this researcher's advocacy of an interdisciplinary and integrative theology in response to HIV (see below at page 259 ff).

Gatrad and Sheikh (2004) set out a number of factors which in their opinion impact transmission of HIV in Muslim communities. They begin by pointing to the limited attention paid to the relationship between religious observance and HIV prevention. Drawing on a range of biomedical data, Islamic texts and conversations with religious scholars Gatrad and Sheikh focus on mother to child transmission of HIV and sexual and blood-borne transmission. They suggest that local Imams take the opportunity at times of special devotion or during Friday prayers to make congregations aware of HIV (a practice reported by her husband and noted by one of the Muslim women participants in Leicester). They call for HIV awareness among Muslims to point to 'spiritual incentives' rather than rely on those programmes and methods driven by what is, in their view, the 'new morality of sexual revolution, a prime example of which is the legalising of marriages between homosexuals' (Gatrad and Sheikh 2004: 68). Just such an approach is taken by Sana Loue (2011) who explores the potential for Muslims to relate notions of Jihad with HIV prevention. Gatrad and Sheikh advocate the creation of HIV prevention materials which are rooted in Islam's teachings on relationships, homosexuality and drugs. The authors' proposals raise

key issues in the faith/health relationship: those between human rights and civil liberties based approaches and principles of universal access, and those rights to and respect for religious beliefs, issues, particularly those of gender, raised in Salma Maoulidi's paper (2003) and which surfaced in the conversations with the Muslims of Leicester who participated in this study.

Gray (2004) tests the hypothesis that HIV prevalence is lower among Muslims than among non-Muslims and asks whether religious constraints on sexual expression and other behaviours including Islamic injunctions to circumcise impact negatively on HIV prevalence. His study comprised a multivariate analysis and literature review using national data for thirty-eight sub-Saharan countries with populations of more than one million. The results supported Gray's hypothesis. Only per capita purchasing power predicted positively for HIV prevalence in the analysis. Although this anomaly is not explored in detail, Gray suggests this may be due to a higher brideprice and a consequential reduction in married relationships and an increase in sexual partners. Agadjanian (2001, 2005), however, may have seen it more in terms of a socioeconomic correlation between the relaxation of religious obedience. Indeed, although not testing for socio-economic variables, Gray concludes that although his prevalence and within-population studies show general support for the hypothesis that HIV is lower among Muslims than non-Muslims, in terms of risk factors he found obedience to Islamic moral codes is mixed and that in some cases, particularly with regard to extra-marital sex, there is little, if any, difference between Muslim sexual relationships and those of non-Muslims.

Gray does not ask whether results reflect that failure to abide by Islamic teachings, poor communication by leaders and others of the tenets of Islam, a lack of understanding on the part of Muslim community members or the variables of social environments and networks which Muslims inhabit. (Agadjanian 2005, Pfeiffer 2002) His study does not cover as wide a range of factors which may impact HIV transmission among Muslims as Gatrad and Sheikh. He excludes, for example, dental hygiene practices, prohibitions on homosexual sex and factors in vertical transmission of HIV and does not discuss gender variables or issues of gender relations (all of which were raised by a group of Muslim women participants in Leicester). In other contexts concerns have been expressed about the lack of reliable data from some

Islamic countries (UNAIDS 2010c) or where statistics have not been disclosed (Gańczak et al 2007: 572). Gray's study calls for Islamic beliefs and practice to be considered a socio-demographic measure and predictor of reduced risk of HIV transmission. Although the prevalence rates of some Islamic countries are understood to be low but increasing there appears to be little epidemiological appetite for Gray's proposal.

In 2009 the Joint United Nations Programme on HIV/AIDS published their strategic framework for partnership with faith based organisations (UNAIDS 2009). It sets out clearly the principles upon which any partnerships and practices are to be based. They include explicit references to equalities, particularly those concerning sexual minorities, women and girls. The potential for substantial change appears slight where religious authorities place a heavy stress on moral codes and behaviours which are to define and reinforce monogamous heterosexual marriage (and, it follows, polygynous and polygamous marriages where these are the religiously or culturally sanctioned norms), male headship and the prohibition of homosexual relationships. These are values which feed into the abstinence-and-fidelity HIV prevention messages espoused by many religious groups in contrast with those of secular public health campaigns which are more likely to emphasise access to accurate information, condom use and negotiation of safe sexual behaviours irrespective of the type of relationship.

Different types of religion will create different types of environment and exercise different degrees of authority to secure common moral standards and influence social change. These differences will be reflected in their openness or resistance to HIV prevention messages, or, at least, to the type of prevention message: secular or religious. It may be legitimate to assume that the secular materials are those based on public health priorities and principles (accurate and full information, openness and choice) and will be designed, produced and provided by public health authorities. The religious resources are more likely to focus on religious texts in advocating permitted behaviours and the avoidance of explicit sexual health information. Some individual members of religious groups may be able to access both types of materials. Are those members at less risk of contracting HIV than those who have access only to, perhaps less explicit, religious prevention materials? Are the limitations of the religion-based resources (limited in public health terms) making religious people, particularly

women, more vulnerable to HIV infection? Or, as members of a particular faith group holding particular beliefs and subscribing to particular moral codes, is the consonance of such beliefs and behaviours a greater protection against HIV infection than openness to secular prevention resources? Would a social theological call – or an integrative theological call – for dialogue between the religious and secular prevention messages, that is between religious leaders and people, between public health professionals and practitioners (and people with HIV?), further an understanding of that which hinders and that which helps HIV prevention?

HIV prevention and care services

Some attention has been paid above to human rights-based approaches to HIV prevention and care which characterise many 'western' public health policies for HIV. However, there are those who have argued (Parker 2003, Allen 2004, Allen and Heald 2004, Putzel 2004) that in public health terms the human rights and civil liberties of people with HIV cannot be 'privileged' over others. Allen (2004) asserts that if rates of infection were as high in rich countries as they are in parts of sub-Saharan Africa, then rights-restricting strategies would be enforced. To what extent such views are finding support within mainstream discourse is difficult to ascertain but there are echoes in the Introduction to 'Learning from HIV and AIDS' edited by Ellison, Parker and Campbell (2003) and Parker's chapter, 'Anthropological reflections on HIV prevention strategies: the case for targeting London's backrooms'.

Parker argues that it is unlikely that backrooms facilitating anonymous heterosexual (as opposed to homosexual) transmission of HIV would be tolerated. There is certainly some evidence to suggest that the enforcement of seemingly draconian health-legislation, however unpopular to begin with, can ultimately succeed in transforming cultural values and social norms (e.g.drink-driving and smoke-free public spaces).

