Like a prayer: the role of spirituality and religion for people living with HIV in the UK

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Abstract

Over 40,000 people are now living with diagnosed HIV in the UK. There is, however, uncertainty about how people with HIV use religion or spirituality to cope with their infection. Adopting a modified grounded theory approach, we analysed individual and group interviews with the people most affected by HIV in the UK: black African heterosexual men and women and gay men (mostly white). For the majority of black African heterosexual men and women in our study, religion was extremely important. We found that gay men in the study were less religious than black Africans, although many were spiritual in some way. Black African individuals constructed their spiritual narratives as largely Christian or collective, while gay men described more individualistic or ‘New Age’ approaches. We developed a six-level heuristic device to examine the ways in which prayer and meditation were deployed in narratives to modulate subjective wellbeing. These were: (i) creating a dialogue with an absent counsellor; (ii) constructing a compassionate ‘life scheme’; (iii) interrupting rumination; (iv) establishing mindfulness; (v) promoting positive thinking, and (vi) getting results. That people with HIV report specific subjective benefits from prayer or meditation presents a challenge to secular healthcare professionals and sociologists.

Keywords: gay men, black Africans, religion, HIV, prayer

Introduction

HIV

The two groups currently most affected by HIV in the UK are gay men (mostly white) and black African heterosexual men and women. Among the Black African heterosexual men and women, most were exposed to – and acquired – HIV in Africa (The UK Collaborative Group for HIV and STI Surveillance 2005). On the other hand, the majority of gay men had acquired their HIV infection in the UK. There is relatively little research which examines the role of religion and spirituality in how people cope with HIV. This neglect is interesting given that among one of the groups most affected by HIV in the UK
black Africans – the overwhelming majority report being religious (Chinouya and O’Keefe 2005). The little research available in the UK and elsewhere suggests that for African and other individuals religious affiliation can have positive effects in terms of coping mechanisms and providing a sense of inner strength to deal with HIV (Anderson and Doyal 2004, Chinouya and O’Keefe 2005, Doyal and Anderson 2005, Takyi 2003). While religious beliefs and practices can clearly provide comfort to those with HIV, beliefs can also pose dilemmas for a person’s health. For instance, some black Africans in the UK believe that prayer itself can cure HIV without medication, and that being religious can help prevent the transmission of HIV (Chinouya and Davidson 2003, Chinouya and O’Keefe 2005).

**Religion and spirituality**

Although religion and spirituality are complex constructs, broadly speaking, religion can be viewed as a social institution concerned with the way beliefs, practices, rituals and communities are organised, while spirituality concerns the individual quest to understand and attribute meaning to life and the sacred (Koenig et al. 2001, Miller and Thoresen 2003). Another useful conceptualisation constructs religion as ‘vertical’ (i.e. more concerned with God and consequences of actions for the afterlife) and spirituality as ‘horizontal’ (i.e. more concerned about consequences of actions on social connections) (Davidson 1975). Modern day sociological understandings of religion followed the early work of theorists like Marx, Durkheim and Weber, all of whom characterised religion as a kind of social illusion (Giddens 1993). Within a grand narrative of gradual Western progress, it was assumed that society would become increasingly secular, and the sociology of religion became separated out from the sociological mainstream (Swatos 2006). But religion continued to be important, leading some sociologists to argue that religion and modernity were much more entwined than previously believed (Davie 2007). For instance, religiosity seemed to confer particular kinds of benefits on practitioners, including an increased sense of social agency (Daaleman et al. 2001). In parallel, patient and illness narratives came to the fore in medical sociology in the late 20th Century, giving patients much more of a voice, and making it harder to ignore their existential concerns, even if they challenged professionals’ beliefs (Hyden 1997). As particular kinds of meaning-making narratives (i.e. stories which attribute specific meaning(s) to events), spiritual and religious stories were no less powerful than other patient narratives (Daaleman 2004). What was missing then in sociology was the ‘cultural turn’ where metaphysical meanings were analysed on their own terms (Davie 2007), as became the case in a host of other fields such as constructions of sexuality and gender (Connell et al. 1991, Oliffe 2005, Ridge and Ziebland 2006, Ridge 2004).

