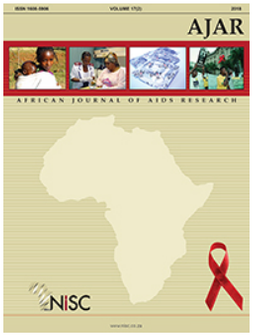

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"Bringing back hope": how faith-based responses to HIV and AIDS differ from secular responses

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This article investigates an assertion by faith-based organisations (FBO) that spirituality is the defining feature of their HIV and AIDS interventions. It is based on interviews with 24 people working on the issue of HIV and AIDS in churches or church organisations in Johannesburg, Rustenburg, Pretoria, Durban, Pietermaritzburg, and Cape Town. The article critically assesses the perceived difference between faith-based responses to HIV and AIDS and secular responses, including government programmes, in relation to the research literature on spirituality. After introducing the article, the argument begins with an exploration of the literature on churches and HIV and AIDS, outlining a gap which the article seeks to fill. The article then discusses the methods used for interviewing and analysing interview material. This is followed by religious leaders' own comments on how faith-based responses to HIV and AIDS differ from secular responses. The article concludes with a discussion which brings the literature to bear on the interview excerpts and then outlines the implications of decreased international funding for the HIV and AIDS programmes operated by the Anglican and Catholic churches, for example, a likely reduction in the accompaniment and monitoring of those who are HIV-positive.

Keywords: churches, civil society, FBOs, South Africa, spirituality

> *"... the first thing that the church does is to actually bring back hope"* (Tsepo Matubatuba, Johannesburg, 19 June 2015)

Introduction

This study investigated an assertion by faith-based organisations (FBOs) that spirituality is the defining feature of their HIV and AIDS interventions. This assertion commonly lies at the core of FBOs' explanations of how their interventions are different from those of secular organisations, including government programmes, and how they include a vital component for people, individually and collectively, to confront and come to terms with the pandemic. The purpose of this article is to engage with a criticism in the research literature that: "…there is not enough nuanced work that acknowledges the differences in religion, or that compares religious and non-religious activities in the context of the HIV epidemic" (Olivier & Paterson, 2011, p. 44). In this instance, I focus on what is arguably the foundation for such "nuanced work", that is, the issue of spirituality. The analysis is confined to the work of Christian FBOs in South Africa. The article is based on research with Catholic and Anglican churches and church organisations which have established and run HIV and AIDS interventions in Johannesburg, Rustenburg, Pretoria, Durban, Pietermaritzburg and Cape Town. In other words, this article discusses a cultural phenomenon in civil society responses to HIV and AIDS, spirituality, which is a premise of FBOs' (not only Christian organisations) interventions and, on the basis of a case study, how this premise has overtly informed these organisations longstanding HIV and AIDS interventions in many African countries.

There are inevitable challenges for this exercise. There is no single, authoritative definition of spirituality. FBOs do not hold a monopoly on spirituality. To illustrate, many secular non-governmental organisations (NGOs) involved in HIV and AIDS programmes emphasise a humanitarian agenda which can be as much about "bringing back hope" (the way one clergy participant in the study summarised the spiritual orientation of FBOs) as about changing people's attitudes and behaviour and providing treatment and care. The approach of this article is to accept the subjective nature of the issue being addressed and to recognise that it is a cultural phenomenon within civil society responses to HIV and AIDS in Africa and, therefore, it merits discussion. Accordingly, the definition of spirituality in this article draws on how clergy involved in HIV and AIDS interventions define the concept, that is, a belief in human connection with a higher power, in this instance God, through which humans can express their deepest values and place in the universe.

Background

There is now a large body of research literature on the role of religion and FBOs in relation to HIV and AIDS interventions. Much of this literature is of relatively recent origin. Denis (2014, p. 2) argues that it was "only in the late 1990s that religious organisations ... started to be seen as partners in the fight against HIV and AIDS in an African continent

notorious for its poor public health delivery." Denis states that there was a "flurry of research" thereafter (citing Olivier, 2014), funded by religious organisations and international agencies such as the United Nations Children's Fund (UNICEF), the World Health Organization (WHO) and the Bill and Melinda Gates Foundation and, after 2000, a "boom in literature on HIV and AIDS and religion in Africa" and increased presence of religious leaders and scholars at the international AIDS conferences (Denis, 2014, p. 2). Denis (2014) further notes that there are 367 publications on HIV and AIDS and religion in Africa listed in The Collaborative for HIV and AIDS, Religion and Theology (CHART) online bibliographic database. The bulk of them are peer-reviewed articles but there are also 27 books and 73 chapters of books (Denis, 2014).

However, there is little in the literature to assist the focus of this article. A publication of the CHART project (Haddad, 2011) argued for the need for better understanding of the intangible assets of religion but Denis (2014, p. 5) notes "the two most common themes of research are sexuality and FBO development". Furthermore, Denis (2014) comments that while social science and theology publications exist they rarely intersect. He further suggests common themes to create more disciplinary interaction: religious affiliation as a predictor of HIV infection; religion and public health; treatment, care and the constitution of therapeutic communities; and a "theology of AIDS".