(Parker in Ellison, Parker and Campbell eds 2003: 18)

In these critiques those tensions between respecting individual rights and freedoms and ensuring public health for all surface again with the focus shifting from conservative religion to conservative politics. However, with calls for greater understanding of public health and its complexities — complexities to do with socio-

economic diversity, differing identities and the behaviours of individuals - those advocates of rights-, inequalities- and diversity-sensitive policies continue to make their case. Speaking to an English public health context Paul Corrigan argues that public health policy and practice which do not engage dialectically with such realities will fail to meet public health needs. As he points out in his invitation to respect the interaction of 'structure and self-activity' in defining determinants of health

People's conditions are not the same and nor are their aspirations. Moreover, these differences must be a theme of all our health-improvement interventions. (Corrigan 2007: 84)

Although multidisciplinary and interdisciplinary, multi-agency and partnership working and collaboration have become familiar aspects of public health action in recent years (Orme et al 2007: 7) it will be the case that in modernity's globalised contexts and localities where continuing shifts in structures and self-definitions and associated and ever changing health determinants can be anticipated and defined, the complexities attaching to the design and delivery of public health policy will require constant re-visioning and re-resourcing; a tall order for any public or private authority. When such degrees of diversity and complexity are placed in the stigmatised context of HIV prevention and religious believing the challenge surely becomes more intense. HIV-related stigma surrounds prevention and care initiatives with silence and prejudice. Religious teaching and believing turns to relational and sexual absolutism to deliver health and security amid globalisation's relativising turmoil and in such contexts rights-restricting public health policy and practice will appeal.

But it is rights-based policies and practice which are advocated and adopted by UNAIDS and by most advanced nations as those which are most effective in curtailing infection and ensuring access to treatments and high standards of care and support. The exceptions often relate to those HIV prevention and care policies which are informed by the strict moral codes of religious groups or conservative political regimes.

It is in rights based environments where universal access is the goal that the potential for partnership working between various sectors can be encouraged and effected at

several levels. The principles and practice of partnership have developed, in some policies and initiatives, to reach the perspectives and involvement of people living with HIV. A similar reach in to and out from religion's perspectives and resources is overdue. But raising the voice of the one with HIV is not guaranteed.

However, there are some good examples, but mainly from regions of high prevalence, and mainly Christian. Agate et al (2005) tell the story of a Florida, U.S. collaboration between churches and public health organisations and their effort to provide HIV prevention and support services to black neighbourhoods. The initiative began with a meeting between local leaders of different Christian denominations and the local Health Department HIV/AIDS Program Officer. The object was to reach communities at high risk of HIV infection. After several meetings during which scientific, surveillance and HIV prevalence information was discussed and issues of transmission including condom use, sexuality and drugs use were addressed, the Churches United to Stop HIV project (CUSH) was born. The intention was to train religious leaders and their congregations to develop a range of HIV education, referral and support programmes. Training materials, technical assistance and other resources, including support from the 'private sector' were produced. During the next few years 32,000 people were given HIV prevention information, 2,850 leaders in the churches given HIV training and counseling and testing provided for 825 people. Progress has been significant but Agate et al (2005) report that many religious groups continue to exclude themselves from the project, unconvinced that HIV is an issue for their communities. The authors are persuaded that partnerships between churches, large and small (the CUSH groups, of course, are all Christian) and public health have a significant role to play in HIV prevention.

The CUSH model has been developed in other parts of the United States. Joint ownership of the project is deemed essential to its success and to this end formal agreements (CUSH use the term Memorandum of Understanding) in which the roles of the religious organizations and the health department are clearly defined are signed by participating groups. This 'sense of ownership' they assert may have helped overcome 'suspiciousness and reluctance to participate' which have been barriers to some collaborative initiatives. Is this a reference to the tensions between rights-based public health approaches to HIV and those based on moral sanction? It is not stated,

but many African Americans are members of Pentecostal or Pentecostal-type churches and some conservatism in approaches to HIV could be expected. Apart from the one brief reference to those groups who did not consider HIV an issue for their communities, there is no explicit reference to the potential for tension between public health responses to HIV and an engagement with the moral codes of religious leaders and congregations and no discussion of whether any barriers of this kind emerged during early conversations with religious leaders or how they may have been overcome.

In the UK there are a number of faith-based or faith/health partnership initiatives, again, usually, though not exclusively Christian. The work of the African HIV Policy Network (AHPN), NAZ, a support organization for Black and Minority Ethnic communities in London and the Jewish AIDS Trust have helped some religious groups, mainly in London, and their leaders to engage with HIV prevention and care issues. For AHPN this has been a major objective of their organisation. But these initiatives are directed mainly at minority religious groups, those with which many people of immigrant communities identify and to which they belong. It is not known whether evaluations of their efficacy and evidence of long term shifts towards non-judgemental and non-discriminatory theologies and teachings have been or could be conducted.

It was clear to this researcher several years ago that with new communities settling in an already extensively diverse city, the ever increasing diversity of issues with which sexual health and HIV service provision would have to engage, was extending into unlooked for complexities (See Figure 1, page 12/13). The presentation expressed a growing concern that the increased levels of diversity and potential barriers to access, not only those, for example, of first language, race and ethnicity, but also those rooted in significant psychological adjustment and social and religio-cultural unfamiliarity, would impact both the provision and the providers of services. The author was responding in 2004 to a sense on her part, supported by her personal experience as a service provider (as Chaplain with people affected by HIV), that existing services would struggle to accommodate the impact of this new diversity in their efforts to meet the HIV prevention and care needs of a changed demographic. Significant numbers of the new communities were from parts of the world with high prevalence

for HIV, mainly countries of sub-Saharan Africa. After several years the evidence from this study's survey of religious responses to HIV suggests there is yet more work to be done before community members concerned about and affected by HIV can be confident of inclusive and caring religio-cultural responses.

The author is aware that such a presentation of diversity could be construed as an argument both for limiting immigration *per se* and also for introducing HIV-specific controls on entry from high prevalence regions. With rights-restricting policies known to increase vulnerabilities to HIV, this is not a case she is making. UNAIDS have become progressively stronger advocates over the years for rights-based approaches to HIV prevention and care. But the context and the circumstances described above shadow the very arguments for the rights-restricting responses to HIV posited by Allen (2004), Parker (2003) and others (Allen and Heald 2004, Putzel 2004) as potentially being a cost worth paying.

Stigma

Like other pandemics of sexually transmitted infections in the past (McCombie 1990, Shorter 1992) HIV exposes an interface between competing realities: between that which could be described as the rational, scientific interpretations of medical and epidemiological realities on the one hand and the interpretations of socio-cultural realities experienced and expressed in symbol, metaphor, myth and ritual on the other. The deep-seated taboos of human relationship which both implicitly and explicitly impact every society (Douglas 1988) bring HIV-related stigma into play.