**Prayer and meditation**

Prayer is an ancient practice and like other spiritual concepts is difficult to define. However, prayer can be viewed as vertical communication (e.g. with God, a higher purpose) which may be verbal or contemplative (Meraviglia 1999). Previous grounded theory research has uncovered many layers to the complex meanings and uses of the practice of prayer, including requesting help from a higher power or organising force, as well as talking to, listening to, thanking, worshipping, and seeking guidance from this power (Walton and Sullivan 2004). Prayer can be structured in an organised way, freely composed to meet individual needs and involve spiritual healing. A recent Cochrane Review suggested that meditation is a contemplative form of prayer (Roberts et al. 2006). Meditation essentially involves concentration and contemplation, and has increasingly become the focus of scientific
enquiry in the West (Melbourne Academic Mindfulness Interest Group 2006). Even though meditation is a varied practice, it is now mainly discussed in terms of ‘mindfulness’ in the scientific literature. There appears to be good agreement that ‘mindfulness’ can be defined as ‘paying attention in a particular way: on purpose, in the present moment, and non-judgmentally’ (Kabat-Zinn 1990). The important dimensions of mindfulness include concentration, awareness of the present moment, as well as openness and curiosity to whatever is experienced at the time (Melbourne Academic Mindfulness Interest Group 2006). In the West, mindfulness has become separated from spirituality to a degree. As such, many people use such meditation techniques without reference to their spiritual antecedents (Segal et al. 2002).

Health
There is increasing awareness of the ways in which religion and spirituality play a part in how people understand and manage their health (Daaleman 2004). A number of studies indicate a positive link between health (physical and mental) and spirituality or religion (Koenig 2000, Thoresen and Harris 2002), including those that examine their role in coping with specific illnesses like cancer (Feher and Maly 1999, Koenig et al. 2001, Stanton et al. 2002). Spirituality or religion could influence health in a number of different ways. These include prayer reducing anxieties and increasing hope; gaining social support through organised religion; feeling a sense of belonging through religion; the group identity and helpful ethics for living associated with religion; and finding a level of security within the clear rules of religion (Craig et al. 2006, Meraviglia 1999, Walton and Sullivan 2004, Wink et al. 2005, Woods and Ironson 1999). Nevertheless, the spirituality-religion-health connection is still not that well understood and calls have been made for more research examining how spirituality and religion relate to health (Holt and McClure 2006, Thoresen and Harris 2002).

From a narrative and sociological perspective, a more relevant question than ‘Does prayer work in an objective way?’ is: ‘How are spirituality and religion woven into the stories of people living with HIV, and how do these storylines influence coping?’ In this paper, we analyse spirituality and religion as one particular kind of narrative, and prayer or meditation as a narrative tool or device in coping with HIV (just as a talking therapy might be useful to recover from depression) (Ridge and Ziebland 2006). This narrative framework allows even secular listeners to consider religious and spiritual stories as aspects of patient experience deserving respect. We were particularly interested in comparing and contrasting the experiences of gay men and black African heterosexual individuals. They are the people most affected by HIV in the UK (The UK Collaborative Group for HIV and STI Surveillance 2005), and they take somewhat divergent approaches in their spiritual narratives. We also wanted to develop a framework for understanding more precisely the way in which prayer is deployed and experienced.

Methods
In this article, we draw on the data from audio-recorded interviews that provided the foundation for the development of a web site covering experiences of living with HIV (www.dipex.org). During 2005, the first author conducted 44 individual and three group interviews with people who were living with diagnosed HIV. People were encouraged to tell their stories in their own words about their experiences of living with HIV. To be eligible for the study, participants had to be over the age of 18 and have a diagnosis of HIV.
DIPEx conducts research into patients’ experience of various medical conditions and has Multi-site Research Ethics Committee (MREC) approval in the UK (with no local investigator). Since we recruited patients in NHS HIV clinics, we obtained approval from the Research and Development (R&D) office in the relevant primary care and hospital trusts and secured honorary contracts for the first author.

Sample selection and recruitment

We used principles of maximum variation sampling to recruit people living with diagnosed HIV. In the first phase of recruitment, 19 black African individuals (9 heterosexual men and 10 heterosexual women), 24 gay men (19 white UK and Irish, two from South America, one from South East Asia, one with Caribbean ancestry and one white Western European) and one white Eastern European heterosexual man were interviewed. Because the approach to interviewing was slightly different for the gay men and black Africans (see below), it was decided to conduct a further three focus groups with black African individuals (two groups each of four women, and one group of four men) to further clarify the analysis.

One of the aims of the study was to explore a broad range of perspectives and experiences. Participants were recruited to include men and women, different age groups, ethnicities, social classes, people living in London and elsewhere in Britain (including Brighton and Manchester), different levels of HIV viral load, plus those who had been diagnosed recently and many years ago. This maximum variation sample was obtained through a wide variety of carefully selected avenues. The authors handed out recruitment packs directly to eligible patients in National Health Service (NHS) HIV clinics where the majority of people living with an HIV diagnosis in the UK received their treatment and care (The UK Collaborative Group for HIV and STI Surveillance 2005). Peer support groups and community organisations also assisted in recruitment. Advertisements were also placed on Internet sites (e.g. Positive Women) and HIV media and newsletters (e.g. the monthly Positive Nation magazine).