Nonetheless, literature contains references to the spiritual orientation of FBO interventions. With regard to FBO interventions in South Africa, Burchardt (2013, p. 49) has argued that "FBOs engage in activities that are remarkably similar to those performed by secular NGOs committed to humanitarianism" and, hence, there are "recurrent debates about the 'Christian values' underlying their work and specifically religious motivations." For example, citing Becker and Geissler (2007, 2009), Prince et al. (2009, v) note that a great deal has been written about the role of religion and faith in relation to HIV and AIDS because, perhaps, religion has had an important role in framing people's understandings of and shaping responses to the AIDS epidemic" and that "Christianity is becoming one of the most influential factors in the engagement of AIDS in some African countries."

However, Olivier and Paterson (2011, p. 35) present a differing view in relation to their summary of common assertions about the role and influence of FBOs:

> Religious organisations, it is said, have unique and extensive reach and access: they are found in all communities, particularly the inaccessible and rural; they have access to dedicated volunteers and educated leadership; they have unique credibility and acceptance in communities, and therefore a particular potential to change behaviour; and they have well-developed networks extending from international to grassroots communities.

Olivier and Paterson (2011) are sceptical of the value of these attributes with regard to prevention, treatment, and care and support activities, critically assessing each in turn. Indeed, Olivier (2011, p. 84) remarks separately that statements about these attributes are: "largely anecdotal, not based on analytical research".

Likewise, Olivier and Clifford (2011, p. 372) record that "[r]eligious leaders are frequently described as community carers and a large body of literature emphasises the role of religious leaders in pastoral care in the context of HIV and AIDS." Furthermore, they comment that "[a]nother cluster of community carers are addressed in the literature as volunteers." After critically exploring the perceived value of churches' volunteer networks, they argue: "[e]ven less is known about the internal, religious-specific aspects that motivate or sustain volunteers in comparison with individuals who are not religiously motivated."

Olivier and Clifford (2011, p. 379) also discuss the presumption outlined in the literature that religion-based activities are "infused with spiritual elements". While not dismissing this attribute entirely, they note that it is contentious and there is insufficient knowledge to support these statements.

In contrast, a set of articles focusing on the Shiselweni Home-Based Care programme in Swaziland (Root, Van Wyngaard, & Whiteside, 2015; van Wyngaard 2013; van Wyngaard, 2014) highlight the importance of faith and spirituality for patients in FBO HIV and AIDS care programmes. To illustrate, in an empirical survey, in response to the question "'What would have happened to you if somebody from Shiselweni Home-Based Care did not come knocking at your door one day, offering their assistance?'" respondents made comments such as ' I would have died' or 'I would have killed myself' (Van Wyngaard, 2013, p. 227). These responses were not only references to HIV treatment and care but also to their need for spiritual care. As van Wyngaard (2013, p. 230) notes: "Spirituality addresses human beings' need to seek and find a meaning within their current suffering which allows them to make sense of that situation." He adds: "[o]ther writers identify topics such as the search for hope, the need for companionship, the question about the existence of God, life after death, and simple presence during a difficult and sometimes frightening journey as further objectives of spirituality in palliative care" (Van Wyngaard, 2013, p. 231).

Specifically, with regard to palliative care, Van Wyngaard (2013, p. 231) states:

> People with strong religious beliefs have less anxiety, death depression, and death distress, radiating a source of inner strength and peace. The fear of dying is often absent because of a belief in an afterlife and the expectation of a reunion with loved ones who have died before them. Furthermore, relatives who have a strong religious conviction and whose loved ones had recently died, also seemed to come to terms with their death sooner than those with little or no religious conviction, although this is not necessarily related to belief in an afterlife.

He also notes several negative aspects of religious belief including "disillusionment with a 'loving' God who could allow this to happen ... It is also possible that some patients may feel that the illness has been sent as a punishment from God, especially if guilt is present over past sins" (Van Wyngaard, 2013, p. 231–232).

Amidst these debates, Burchardt, Patterson & Rasmussen (2013, p. 174–178) have drawn attention to sources of the cultural and material power of FBOs: "[r]eligious institutions are some of the most powerful, well-funded organisations

within African civil society" as a result of several factors. These factors include African belief in spiritual power and an understanding of religious leaders as mediating between physical and spiritual realms, the growth in donor funding for FBOs, "the increasingly institutionalised voice these religious actors have in HIV and AIDS policymaking", and success of FBOs in "active and successful in lobbying for AIDS resources", based on their claim to represent "huge numbers of people." Burchardt et al. (2013, p. 180) also comment that "shared religious identities produce shared understandings of HIV and AIDS and of the position of one's religious community within the complex moral territories of blame and stigma or respectability and moral selfhood associated with the disease." Likewise, Patterson (2011, p. 210) argues, "African pastors have unique qualities that give them the potential to serve as leaders in HIV and AIDS mobilisation", not least of which is "on average forty percent of respondents in eighteen African countries had contacted a religious leader about a problem at least once during the last year."