Stigma is fuelled by attitudes and anxieties rooted in personal and cultural histories, attitudes and anxieties which will often appeal to religious belief and teaching or sacred texts for justification and authority. Anthropological theories of norm and anomaly shed light on the stigma attaching to HIV. Taboos, particularly those categorised by sex and relation, set powerful and enduring themes in social systems of myth, metaphor, symbol and truth and are central to human discourse. They are deeply embedded in cultural and religious identity and belonging, in moral codes and in socio-psychological appropriations of meaning and in politico-cultural infrastructure (Douglas 1988). Not only does HIV cut across each and any combination of those themes and discourses, but sexual and reproductive violations or

anomalies signal particularly deep rooted taboos. Indicating danger and toxicity (Goffman 1963), it can be argued that any response to HIV, whether collective or individual, will be informed by them. The taboos shape the most and the least effective responses to HIV prevention and care. They are as integral to policies of openness and universal access to services (which will be regarded as the breaching of them by many), as they are to attitudes and beliefs which further prejudice and discrimination (which will be regarded by many as normative and conforming). An understanding of such themes and responses to them are essential aspects of good HIV service delivery. Indeed, urging a broader understanding of stigma which takes seriously ethnographic enquiry, Castro and Farmer (2005) argue that confused or partial conceptualisations of stigma can inhibit integrated HIV treatment and care and collude with inequitable provision.

Following Veena Das' assertion that no institutional, group or individual response to HIV will be 'uncontaminated by social norms regarding stigma' (Das 2001) or Strassberg's that human relationships are informed not by events in social, cultural, political or economic isolation but by contextual interpretations of those events (Strassberg 2004), the analytical and strategic boundaries for debate and praxis begin to diversify. In a world with HIV, in a local community with HIV, dominant western bio-medical responses vie with situational religio-cultural approaches to express and meet public health need.

The complexity of the religious environment and the tension between the stated aim of many religious groups to respond compassionately to people with HIV and their desire not to compromise religious teaching on sex and sexuality and condom use are representative of the realities which surface in a number of studies (Genrich and Brathwaite 2005, Hartwig 2006). But a lack of compassion towards people with HIV and limited knowledge of HIV among religious representatives are not uncommon findings. In this study stigma affects the life of each participant with HIV. In response to the tensions between religious calls for sexual rectitude and also for compassion, there arises a clear need for faith-based initiatives grounded in dialogue between people with HIV, local religious leaders and the secular health and social care providers: for the religious and the secular alike, following Johnston's view (Chapter

Two above, page 44) that the world is theologically constructed and perceived (Johnston 2001), a potentially integrative theological approach to consensus.

At the level of individuals affected by HIV and stigma's impact on their experience, a number of studies raise issues which chime with the experiences reported from Leicester. Scambler's account of the 'felt' stigma experienced by people with epilepsy, for example (Scambler 1989), connects with those efforts of people living with HIV to distance themselves from the disapproval of those who may know of their HIV status. In this research several participants with HIV, when narrating the circumstances of their infection spoke of the thoughtless or unfaithful behaviour of their partner. Colluding with stigma's power to divide those with the virus between 'innocent' and 'guilty' they sought to be known as the 'innocent victim'. Catherine Dodds identifies similar responses in her enquiry into the experience of gay men and heterosexual African migrants (2006) concluding that

Stigma does not only reinforce power boundaries between those of different sexualities, ethnicities and migration status, it reinforces and maintains distinctions within these groups in an attempt to promote the best possible group image. The ultimate impact of this will be to fracture and weaken these fragile support structures and the group identities even further.

(Dodds 2006: 479)

Ultimately, it is in the transformation of power relations that any dissipation of stigma's influence will be made possible. And power in this case relates both to that which characterises the self in its appropriations of esteem and agency and internalisations of stigma and that which shapes and bolsters social hierarchies including religious hierarchies in their fostering of insider-/outsider-ness. For stigma is a child of inequalities and exclusion and any action to bring about change has to engage at the political and personal levels in Freire-like 'problematising' or 'conscientising' ways.

The social order is problematized when subjects can conceive of alternative social arrangements to those that currently exist. Stigma is problematized when those who are stigmatized do not accept their stigmatized status as 'the

way things are' but believe that things could be different, and that they may legitimately demand and expect better.

(Cornish 2006: 463)

Cornish's research into the experience of stigma among Indian sex workers suggested that in the sex workers' identification of a lack of rights, in their contrasting the stigmatised and the non-stigmatised, and in their designing material solutions, that is, in their own experience lay the capacity to effect change, particularly local change. Cornish urges localised 'problematising' as a means to effect change but draws attention to the need for material as well as 'symbolic' (the frameworks of understanding) results.

In debates about mobilising collective action efforts to bring about change at the material level are often seen in opposition to attempts to bring about change at the symbolic level. However, my argument is that material changes that are not discussed at the symbolic level as part of a community's political agenda, and grand ideals with no material backing are equally incomplete ... For material changes to become more than individual changes and to generate a wider process of politicised collective action, they need to become part of community members' symbolic understanding of their potential for action. Material and symbolic changes are complementary aspects of a single process of politicised change.

(Cornish 2006: 470)

Her argument reflects this author's calls for a fully integrative process through which religious frames of reference also can be similarly transformed and transforming in the interests of comprehensive public health outcomes, that is, reduced incidence of HIV, in the wake of problematising's challenge to power differentials and other inequalities.

Chapter Six has set out and discussed the main concerns arising from the data collection, analysis and associated reflections. Issues of diversity, power, religious

authority and stigma are central. The several exposures of religion's often toxic relationships with HIV prevention and care and those most vulnerable to infection have highlighted the tensions inherent to many religion-informed responses to HIV and the potential or otherwise for partnership with universalist public health policy and provision. Silence, prejudice and judgementalism have been shown to build up barriers to wider collaborations with health and social care agencies in the interests of community health. After owning the study's limitations, Chapter Seven sets out complexity theory's contributions to progressing an understanding of and adoption of diversity's realities. There follows the modeling of an integrative practical theology which calls for the involvement of a diversity of players, including different religious groups, health and social care agencies and people with HIV. The study concludes by proposing a group counseling approach to authentic partnership between religion and public health in the strategic design and delivery of HIV prevention and care.

CHAPTER SEVEN

Conclusion

Study's weaknesses and limitations

Introduction

A range of issues were considered in Chapter Three on methodology and method design (researcher positionality, for example, and identifying, accessing and recruiting the research population). However, it became clear that as the data were subjected to analytical organisation, as theoretical arguments were honed and as the study faced completion, the practical and methodological assessments made prior to the collection of primary data were vulnerable to further critique. Such tensions, given expression most particularly in the positivist versus phenomenological debates, relate to this study's

- degree of replicability and consequent questions concerning validity and reliability,
- researcher perspectives and realities,
- research location and issues of participant identification.

Non-replicability, validity and reliability

Although replicability is not an anticipated criterion, challenges to the validity and reliability of any small-scale qualitative study with a sole part-time researcher and limited resources are likely to find significant endorsement in the fields of both quantitative and qualitative methodologistics (Haralambos 1985: 518 ff, Neuman 1994: 127 ff, 356, Denscombe 2010: 103). However, one of this study's characteristics lies in its bringing the views of local religious leaders alongside the voices of congregants and people with HIV and placing that data from 'grass roots' or 'street' level perspectives at the forefront of an analysis (Basset and Stickley, 2010). Institutional public health and mainstream religious responses to HIV prevention and care occupy established and visible places in the HIV research field. Those of people living and working in an intensely diverse community in the middle of England are neither established nor visible. This study identifies the need for further research on a larger scale, both of the structured quantitative survey type and of the more iterative flexible kind, and involving the participation of a more diverse section of the

community and more people with HIV. Increased resources could help ensure that the potential for misunderstandings due to the absence of interpreter services would be minimised; that childcare could be offered to parent participants with a view to widening participation; and that researchers with appropriate technological skills could maximise the use of software-enabled collection, organisation, storage and analysis of data. The challenges to replicability, reliability and validity will still be heard but the force of the challenge may be weakened by further and larger non-positivist studies raising the voice of the socially and religiously marginalised participant, in this case those most directly affected by HIV.