The interviews

Open-ended, in-depth interviews gave respondents as much time as required to talk about their experiences in their own words and to focus on issues about HIV, contemporary life and coping that were important to them. The concept of a ‘life journey’, with a focus on HIV, was used as a sensitising device by the first author to frame the interviews (Reeves et al. 1999). In this way the interviewer asked questions in a manner that elicited stories about people’s lives and HIV infection as happening on a trajectory from past, present to future. With gay men, the researcher asked participants to begin talking from their early life experiences. Many black African immigrants to the UK have traumatic histories due to multiple losses of friends and family to HIV, escape from political instability, experiences of violence, ill health, HIV diagnoses and being separated from extended networks back home (Doyal and Anderson 2005). It was decided therefore generally to begin interviews with these black Africans from around the time of diagnosis with HIV to avoid delving into earlier traumatic experiences in Africa. The interviewer adopted an approach that allowed all participants to define the boundaries of the information they volunteered, and some people did in fact volunteer earlier life stories. Using a life-history approach led to the collection of richer narratives from predominantly white gay men compared to African respondents. Hence, focus groups with black African people clarified and supplemented the individual interview data here. A referral sheet with contacts for telephone and one-to-one counselling was provided to participants where necessary.

A topic list was used in the final part of the interview to ensure that broad topics of relevance to the study had been considered for discussion (Ridge et al. 2007).
questions about spirituality, religion, prayer and meditation were asked by the interviewer towards the end of the interview if participants had not already raised the topic for discussion; for example, ‘What role if any does spirituality or religion play in your life?’ ‘What role does prayer or meditation play?’ While there are many different religions in the UK (including Islam, Hinduism, Judaism and Christianity), this paper focuses on Christianity because the people we talked to only discussed this religion in any detail. Interviews ranged from 60 to 180 minutes and were audio – or video – recorded with the informed consent of each participant.

Analysis
The audio recordings from the interviews were professionally transcribed, corrected by the first author, and returned to the participant for review. The software MAXqda version 2 was used to aid the coding, organisation, and searching of narrative sections from each interview. MAXqda enabled themes across a range of interviews to be compared and linked for a systematic analysis. The first author identified emerging themes using a modified grounded theory approach and multiple levels of analysis as described elsewhere in the literature (Glaser and Strauss 1967, Ridge et al. 1997). The analysis was a cyclical process: continually moving between reviewing the literature, data collection and coding, linking codes, and revising and reshaping the analysis. The analysis was scrutinised by the other authors through regular meetings and electronic exchanges. All authors were involved in refining the final analysis and commenting on drafts of the paper. Any names used in this article are pseudonyms.

Spirituality and religion
The overwhelming majority of black African individuals we talked to were deeply spiritual in their approach to coping with HIV, and attending their place of worship was important to them. Many African individuals turned to religion to help them cope with difficult and at times traumatic life circumstances including illness, uncertain immigration status and poverty. People reported losing faith in their religion from time to time, yet mostly their faith was strong, and religion was more often than not a source of great support, encouragement and hope:

I believe in God, my faith is very strong, I come from a very strong Christian background. When I became . . . when I was diagnosed, I lost my faith in God. It was like why me? Why me?. . . After some time, because there is nothing else I can run to except God, I became so close . . . My faith became stronger and I still believe in God (Black African woman, mid-30s).

Nevertheless, black African people were well aware that religious people and communities could hold very unhelpful ideas about HIV, such as HIV being a marker of sin. There were many narratives about navigating high levels of misinformation, stigma and hostility towards those with HIV in places of worship:

. . . people can be hysterical . . . I’ve [heard of] people who have tried to use the church forum to disclose and the outcome has been disastrous (Black African man, mid 40s).

Yet the people we spoke to had become adept at using what was useful in their religion and in distancing themselves from extreme ideas that they had come to consider misguided.
For instance, people generally believed the public health discourse that condoms had a place in preventing HIV transmission, regardless of anti-condom discourses within their religion. They also expressed views that being spiritual helped the medical treatment to work better or that medical treatment itself was the work of God:

I am a Christian and I value my religion very much... Some of the churches... [say]... leave your medication, they are coming to pray for you and... I disagree completely... God created us with wisdom, the wisdom to create medicine, which is the wisdom that is coming from God (Black African man, late 20s).