Researcher's perspectives and realities

Researcher positionality was considered in depth prior to the process of data collection (page 106 ff). In the community through and from which the study would be conducted the researcher's identity as a Christian priest engaged for many years in the field of HIV support was known to many health and social care professionals and people affected by HIV. She was known also as a hospital chaplain, as a religious leader engaged in interfaith dialogue, as a white older woman, a wife, mother, grandmother, colleague and friend. All these aspects of her identity and the constructs emanating from them were taken into account when decisions were made about the information to be communicated to potential research participants. By and large principles of openness at every level governed the process. However, in spite of personal confidence in her high degree of self awareness and insight into the nuanced proclivities of projection, introjection and transference to influence the interviewer/interviewee relationship, to say nothing of the priest/interviewee dynamic, a growing awareness as the study progressed of the difficulties in eliminating the potential for bias residing in the researcher's own ideological and theological positions caused her some unanticipated concern (Denscombe 2010: 87; Bhopal 2003: 71-76).

Locating her religious and socio-political approaches to HIV in the liberal progressive if not radical domain of social and theological thought and practice, the researcher has known for many years that such views held a minority status in mainstream religious, political and social positioning. The risk and fear of delivering a lengthy polemic was

real and the constant checking for academic objectivity was experienced as significant pressure – an unanticipated lesson in competing realities.

Naming the research location and issues of participant identification.

As the study progressed an early intention to name the location in the title of the study and to use the demographic data of the community to both contextualise and inform the research and its findings was reviewed. Concerns about identifying the city and some of its communities with the stigma of HIV drove a change in that early decision. The location would become known as City N and the study's title amended. However, it was realized that using the researcher's identity and other details of her professional background as recorded in the study (their inclusion deemed significant, particularly in terms of positionality and issues of reflexivity, by the researcher to the method design) the source of the local data could readily be ascertained. Furthermore, the removal of the city's name from the cited references, bibliography and appendices would not only deter access to meaningful resources but also frustrate those readers wishing to follow particular lines of data and argument. Requesting the study be withheld from publication appeared too severe a step. It was decided to name the city and scrutinize the transcribed material for potential trails to identification, paying particular attention to the participants with HIV by revisiting, for example, any naming of their religion or places of worship (Fetterman 1998: 140-145).

Towards a new practical theology

This study's investigation into religious engagement with HIV prevention and care has exposed tensions between preferred public health approaches to HIV prevention and care, that is, those governed by principles of universal access, and those religion-informed responses to HIV, particularly as they relate to contexts of local and global religio-cultural diversity, which limit access to HIV information and an individual's capacity to protect their health.

This interdisciplinary enquiry has asked whether strategic public health responses to HIV prevention and care are adequate to the multiplicity of psychosocial realities and needs of religio-cultural diversity in a UK community and positioned itself at the outset in the traditions and potential of practical theology and in public health theory and practice (Chapter One).

It has delivered a complexified range of perspectives on religious responses to HIV prevention and care and problematised their influences and impacts. Through primary and secondary resources it has evidenced the relevant complexities at global and local levels: the religion/secular dichotomy, socio-political and economic power relations, the distribution of resources, gender inequalities, homophobia and HIV-related stigma. A return to those early questions, reproduced below, which undergirded and shaped the research strategy and its implementation gathers again the fundamental findings and points to appropriate recommendations.

But what are faith leaders and religious teachers at grass roots levels saying about HIV? How are faith community members appropriating the teachings in the context of their beliefs? Reflections on these and the questions below helped inform the content and structure of a research proposal.

- Are public health principles and the prevention and care strategies and practices they inform undermined and access thwarted by sensitivities to personal and corporate philosophies, beliefs and traditions?
- How do religious groups/communities (leaderships and 'street') in the UK and internationally respond to HIV? What do people affected by HIV want from their faith group? What do religions offer a world with HIV?
- Can responses to HIV which conform to those of specific religious and cultural beliefs and contexts prevent transmission of the virus, ensure adequate care and treatment of those affected and have long term application and impact? Can the health of sexual minorities and other marginalised groups, women and their babies and girls be protected?
- If stigma is a major barrier worldwide to effective HIV prevention, treatment and care can HIV education and other prevention initiatives navigate the barriers stigma generates, particularly any religio-cultural fuelling of stigma, and work creatively and effectively within them?

- Where lies the potential for any necessary change when the beliefs and practices which are deemed to have served the well-being and survival of individuals, communities and societies for generations risk transmission of HIV, for example such practices as widow inheritance, wife sharing, Female Genital Mutilation, polygyny? Does religion reinforce the vulnerability of women to HIV and if so what options for change are available and effective?
- Do the beliefs of education and health and social care professionals influence the delivery and efficacy of strategic Public Health responses to HIV and people affected by it? Is there prejudice towards those with religious convictions and if so does it impact access to services?
- In a world with HIV can an allegiance to religion as truth incorporate an appreciation of religion as phenomenon? Can theologies accommodate the multiplicities and complexities of contemporary socio economic confusions and realities in responding to HIV?

(Chapter One, pages 32-33)

Each question has found resonance in the responses of the primary and secondary data. The wisdoms of the wider discourses and those of the local have informed both the one and the other in analysis, in discussion and in recommendations. And the study has uniquely exposed the impact of those religious responses to HIV on access to prevention and care resources, on the ritual and pastoral needs of affected individuals, on attitudes to difference and diversity and on public health provision and partnering. It moves now towards proposing a new way of doing practical theology.

Religious responses to HIV, individual and collective, are tied to personal appropriations of beliefs and the interplay between hegemonic and hermeneutic authorities. They will be influenced also, to varying degrees, by personal histories, socio-cultural, political and economic environments. And the diversity and shades of those influences will generate both retreats from and embracings of their inherent complexities. For many of those who inhabit environments of high religio-cultural diversity it is religious belief which secures belonging and identity. It may also place

an individual under a religious authority. Those who set the rules of engagement and define the religious milieu may not readily cede that authority. The porous and flexible boundaries to hegemonic controls amid and open to diverse hermeneutic choice and preference described by Aune (2006) and Yip (2005) will have little sustainable reach. Religious responses which express and call for supportive rights-based and stigma reducing responses to HIV find little purchase in contexts where needs for conformity, belonging and place head the priorities and needs. Determining insider and outsider status becomes the most important game in town.

Leicester prides itself on its diversity and social cohesion. The faith communities and their leaders play a high profile role in this cultural and commercial marketing. The annual Diwali celebrations attract visitors from far and wide, but this rainbow city rarely, if ever, includes in the representations and marketing of its diversity and its references to local services the local LGBT community and the Gay Pride celebrations. It does not acknowledge that diversity begets diversity and that exclusions multiply also.