Despite very high levels of stigma in religious organisations, the narratives clearly showed that people relied heavily on their religion for all kinds of support. This contradictory tension means that people had to be vigilant in seeking support from religion: ‘You are even worried to tell even your pastor about it. If you tell your pastor it’s going to spread, now it’s another stigma’. While this situation places limits on the support people can gain for living with HIV, widespread stories about the unconditional compassion of Jesus were recounted to good effect by HIV positive people to confirm that they were included rather than excluded by Christianity:

God has not cast you out because of your condition. God loves everybody... The lepers were just at almost the same situation as ours... Jesus (put) out a hand and took them on (Black African woman, early 30s).

Despite the stigma, people were able to obtain support in places of worship including one-to-one counselling, collective prayer (considered more powerful than individual prayer), networking with others for emotional and material support, assistance with financial and asylum seeking issues, participation in meaningful and culturally relevant activities, physical contact and a sense of family and place to belong:

I find my church very accommodating. It’s just like a family... They are so loving. I really feel at home (Black African woman, early 30s).

The gay men, on the other hand, said their sexuality, sexual activities as well as their HIV were all targets of religious intolerance:

It was all within the teachings of the Catholic church, about it [homosexuality] being a sin... and thinking oh that’s me. And this is such as... something so dark and shameful I could never talk about it (White gay man, late 30s).

While a few gay men in the study said they originally considered being more involved in religion (such as by becoming priests), gay men’s stories were much more around needing to find ways to recover from the wounding messages of religion that historically connected homosexuality with sin (Fortunato 1982). These men deployed various discourses – including appeals to a non-homophobic God, rationality and science – to defend themselves against religious attacks:

You weren’t born an evil person, you just happened to be dumped with a whole stack of principles that you didn’t ask for... When those rules are based on appalling science, life really becomes intolerable (White gay man, 50s).
Some gay men we spoke to who tried to come to terms with their sexuality were left with
deep misgivings that made it difficult to engage with religion at a deeper level. These men
more or less tended to reject the teachings of religion. One man put it this way: ‘To me it’s
a crutch. Some people need a crutch. Some take alcohol. Some take Jesus Christ.’

However, gay men in the study who rejected religion did not necessarily reject their
spirituality, or all that religion could offer. They could be as pragmatic as the black
Africans we spoke to. Additionally, these men sometimes (re)discovered their spirituality –
and even religion – when they felt they were in serious trouble, such as when facing issues
of death. Despite deep misgivings about organised religion because of its hostility to gay
sexuality, many gay men did in fact describe themselves in spiritual terms. These men's views
were less religious and more eclectically spiritual (as defined in the Introduction), and included
finding the meaning behind life; living in harmony and balance; the operation of laws of
karma; the connection with others; and earth as a stepping stone to another existence:

But spirituality is [sigh] it’s that being, belonging sort of [pause] . . . knowing there’s a
reason but you don’t know what the reason is. It’s a sub-conscious thing. . . . It’s that
feeling and that being able to live in harmony with everything else. . . . I suppose that’s
the point I’ve come to with my spirituality (White gay man, early 50s).

The spirituality, I think the way I’ve come to it now, through Catholicism and through
the Anglican business, through the Jean Paul Sartre. . . . the existentialist approach, I’ve
found really very useful . . . But the Buddhist business, what sort of Buddhist I am, I
have no idea (White gay man, 50s).

The role of prayer and meditation

In this study, our analysis revealed six key levels at which prayer or meditation operate
(similarly and differently) for predominantly white gay men and black African heterosexual
individuals. These were: (i) setting up a dialogue with an absent counsellor; (ii) constructing
a compassionate ‘life scheme’ as a context for prayer (a ‘life scheme’ is the heuristic
cognitive framework used to interpret all life events (Daaleman et al. 2001)); (iii) interrupting
negative rumination; (iv) promoting mindfulness; (v) promoting positive thinking;
and (vi) getting results. This six-level typology is a heuristic device to help elucidate how
prayer or meditation might operate to improve subjective health and wellbeing. Rather
than functioning discretely, there are links and overlaps between the different levels, as will
become apparent in the following discussion. As outlined below, black African individuals
tended to use more traditional forms of prayer (talking to God). The gay men in the study,
on the other hand, tended to rely more on self-development and meditation approaches;
few said they prayed.

Absent counsellor

One of the most consistent themes across the narratives was the priority given to talking
through feelings with other people as a means of coping with HIV (see www.dipex.org/hiv
for more detail). People said they ‘felt much better’ when they talked. Talking and telling
stories about the self were clearly essential to sorting out problems and developing life
enhancing narratives: ‘[i]f you ask yourself questions . . . you never answer them’. While it
was recognised that people may not always feel like talking, verbalisation was considered
a valuable tool for people living with HIV: ‘Talk. Talk. Talk. Talk until you’re blue in the
face. Then talk again!’, said one man. The implication was that staying silent could adversely affect the development of that vital story about the self coping and recovering from a diagnosis or ill health: ‘If you do not say something, that kills you more’.

What is interesting in terms of narratives of spirituality was the way that prayer was constructed by some participants (mainly Africans) as akin to talking to an absent counsellor. This was an advantage of prayer that was additional to distracting people from negative cycles of rumination and encouraging greater mindfulness (see below):

I think when you pray, usually you feel relieved that you’ve talked to somebody . . . Because you’ve talked to God. You haven’t talked to anybody, but you’ve talked to God . . . He’s above all, and he’s going to give me an answer . . . (Black African woman, mid 40s).

Because the absent counsellor was considered a higher power, people believed they could get additional benefits compared with talking to another person. Such advantages included handing over control of uncontrollable situations to the higher power and reduced anxiety through constructing their life narrative as being protected by a higher power who could intervene and prevent their story from taking a turn for the worst. One man said:

So religion keeps you strong as well . . . there’s that invisible hand, that support, that you feel, there’s that further support there . . . and when you’ve had a pray and you can calmly reflect you know . . . There’s another being that’s looking after . . . looking over your family and stuff and it’s not just yourself and your wife and your child (Black African man, 40 years old).

Constructing a compassionate ‘life scheme’
The way that people interpreted the setting for the spiritual story of their life (or their ‘life scheme’) was an essential backdrop to prayer. The participants were generally doing relatively well in coping with HIV at the time of the interview (see Discussion). As such, spiritual participants tended to construct their life story (if not their material circumstances) as ultimately fair and just. Similarly, their God or higher power was seen as benevolent and compassionate (rather than vengeful) towards those with HIV. This compassion stood in marked contrast to the perceived hostility directed towards people with HIV from religious organisations:

God loves everybody, he loves all despite what you’re going through . . . the lepers were just at almost the same situations as ours. But Jesus went out . . . and took them on (Black African woman, early 30s).

With the stage set for rewards from a compassionate God or universe for participating in prayer, people were able to write their spiritual story as involving the receipt of favourable outcomes in return for prayer. This story was particularly important for many black Africans who tended to attribute considerable credit to prayer for their wellbeing and good fortune. Their life circumstances were relatively difficult and uncertain, especially if they were seeking asylum in the UK. If not for spiritual narratives, their life narratives could easily prioritise far more pessimistic storylines (e.g. loss of entire family or friendship networks to HIV in Africa, threats of deportation to Africa and concomitant lack of access to effective medication). For instance, a number of Africans believed that they had access to effective treatments in the UK because of their prayers and the grace of God:
I saw that my CD4 count is getting up, and I get the discretionary leave [to remain in the UK] which other people they have been in this country for years and years, they didn’t get this discretionary leave . . . Really, God is helping me, and God is answering my prayers (Black African woman, early 40s).

Given an ultimately compassionate spiritual life scheme construction, prayer was elevated by African individuals in particular as one of the most effective approaches to promoting their physical and emotional wellbeing:

And I said, ‘God, you are in control. You know every part of my body. And wherever this pyrexia is coming from, I want you to, to deal with it’. And, you know, it . . . What, what more do you want? If that pyrexia goes down without even an antibiotic. You, you say it’s God, isn’t it? (Black African woman, mid 40s).

The problem with a compassionate life scheme, however, was that this backdrop for spiritual narratives sometimes created expectations that could not always be fulfilled. As such, it was not always possible for people to interpret their circumstances within their life scheme all the time. This effectively meant that people could experience a ‘fall from grace’ as they moved outside the life scheme they had constructed as part of their spiritual story:

. . . so getting that [AIDS] diagnosis for me was, was such a horrible feeling of failure. And I was really angry, and I felt like I was being punished . . . I have done all of the right things, why the hell should I have to put up with this now. . . . (White gay man, late 30s).

Nevertheless, the compassionate life schemes that were successful were flexible enough to allow people re-entry following apparent ‘falls from grace’. For example, a 40-year-old father re-narrated his family’s difficulties with HIV (himself, his wife and his child were infected) as an infallible God working in mysterious ways:

I also believe, there was, there was some sort of God’s purpose to it all. . . . I used to pray, I used to get angry with God. Say ‘Why, why, why me? Why my, especially my child, why my child,’ you know what I mean? And then, now I’ve stopped all that. Now I just say just keep us safe, healthy, as long as we’re healthy we are fine . . . when I see my child at church playing . . . and he’s healthy . . . I think that’s good. That’s good enough for me. . . . (Black African man, 40 years old).