Although her analysis is substantially specific to American culture and experience, Barbara Strassberg (2004) explores the arc of such issues and offers a socio-cultural analysis which regards HIV and responses to it as symptomatic of a changing world order. She makes connections between responses to HIV, cultures of violence and changing interpretations of human sexuality, gender and power. Noting the adoption of conflict language in articulating responses, even scientific responses, to the HIV pandemic - 'combat', 'waging a campaign', 'war chest' of funding, 'invade' and 'kill' - (Stine 2002: 451 quoting Kofi Annan, Treichler 1999: 31), ¹⁸ she asks, why solutions to human struggles for survival invariably are couched in terms of conflict and violence rather than well-being and harmony. Strassberg explores the use societies make of metaphor and narrative, including religious narratives, in transforming meaning, enabling a cultural 'fit' or coherence between potentially conflicting strategies; that which others, using other discourses, John Hull (1991), for example, may name as avoidance of dissonance. Psychotherapist Bernard Ratigan refers to the

¹⁸ Though not cited by Strassberg, there are echoes here of 'AIDS and Its Metaphors', Susan Sontag's contribution to an understanding of societies' need to metaphorise illness and in so doing both confer and deprive it of meaning (Sontag 1989).

threat a diagnosis of HIV can deliver to a person's 'psychic equilibrium – melting the glue which holds us together psychologically' (Ratigan 2000: 473).

Strassberg notes that 'from a social scientific perspective people do not respond to events but to their own interpretations of those events' (Strassberg 2004: 438). There is 'knowledge' which informs those interpretations and shapes human interaction. That which or who is 'known' as similar, for example, will elicit feelings of connectedness, compassion and social action offering opportunity for social transformation, cultural change. That or who is 'known' as different is more likely to elicit feelings of fear, retreat or even a will to destroy. When the one who is not known is excluded from the table on account of being the one not known, a vicious circle of not knowing risks establishing a boundaried norm.

Through an application of world-systems theory and the connections Strassberg makes between the macro- and the micro-levels of global interpretations of HIV's and terrorism's realities, she concludes that hegemonic shifts lie behind this age's apparent chaos, diversities and differences and that an immunological deficiency of 'biological, socio-political and technological information systems are in fact new aspects of the emerging order' (Strassberg 2004: 441). Referring to U.S. supremacy in military power she quotes Robert Elias.

...militarism is often the last gasp of power for dying empires. Our obsessive rallying around the flag belies fundamental weaknesses and insecurities.

(Elias 1997: 142 in Strassberg 2004: 436)

She asserts the decline of American power and argues that global chaos and confusion are expressions of the 'death spasm of the dominant position of the rugged white Christian heterosexual American male'. And Strassberg is writing before 2008's fracturing and re-aligning from west to east of global capitalism's economic force; before Middle Eastern agitations for democratic representations and increased grass roots demands world wide for fairer distribution of financial, social and natural resources.

In the light of these more recent global developments does Strassberg claim too much for HIV, go too far, in the light of these developments, with the connections she makes? Perhaps not, for this study, in its local dimensions and its engagement with wider discourse, has evidenced the pervasive influence of this virus in both reinforcing and confusing, if not overturning, present or desired order. Furthermore, the stigmatizing influence of HIV exposes what Strassberg describes as western pedagogic assumptions in communicating an AIDS reality. Early western stereotyping and exoticising of the 'otherness' of HIV-identified individuals and societies allowed and allows stigma to run riot. She obeserves it is always 'them' and never 'us'. With that arguably idealised call for a compassionate and just world order to 'lessen the suffering of strangers', Strassberg draws added attention to the complex human sociocultural and political interaction of a world with HIV and sets the stage for the realities and needs of complexities and inequalities to assume yet more characterisations.

Complexity's calls for democratic and dialogical approaches might postulate the creation of localised religious dialogue, informed by scientific knowledge and theory, to agree responses to local concerns, in this case HIV prevention and care. In so doing it would identify a shared reality and progress towards a shared ethic. Inter-religious dialogue connecting continually with concrete applications in the context of HIV will create more difficulties for some than for others. There will be those who argue that their religion's traditional approaches to disease would be adequate to any contemporary need and efforts to create a shared response would threaten the traditional resources with which religions respond to the impact of disease (Moore, 2003). There will be others who are concerned to stress those views held in common rather than those which differ.

There were perspectives described in the responses of religious leaders in Leicester which drew attention to the concepts and language of universality, compassion and care. These may offer a ground in which the seeds of an inter-religious theology of HIV informed by up-to-date bio-medical and socio-cultural knowledge could be sown and grown. However, as noted by Moore (2003), questions arise as to whether religions *can* re-appropriate traditional theologies to take account not only of such scientific and ethical complexities, but also of the very diversity and confusions which

surround presenting issues. Doubt about their capacity or willingness to do so must surely be justified given the epistemological shifts in scientific understanding and the ever changing complexities of the relationship between the micro and the macro fields of global, local and environmental aspects of human experience. It is one thing for theologies to be tested against the realities of an HIV pandemic at the global level and another when theologies are being tested by local leaders and communities in messy contexts of high diversity and multiple marginalities and needs. For here religion offers 'place' and has difficulty responding to a 'quantum' world. Another point: religions have tended to focus on behaviour change, sexual behaviour change, as their response to HIV and yet the evidence that such approaches have other than very limited success is mixed (Mathematica 2007, Marmot 2010, World Health Organisation 2011a, 2011b, UNGASS 2011a). Will the impetus for action and change rest with those individuals who can bridge the religious and scientific/public health divides? Clearly, a significant shift in vision is necessary before any impact will be made.

Some will argue these shifts can and do occur when facilitated using organisational development and change theory (Goodman and Steckler 1990, Chin et al 2005), even in contexts of religio-cultural conservatism. Adopting such an approach Chin et al worked with Chinese and South Asian immigrant religious institutions, Buddhist, Hindu and Muslim, in New York. Chin et al, in contextualizing their study refer to the 'language and cultural barriers as well as discrimination' (Chin et al 2005: 485) which contribute to the isolation from wider society of the immigrant communities. Such realities are reflected in the diversity of Leicester and in the responses of this study's participants.

Chin et al note the recurring tensions between morality and compassion, that is, between the religious respondents' wish to preserve their moral codes of sexual discipline and family traditions and, for many, the wish to serve their members creatively and effectively as they face new challenges. They describe the responses as 'conservative' and 'innovative impulses'. Rather than acting as a barrier to effective HIV prevention and care, these impulses can lead, they suggest, to 'conservative innovation' (Chin et al 2005: 499) which will generate opportunities for awareness-raising and dialogue, though some of these will be more challenging and complex

than others. That the 'impulses' chime with the themes of dissonance and quests for coherence tracked in this author's study suggests a compatibility with psychology theory and practice and the potential for creative group-based interventions by which to generate theological innovation. There are echoes also of Petchey et al's (1998) 'innovative alliances' and Ballard's and Pritchard's (1996) creative marginalization (this study Chapter One, page 9/10).