Interrupting negative rumination and promoting ‘mindfulness’
Praying to what people considered a ‘higher power’, using a mantra in prayer or concentrating in meditation were reported as having specific subjective outcomes for the people we interviewed. In particular, the accounts suggested that such approaches could be an effective way of removing people from destructive cycles of thought rumination. Rumination involves the continuous replaying of destructive fragments of personal stories like a broken record, often without us being aware of it (Segal et al. 2002). Rumination is known to emerge from, as well as contribute to, negative mood states including depression (Watkins and Baracaia 2002). For instance, one gay Asian man who had only recently migrated to the UK used the Catholic Rosary to interrupt a disturbing narrative about committing suicide:
If I say, ‘Why do I have to kill myself?’ Then, then, I hear another voice say, ‘Yes, you have to kill yourself because you’re, you are, you are dirty, you are virus, you can’t change anything yourself’. For some . . . I don’t know. I don’t know. I do lots of pray. I read the Rosary and everything. I have some courage . . . I stop having a conversation with myself (Asian gay man, mid 30s).

There were limits to the value of using prayerful approaches to stop rumination. For instance, when people become depressed, prayer as an approach could hold little appeal, or may be experienced as too difficult to undertake, or feel ineffective at the time:

With me, honestly, personally, when I am depressed I don’t pray. I don’t do anything. I shut my windows, I shut my curtains, switch off my mobile, don’t want anything and I just sit down and then I will cry, cry it out. And I just get negative (Black African woman, Focus group).

More than just meditation, we use ‘mindfulness’ as a term to describe a discourse that was spontaneously articulated by some gay men, yet embedded in the prayerful practices of the black Africans we talked to. In the current study, the mindfulness approach was an elaboration on the broader ‘interrupting rumination’ and ‘getting results’ aspect of prayer (see below), associated with greater calmness and clarity of thought. Some gay men talked explicitly about a philosophy of living ‘now’ which corresponds to the concept of mindfulness (Teasdale et al. 2003). We are not suggesting that the men who talked about mindfulness in the current study adopted the approach in the meticulous way currently advocated in Western psychology and Eastern Buddhism. Instead, the focus of mindfulness narratives here was on being more fully aware of – and living in – the present moment, and benefiting subjectively from this philosophy. Put another way, men here wanted to focus more deeply on their present quality of life. One man was firm about it when the interviewer asked about the future: ‘Forget the future . . . I don’t know what is going to happen in the future! The moment is now, that is more important.’

Focusing on ‘now’ was no ordinary narrative turn, since it was linked by the men with all kinds of potential benefits for subjective and real-world experiences. These included interrupting rumination, taking greater responsibility for their decisions and lives, doing things that were going to be (ironically) beneficial for their future, making choices to better look after oneself and greater enjoyment of life:

Yes by all means think about who you are going to send Christmas cards to. Or who you are not going to send Christmas cards to. But only actually worry about it when you’re doing the writing. Plan next January’s holiday by all means. But enjoy the planning, because now is the time you’re doing it. The holiday might never arrive! (White gay man, 50s).

Promoting positive thinking
Gay men and African individuals alike – regardless of spiritual beliefs – tapped into a spiritual and personal development story with wide currency in the narratives collected: it was important to find ways to think more positively to support your health. ‘For me, 90 per cent of . . . getting well, it’s in your brains. It’s in the mind’, said one man. ‘You need a positive state of mind, you need to be optimistic basically’, said another man. ‘I think if you have a positive mind, you’re determined not to let it get to you and get you ill’, said one woman. Faith and prayer were just one of the tools that people used to promote hope and a positive state of mind (see www.dipex.org/hiv, Talking about ‘Dealing with your
thoughts’ for a more comprehensive discussion). Faith in a higher power and the use of prayer helped people to think more positively by placing them within the compassionate life scheme and so offering greater hope, irrespective of current circumstances.

What faith teaches you is to stay positive and fight on (Black African woman, mid 40s).

Nevertheless, there were limits to the way that spiritual or religious beliefs could help support a ‘positive mental attitude’. Additionally, discourses about punishment for sins could feed into negative thinking (e.g. see first quote by a White gay man, late 30s) and beliefs about life after death could sometimes increase anxieties.

I worry about being dead. . . . What, what is beyond death? . . . I honestly don’t know [pause] [laughs]. What do I believe? [pause] On the very scienti-scientific sort of level, and this is perhaps clutching at straws, but every thought I take is an electrical impulse. Electrical impulses are energy. Energy cannot be created or destroyed. It just changes form. So, fingers crossed, I will just change form (White gay man, late 30s).

Getting results

Spirituality, religion, prayer and meditation were linked with outcomes for the self and the real world. When people used prayer, they were sometimes trying to find answers to burning questions they had. According to the narratives, having faith and participating in prayer or meditation could lead to improvements in thoughts, feelings and even bodily sensations. The narratives link these spiritual practices to a range of subjective shifts in people including greater insight, feelings of peace and calmness, courage and strength, and even reductions in pain:

. . . actually belief in the Bible can also help . . . I became strong. And I am still strong up to today . . . Because you change, there are a lot of things that change you in prayers (Black African woman, late 30s).

But the fact remains, it’s [neuropathy] damn painful . . . so with breath control I can sort of help it . . . it’s an old Buddhist breathing thing that basically I use it through abdominal breathing. . . . And the extraordinary thing is if you can get through that process, the pain suddenly vanishes (White gay man, 50s).

Importantly, secular meditation could also be used to work towards the same kind of subjective improvements. For instance, some gay men talked about using visual meditations to feel strong and in control of the virus. Strength is also a quality that people associated with prayer:

I talk to my virus . . . And I would literally talk to it. I would visualise that I would get rid of it (Latino gay man, late 30s).

For many black African women, who assumed they were infected by unfaithful male partners, prayer was often integral to their method for coming to terms with their painful sense of betrayal. While it usually took years to come to terms with such issues, the accounts show that praying could be a useful tool – along with other approaches (e.g. support groups) – as a space to air and process complex emotions, just as counselling might:
When I was diagnosed I was bitter. I cried, I was angry, I said, ‘What did you (her husband) do to me? You knew, why didn’t you tell me?’ So to me he had killed me, even my children . . . I had to learn to forgive him. I went to churches, . . . trying to pray and it would just come into my mind and then I would start crying, cussing and calling him names. . . . I said I have to forgive him and go on, and leave the past, and look after my children. That is how I got over it (Black African woman, early 50s).

One woman who was very ill in hospital (and who considered herself close to death) talked about an apparition where she met Jesus Christ and was able to discuss her life problems in detail. This experience allowed her to create a mental ‘counselling’ space to think about her problems and conclude that she was not ready to die. Additionally, she also came out of the experience with a powerful endorsement of the biomedical approach that was at times rejected by other black African patients in the UK (Chinouya and O’Keefe 2005):

And Jesus said to me, ‘You are healed. You are healed. But you take your medication. It is through your medication that you are healed. It is through me that you have the right doctors, have the right medication, that you are healed’ (Black African woman, early 40s).

Finally, such was the faith of some people (mainly black Africans) they held out hope that prayer could result in miraculous outcomes: ‘If you ask for anything from God, you’ll be given it’. However, in this sample (where people were mostly recruited from NHS HIV clinics or social support groups and were managing HIV relatively well), people tended to accept that any spiritual healing would go hand-in-hand with medication:

[My viral load] it is undetectable now . . . It is my faith . . . I think I’m going to get healed one day because I, I believe when you take up combination [anti-viral medication] you should ask Jesus to give them power. . . . Leprosy . . . was healed by Jesus. . . . It came to pass (Black African man, late 30s).

Discussion

This study offers an important insight into the ways that prayer and meditation feature as narrative devices in spiritual stories about successfully coping with HIV. Measuring the objective effectiveness of prayer in promoting wellbeing was not the focus of this paper. Rather, we were concerned with the ways in which prayer and meditation are incorporated into people's stories about coping with the infection and the implications for subjectivity. Our findings show that one of the key narratives in coping with HIV concerns spirituality and religion for most black Africans and many gay men we interviewed. Using a modified grounded theory approach we developed a typology of prayer that could provide an insight for sociologists and health professionals wanting to better understand the role of religious and spiritual beliefs in the lives of people living with HIV.

In our study, the spiritual narrative was central to most black African individuals we talked to but, somewhat surprisingly (given the long history of Western religious intolerance of homosexuality (Plummer 1999)), important to many gay men also. Those who derived benefit from spiritual narratives were able to down-play stories that were detrimental to living well with HIV, and to select those stories that were conducive to the ongoing project of good living. For instance, the common narrative deployed about Jesus accepting
all people regardless of illness or social status was powerful in combating HIV stigmatising discourses within organised Christianity.

Compared to gay white men, black Africans with HIV describe less room to manoeuvre to avoid the discredited identities associated with HIV (Dodds 2006). Additionally, the silence surrounding HIV in black African migrant communities and the relative lack of social support for black Africans with HIV in the UK means that the stakes appear high in terms of ‘passing’ as normal and avoiding spoiled identities in religious settings. Chinouya and O’Keefe (2005) thus argue that any empowerment gained through participation in religion for black Africans with HIV is unstable and imbued with contradictions. For example, people feel they can’t talk about their HIV in their church because of the associated stigma. Our study confirms these findings. But we also found that the contradictions could be managed by locating the problem of HIV stigma in the fallibility of religious others. That is, participants had enough agency to take what they needed from religion, avoid discredited identities and leave behind what was unhelpful.