Chin et al's example of movement from co-operation to innovation is representative of a range of diversity-engaging community-development initiatives which are surfacing in response to the complex needs of diverse communities. Although, not guaranteeing successful outcomes they echo this author's calls for an integrative theological relationship with social policy, a relationship to be shaped and endorsed by drawing further on Sylvia Walby's treatment of complexity theory (2009).

Walby's principal concern in her book 'Globalization and Inequalities' is to shed theoretical light on sociology's neglect of complexity theory's 'trans-disciplinary' (Walby 2009: 48) significance in addressing the impact of globalisation particularly in respect of inequalities and social change.

... an understanding of globalization requires concepts that grasp notions of inter-connections on a large scale.

(Benhabib 1999 in Walby 2009: 50)

In a similar way it has become clear during this researcher's study that local experiences and impacts of HIV, whether of a socio-political or bio-medical kind, cannot be assessed without positioning the multiplicities of the local in those of the global. And for Walby this process is to be embedded in a re-worked, complexified notion of social system which allows for conceptual inter-relationship at macro and micro levels. She shows how any assessment of those systems she names institutional 'domains' (economic, polity and civil society) and 'regimes' (sets of social relations) will only be partial without the inclusion of a full appraisal of the complex intersectionalities involved within and between those various systems. Walby added a fourth domain, violence, to those more familiar categorisations of economic, polity and civil society in order to bring 'ontological depth' to a complexity analysis. She

argues that the additional domain enables complexity theory to bring the fuller extent and wider impact of modernity's globalised diversities and inequalities into view, particularly those relating to gender and intimacy. This study has demonstrated the need to be alert to diversity's place in social relations, and in this context the HIV-religion-public health trinity. Although there may be an awareness of such an impact Walby reminds readers that any known diversity is much more diverse than it appears.

With that lesson in mind it can be argued that this study points to the need for health and social care services (following Corrigan and Orme at page 249) to have a greater awareness of the extensive complexities which the presence of diversity brings to policy design and service delivery, particularly, in this case, HIV prevention and care. Without a recognition that competing hegemonic influences, including those of religion, shape the meanings and realities which institutions, communities and individuals draw from their 'knowledge' of HIV, public health and many religions' responses to the virus will be found wanting.

Johnston's contention that engagement between the secular and the religious is theologically constructed and perceived and that globalisation's force will be identified in inter-religious if not sectarian terms (this study Chapter Two, page 44/45) is significant here. For if this is the case, does not Walby also persuade religion that theologies are indeed inadequate to the complexities of globalised modernity? And in a context of such extensive inter-relationship do not the powerful pulls of both particularism and universalism demand an attention few are delivering? Present systematic, practical or social theological discernment is inadequate to the diverse needs and competing realities of a world and a community with HIV. It is inadequate to the complexities of modernity even before diving more deeply into the relative securities and certainties of neo-liberal, anti-democratic mode. The barriers of HIV stigma are rooted in each of Walby's domains and regimes and will not break down until opportunities are seized for multi-sectoral and inter-disciplinary, institutional, social and individual representations to be gathered and heard. And it is just such a model which theology, and, the author will argue, public health, are now called to employ before religion can either participate in or deliver an integrative and authoritative response to a world, communities and individuals with and affected by HIV.

Extensive overlaps between the social scientific disciplines of sociology, anthropology and (social) psychology can be identified within and between the clusters tabled at page 234/235 (see also Figure 7 at page 232, Table 19 at page 136, Table 14 at page 120, Table 8 at page 71). Not only are the interdisciplinary relationships of the key data clusters exposed, but also the intra-disciplinary characteristics of those clusters. The anthropologist's interest in ritualistic and symbolic expressions of exclusion may be the sociologist's interest in religion's power relations and diasporic diversity; the social psychologist's interest in multiple identities may be the theologian's interest in existential contingency and reconciliation. The public health practitioner's interest in partner notification may be the person with HIV's interest in potential isolation failed relationships. But questions arise as to the capacity of traditional theoretical analysis to offer adequate instruments by which diverse and overlapping realities and their treatment at the levels of both micro essentialisation and macro universalisation and combinations of both can be assessed.

That interdisciplinary tensions and characteristics present in any attempt at a comprehensive understanding of globalised, diverse and ever shifting human contexts, not least religious contexts, appears to have attracted minimal attention among researchers even after familiar corrective discipline-specific developments. For example, sociology's early engagement with religion's functionalist properties stressed the integrative role of religion and its companion institutional systems (Haralambos 1985: 521 ff). The religious norms examined were those which resided in Christian paradigms and it was Robert Merton who challenged the hitherto undisputed notion of 'functional unity' which claimed that a change in one part of the system would result in a comparative but integrative shift in another (Haralambos 1985: 530). Merton argued that in a pluralist society with many religions and beliefs, functional unity could not be assumed. Division and 'functional autonomy' could be the reality with no integrative impact on the social system. Merton also noted that previous assumptions that the various functionalist aspects of the social system identified by Talcott Parsons as

adaptation

- goal attainment
- integration
- pattern maintenance

(Haralambos 1985: 528)

could be deemed neither sustainable nor indispensable. For Merton an assumption that any part of society could be 'functional, dysfunctional or non-functional' and that 'functional equivalents' could not be identified should be central to any functionalist investigation. The tendencies to both differentiation and integration in a society's appropriations of religion-generated and religion-protected cultural and moral norms are now well established in sociology's theoretical approaches to religion and its effects (Davie 2007). In similar ways anthropology and social psychology engage with theologically and ritually expressed cognitions and appropriations of beliefs and teachings (Douglas 1966, Campbell and Jovchelovitch 2000) and bio-medicine is learning to accommodate ever more comprehensively social determinants of health (Marmot 2005, 2010). But interdisciplinary partnering and the drawing of alternative discourses into both micro and macro and micro/macro analyses appear scarce. As was outlined in Chapter Three above at pages 77 to 81 in an introduction to another interdisciplinary record, theology can claim no exemption.

Sitting under practical theology's umbrella, the theological 'P's - Pastoral Theology, Public Theology and Practical Theology – do engage with other disciplines, primarily sociology, psychology and anthropology, but by and large it is a one-way street with theology in these and other theological reflections and analyses continuing to suffer from the positivistic and atheistic charges of irrationality, 'supernaturalism' and an absence of intellectual rigour. For theologies to contribute to the shaping of public policy in an informed and authoritative way an engagement with social, economic and political players requires an interdisciplinary commitment to the public good (advocated, though in a different context by Amartya Sen 1995). While it can probably be argued that 'P' theologies' take interdisciplinary engagement more seriously than has traditionally been the case in theological studies, nevertheless it appears to be a significantly Christian as opposed to inter-religious engagement and only tentatively reaches into the pastoral, practical or public theological implications of socio-religious and cultural diversity.

S. Wesley Ariarajah's has been a rare voice speaking to the inter-relatedness of religious traditions. Originally from Sri Lanka and for many years the Director of the Interfaith Dialogue programme of the World Council of Churches in Geneva, he used the terms 'partners and co-pilgrims' to describe a joint journeying to a new global

'paradigm of a life-affirming culture in which compassion, responsibility, a sense of proportion, and the quest for justice and peace tempers and directs our quest for material well being'.

(Ariarajah 2003: 13)

However, there is a theological characterization known as Social Theology out of which Michael Taylor (2006) urges a distinctly 'pluralist' engagement.

Social Theology aims more for political and social transformations which will reflect religious principles than for individual conversions. Taylor takes some account of the conflicting positions to be found both inter and intra the various theological and social scientific and political schools of thought. It is one thing, for example, referring to the 'heresy' of apartheid, the 'preferential option for the poor' and the integrity of the planet, but it is another when sexual minorities and women's sexual and reproductive rights are in the frame (Taylor 2006: 64). Consensus may be particularly difficult in the shaping of HIV prevention policy.

Arguing the insufficiency of any single belief system to foster in full the 'common good' Taylor is advocating a dialogical engagement which can express a non-confrontational multi-faith approach to and engagement with civil society.

No faith is self-sufficient. No faith can speak for all. All faiths are fallible. We need one another in order to be wise, certainly wiser than we can ever be left to ourselves.

(Taylor 2006: 32)

To facilitate such a process Taylor argues the 'human' and complementary nature of religions.

Rather all of these traditions are the attempts of human beings in different times and circumstances, with different histories and interests, to make sense of their experiences and their lives. None of them is complete and self-sufficient. But fortunately they are incomplete and insufficient in different ways so that again and again one need not necessarily threaten the other but complement the other instead so that, listening and learning from each other, knowledge widens, understanding deepens and what we believe and value becomes more productive of human flourishing.

(Taylor 2006: 24)

Taylor is calling for a democratic process by which to identify and promote the common good; a fully participatory process involving more than a few, often self selected, leaders or representatives. Taylor acknowledges the idealistic nature of his proposal but advances the value of public debate which will include open (that is, not restricted to religious groups or leaders) debate on religious beliefs and moral values, leading to decisions taken on their incorporation into social policy

The common good cannot be decided a priori, for example, by some religious authority claiming to base its judgment on divine revelation, any more than it can be decided by some intellectual, or moral, or powerful, or social elite. The common good (or its embodiment in a social policy) can never be `what is good for them`: one deciding for another. It can only be what all involved have decided `is good for us`. No justifiable independent arbitration exists.

(Taylor 2006: 25)

Taylor's case for a Social Theology challenges both religious claims to divine authority and secular society's attempts to inhibit 'privatised' religion from legitimate participation in the formation of social policy and practice.

Social Theology's principles of engagement as set out by Taylor align with the findings of this study: with the calls, for example, for religious authorities to hear the voices of people affected by HIV along with those of health and social care

Professionals before taking a theological position and expressing a religious view; and with the need for wider sectoral and community engagement to inform sexual health education policy and practice in schools. Indeed, the Joint United Nations Programme on AIDS sets out just such a model in its strategic framework for 'Partnership with Faith-based Organisations' (UNAIDS, 2009). Taylor's characterisation of his proposals as idealistic both in their calls for widely democratic participation and their need for religion and any engagement with it to be regarded as a human construction suggest Social Theology's innovative thrust may (and UNAIDS' strategic principles), for all its attractions in some quarters, encounter impenetrable theological and epistemological barriers in others. With the ever-present and always expanding capacities of globalisation's diversifying impact on human experience and any analysis of it, HIV's globalised and personalised situatedness and religion's struggle to engage competently with the post modern pulls of both relativisation and particularisation, existing theological constructs, traditional, existing and emerging, appear wanting. A new model is tentatively offered at row 3 of Figure 8 below.

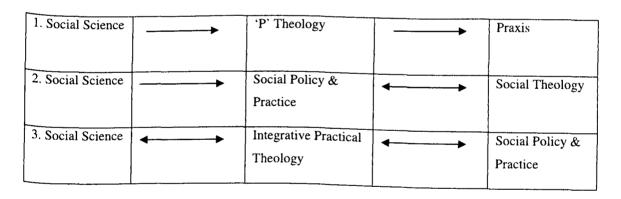


Figure 8. Towards an Integrative Practical Theology

In a minimalist format and mindful of the limitations outlined above, Row 1 of Figure 8 tracks the recent routes of practical, pastoral and public theological discernment and engagement. The social sciences alerted theologians to new modes and understandings of being and relating which were assessed and used to inform religious engagement and practice. Row 2 shows Social Theology's emergence from its interest in and commitment to social policy and practice informed by social science and religion-informed engagement with social policy and practice as Taylor may describe it. Row 3 calls for an Integrative Practical Theology which places itself

within and between, informing and informed by social science and social policy and practice.

Susan Walby's (2009) treatment of complexity theory is advanced as foundational to any theoretical and theological integrity of this study. Although her ideas emerge from a sociological stable they are earthed in the multiple dynamics of global networks and perspectives with clear interdisciplinary thrusts in the evidence she gathers and the critiques she summons (2009). Walby appropriates the concept 'complex inequalities' to speak of a 'complex combination of inequality and difference' (Walby, 2009: 60) and to frame her argument that social theory takes inadequate account of the specificities of differentiation in a globalised context. And, this researcher would argue, religion and public health and their respective engagements with HIV also. For, in the same way, in the light of the evidence drawn from this study, local and global, particularist and universalist, a strong argument emerges for religion, with its attendant theologies, and public health policy makers and service providers, together to speak more clearly of and engage more fully with the same combinations and differentiations – particularly as they impact the local.

This study has found that public health policy and religion-informed responses to HIV and to people affected by it are inadequate to the competing realities and diverse needs of globalised localities and will remain so until public health strategic planning for HIV service delivery and religious authorities' engagement with HIV prevention and care take seriously religion's role in global and local efforts to become a world without HIV. Both disciplines have the capacity within their respective traditions, principles, vocabularies and praxis to engage dialogically with one another and with a diverse range of additional partners and practitioners. Present generalist religion/secular tensions and conflicts are an unhelpful distraction, though perhaps symptomatic of a 'felt' inadequacy to engage positively in the interests of consistent HIV prevention messages and supportive care for those affected.

Suggestions for further research

Although continuing to acknowledge the limited scope and generalisability of this study, some assessment of its findings in respect of future research will not be entirely without justification or authority. Although a larger study following a similar

methodological strategy and affirming these findings would be necessary before substantial validity could be attached to the propositions set out here, an attempt will be made to outline a practical implementation of the proposed theoretical framework.