New Age discourses were deployed by some gay men in our current study, but were not evident among the black Africans. New Age discourses are diverse and eclectic by nature, drawing on a range of religious traditions, philosophies and personal development concepts (Heelas 1996). New Age spiritual discourses draw from a ‘radically private symbolism’ that focuses on the individual self and its growth (Hanegraaff 1999). Such narratives allow those who have rejected organised religion to try and develop meaningful narratives that go beyond the material world. HIV infection is no different from other serious conditions in that patients may prioritise spirituality-based self-management approaches (Kemppainen et al. 2006). Some theorists claim spiritual marketplaces have opened in the West, allowing consumers to choose selectively from a range of approaches (Beckford 2003, Roof 1999). The notion of ‘mixing and matching’ spiritual approaches fits well with individualised New Age discourses. However, a collective focus on organised and institutional Christianity was common among the black African people we spoke to. There is little evidence of ‘mixing and matching’ religious tastes in the Christian approaches reported. This finding is consistent with a picture of diversity within multicultural societies as well as some recent thoughts about the separation between organised Christianity and New Age discourses: Christianity emphasises a God that people submit to, rather than a God to be discovered within the New Age self (Davie 2007).

Adopting a philosophy in line with mindfulness-based cognitive therapy (Teasdale et al. 2003), and focusing on the present moment with all its uncertainty is an important discourse for managing life with HIV for some gay men, and has been noted in earlier research (Ezzy 2000). What the current research adds is the link to newer discourses on mindfulness, and the finding that some forms of prayer may have the added advantage of increasing aspects of mindfulness through practice (e.g. by interrupting habitual thinking and rumination, increasing concentration), without necessarily articulating a mindfulness philosophy. It appears that we have found a possible link between secular forms of meditation and prayer that may require further investigation.

Generalising for all people living with HIV was not the aim of this study. Rather, we aimed to explore a complex phenomenon which is little understood in the literature. While a reasonably diverse sample was gained for this purpose, there are limitations to the current study. We were able to interview only people who were willing to talk about their HIV, so we are unlikely to have identified some of the most isolated and ill. Our participants mainly regarded themselves as being in good health (but not always), and were willing to help others by having their story on a web site. They were likely to be ‘role models’ for coping with HIV. This is a potential strength of the study as we were able to examine approaches
that people believed contributed to wellbeing. Both the success and limitations of the maximum-variation strategy are evident in the way that hard-to-reach participants were included. For instance, we held individual interviews with nine black African men and conducted one focus group discussion with African men: men who are often considered isolated and less willing to speak about their experiences of HIV than African women (Doyal et al. 2005). We were also able to locate five gay men for interview who did not have a white British background. But we were not able to include gay and bisexual black African men due to the difficulties in finding such men, and the limited resources we had for recruitment.

Our study reveals that prayer could be secular (e.g. mindfulness meditation), spiritual or religious in nature. Further, prayer can be recast by secular professionals as a do-it-yourself health-promotion technology that some patients with HIV use to modulate subjectivity and develop personal narratives that support good health. We found that people attributed specific subjective changes in wellbeing (e.g. reduced anxiety, increased strength) to prayer and meditation. What the current study adds is an understanding of the mechanisms that might be involved in modulating subjective experience through prayer and meditation. For instance, prayer may simulate aspects of counselling, may interrupt negative ruminations by taking people out of their habitual thoughts, and may have links to mindfulness. Our findings confirm that religion and spirituality can at times potentially undermine wellbeing, such as when sexuality and HIV are seen as sinful (King et al. 1999). However, it is the skillful ways in which spiritual beliefs and devices are constructed and deployed that are the key to any positive health benefits (Ellison and Levin 1998). Given the importance of prayer as a narrative tool, and places of worship as a source of social support for many people with HIV, bringing spiritual and religious narratives back into the mainstream of sociological investigation (and NHS care) would appear to be a valuable undertaking.

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Acknowledgements

We are most grateful to the participants for thoughtfully sharing their experiences of living with HIV, and those who helped us to recruit our participants (see credits www.dipex.org/hiv for details). We would also like to thank Sue Ziebland and the anonymous reviewers of the manuscript, whose constructive feedback led to a much improved paper. This HIV DIPEx project was funded by City University London, the Health Department, Gaydar and the Terrence Higgins Trust. Damien Ridge and Jonathan Ellford were funded by City University London, Ian Williams was funded by the Royal Free & University College Medical School London and Jane Anderson was funded by Homerton University Hospital, NHS Foundation Trust.

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