It is this researcher's view that the realities identified, explored and analysed in the course of this work are of value not only to public health and epidemiological theory and strategic application but also to theological enquiry into HIV, enquiry which has delivered nothing new in over twenty years. For it was in 1990 that, in this researcher's opinion, that which remains the best UK-based collection of theological responses to HIV was gathered and published by James Woodward. The book, *Embracing the Chaos*, assumes theology's genesis in critical engagement between communities of faith and their perceptions of realities (Woodward 1990: 3). Although Woodward's focus is specific to the Christian community and to Christian theology, nevertheless theological reflections he invited were to accord a particular authority to the narratives of people living with HIV. He arranged a meeting between contributors to the book and people with HIV. 'It was a remarkable experience for the whole group', he wrote, 'as we were led into richer perceptions as well as new problems and challenges'.

This willingness to share in each other's stories enabled us to glimpse the experience of a theology that could support, listen, change, evoke response and create movements towards people who were striving towards a sense of inclusiveness, mutuality and creativity in the face of HIV'.

(Woodward, ed. 1990: 3)

It is just such a process of critical encounter and reflection which this researcher suggests is necessary to any response to HIV, a process which would find support in the discourses of public health and practical theology. Although anticipating significantly increased evidence and experience of the levels of chaos and anxiety which Woodward's contributors faced in 1990, moving his model into multi-sectoral and multi-religious fields of engagement surely signposts a route to more adequate, more integrated religion-informed and public health responses to HIV in 2011. For this study has shown how HIV exposes the need for a new way of doing and constructing theology which enables an authentic engagement with the multiplicities

of many-layered global and local systems and realities. Identifying and theorizing the problem is but one stage of a process; addressing it in practical terms yet another.

And here initiatives using a group counseling model are suggested. It is a model, like Woodward's, which assumes group participation will comprise people with and affected by HIV, and also religious leaders, congregants and public health practitioners. With a qualified leader or 'conductor' the potential for such a process, though not relating specifically to this study's context, is described by Ratigan (2006) as that in which 'human beings can be helped to meet each other as persons in what the Jewish writer Martin Buber called the 'I-thou' encounter' (Ratigan 2006: 106). Ratigan's commendation of group work resides in his hope that

exposure to group processes may help to improve our world by helping group members to see that what is happening in the group also happens in relations between peoples, states and cultural groups.

(Ratigan 2006: 106)

Such an approach is more than dialogue. It offers the potential for a deep exploration of competing realities and diverse needs and for ideological and theological positions to be challenged or affirmed, changed or embedded at individual and group levels.

However, in so far as this study's contextual theorization is new, questions remain as to how far existing models of practice can become the integrative agents in global, community and individual responses to HIV. Chin et al (2005) advance a process modeled on organizational change theory which may offer some potential, but resilience, in the longer term, to conservative challenge is neither tested nor known. The same reservations will apply to the group counseling model. There are democratic community development approaches informed by a social psychology of participation and notions of critical dialogue which are deemed by researchers and practitioners to drive and to have driven successful participatory efforts (Beeker et al 1998, Campbell and Jovchelovich 2000, Maoulidi 2003, Parker and Aggleton 2003, Campbell 2003a, Campbell and Murray 2004, Chinouya and O'Keefe 2008a, 2008b). But Campbell's critique of her own initiative draws attention to the potential for dispute and misunderstanding within that which appear to be the most carefully designed and

democratic of systems. Stillwaggon (2002), Strassberg (2003, 2004), Moore (2003), Hunt (2004), Allen (2004), Barnett (2004a), Heald (2003) and Walby (2009) note similar failings at global institutional levels. Everywhere historic and present constructs and the associated dynamics of power and identity are contributing to misunderstanding and unsustainable participation. Clearly, this impacts the need for and delivery of access to consistent, accurate and regular HIV prevention and care messages and services and delivers a cautionary note to any innovative efforts to engage dialogically, if not integratively, with institutional and individual cognitions and epistemological constructs.

Looking to the future

HIV in the UK remains a serious public health issue which continues to challenge strategic policy design and delivery, not least, as this study has demonstrated, in communities of religio-cultural diversity.

Following an outline of the research context and the key dimensions of its positioning in the dialogical creativities of practical theology and public health, this study set out to identify the adequacies and inadequacies of religious and public health engagement with HIV and propose for practical theology a new and integrative approach to religion-informed engagement with public health policy for HIV prevention and care. The interdisciplinary investigation into the competing realities and diverse needs inherent to religious engagement with HIV prevention and care systematically exposed a range of contestations. Through an account of the author's professional background, through epidemiological mapping and through the identification of conceptual tensions and strategic conflicts in the literature and from qualitative data gathered from a local community rich in diversity, the study has described a complexity of realities and needs.

Leicester's early and, almost twenty-five years on, continuing efforts at multi-sectoral engagement are salutary, (how far these can continue in a climate of financial austerity and NHS restructuring remains to be seen), but, as evidenced by the local data in this study, the city's religious responses to HIV have not delivered a fully consensual approach. That model of HIV-informed local religious practitioner with the capacity to cross and re-cross multiple institutional boundaries and engage with

HIV's socio-political discourse at many levels and in numerous contexts as advocated by Johnston (2001) and Petchey (1998) has to a large extent been adopted and resourced there (Chapter Two page 49 above). However, as the local data has shown, consistent community-wide prevention and care messages for HIV remain elusive. Further community development and empowerment initiatives are planned. The invisibility of the LGBT presence in promotions of community diversity and city services is beginning to be addressed. But the resistance of some religious advocates, primarily those positing heterosexual rectitude and traditional marriage, to engagement with the rights-based agenda of public health policies and the delivery of consistent HIV prevention messages would put at risk any testing by the group counseling model and an integrative practical theology of the potential for mutual understanding and transformative change. The challenges of addressing present inadequacies in religion's and public health's engagement with HIV prevention and care are real.

The study has shown that many of those who attach religious authority to their responses to HIV appear unable to acknowledge the stigma-inducing potential of the needs and anxieties brought to expression in religio-cultural frames of meaning and identity. Silence has surfaced as a major concern: both the silence of those who are rendered voiceless by the stigma, and the silence of the religious and wider communities. A non-judgmental attitude may be offered but not always freely. It may be subject to a patronizing conditionality. The price of belonging and coherent meaning may be the HIV-affected individual's dignity and agency. While the national and international engagement remains important, it is clear from this study that, in practical terms, it is the grass roots approach which matters, or also matters. And practical theology and the UK's public health policy for HIV share emancipatory principles of inclusion and open access. And where good community relations are high on the agenda of religious leaders, interfaith dialogue will also be informed by the language of relationship, friendship and mutual concern. In the interests of community health, this study has made clear both the need and the potential for religion-informed responses to HIV and public health policy for HIV prevention and care actively to pursue deeper dialogical relationships, relationships which would include people with HIV, and deliver consensus. It will be remembered that it was in the group discussions that opinions were exposed to dissonance and authority

questioned (Chapter Five, pages 166-172). Notwithstanding the challenges, as this study has demonstrated, epistemological boundaries, local and global, strategic and personal, can be as resistant or as amenable to global impact as they are to local pressures of socio-economic, cultural or political change. The quest for and the establishment of cogent and right realities when no reality is wrong and every reality is both relativised and particularised (Beyer 1994) is a daunting but necessary task in a city in a world with HIV and one for which no single discipline offers a discourse commensurate with such an undertaking.

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