A final point which has not been addressed in the research literature to the best of my knowledge was highlighted by my informants. This is the loss, when donors stop funding FBO HIV and AIDS initiatives, of the particular contribution of FBOs' pastoral care for HIV infected and affected individuals, families and households, that is, the spiritual expression of their care. Burchardt et al. (2013) touch on this issue in their introduction to a special issue of the *Canadian Journal of African Studies* focusing on "The politics and anti-politics of social movements: religion and HIV and AIDS in Africa", where they discuss donor motivations in funding NGOs, FBOs, and community based organisations. They argue this is in keeping with a general trend of neo-liberalism in which private organisations are viewed as best promoting development in Africa but that there can be, and have been unintended, consequences of this belief:

> First, African civil society groups may become dependent on international donors or transnational NGOs. ... Second, this massive infusion of donor funds has contributed to the rise of "suitcase NGOs", or local groups without indigenous constituencies that form merely to access funding. ... As these non-state actors become empowered through external resources, a third consequence may arise: they may directly or indirectly challenge the state and its legitimacy (Burchardt et al. (2013, 173–174).

The first caveat made by Burchardt et al. (2013) is particularly apt in the case of the Anglican and Catholic churches' HIV and AIDS initiatives in South Africa. For example, at the height of its PEPFAR-funded programme the Catholic Church was running 22 antiretroviral therapy treatment centres (Kevin Dowling, Johannesburg, 26 June 2015). These centres have now been handed over to the South African government. In 2015 a Joint United Nations Programme on HIV/AIDS (UNAIDS) funding agreement with the Anglican church was about to end. That funding assisted the Anglican Aids and Health Trust amongst others.

As discussed in more detail later, the informants for this study drew attention to inevitable change in the quality of care when HIV and AIDS clinic services are transferred to the Department of Health, even while acknowledging that the department should be responsible for providing these services. Government hospitals and staff are simply unable to give the continuum of care in and beyond clinics, ranging from counselling to treatment support and, where necessary, to palliative and bereavement care (to communities as well as families) that, for example, the Catholic church services provided. Clinics are packed. Department of Health medical staff overworked. And the number of patients keeps rising as evidenced by the increase in infection rates from 10.6% in 2008 to 12.2% in 2012 (HSRC, 2014).

Methods

This study is based on interviews with 24 individuals who are leaders, including priests and lay persons, in the HIV and AIDS interventions of the Anglican and Catholic churches in South Africa and of ecumenical organisations such as the Diakonia Council of Churches. These were individuals who agreed to be interviewed following my approach to a larger number of individuals. I initially drew up a list of potential informants, targeting those individuals who have been involved in HIV and AIDS programmes, in the past or the present, either at the local level or through FBOs. My list was drawn from contacts previously made during my doctoral research in the early to mid-2000s (Simpson, 2006) and from a search of ecumenical organisation websites and Anglican and Catholic databases which list priests and their contact information. I emailed all potential informants, requesting an interview and providing a brief description of the project.

Interviews were conducted in person and recorded. Respondents were asked four open-ended questions to elicit their own experience and analysis of the church's response to HIV and AIDS. These questions were: (1) what is their church in general doing to respond to HIV and AIDS?; (2) what is their church or church organisation specifically doing to respond to HIV and AIDS?; (3) how could churches improve their response to HIV and AIDS?; and (4) do faith-based responses differ from secular responses? If so how?

Interview records were largely transcribed, in particular the question asking if and how responses to HIV and AIDS differ from secular responses. The responses to the first two questions outlined the main areas of church activities in responding to HIV and AIDS. These include: establishing institutional structures through which a church response can be made; developing and implementing education and awareness-raising programmes; running testing, treatment and counselling programmes; and providing pastoral services and support to those who are HIV-positive and to those who are HIV-affected. Asking the question at all may have influenced subjects to speak about responses in a binary fashion. However, one respondent noted she did not think there was a difference between religious and secular responses to HIV and AIDS, so it was possible to disagree with the question posed (Jill Olivier, Cape Town, 20 July 2015).

Once the responses to the third question were transcribed, a text analysis was undertaken of each interview transcript to identify common issues raised by the 24 respondents and common themes in their responses to the questions.

Six common issues and themes emerged: the moral and

ethical basis of church programmes; the negative impact of the alternative churches and especially faith-healing; the importance of spirituality and the hope it provides to those who are HIV-positive; church structures and ability to deal with socio-economic issues; the place of churches in the community; and the role and importance of pastors.

The research design and interview questions were approved by the University of Regina's Research Ethics Board which subscribes to tri-council research ethics procedures.

Religious leaders' perceptions: how do faith-based HIV and AIDS responses differ from secular responses?

All but one of my respondents believe a faith-based approach to HIV and AIDS differs from a secular one, including both secular organisations and government-run HIV and AIDS programmes. This majority of respondents asserted differences in what motivated FBOs and secular NGOs to intervene and, consequently, differences in the care and treatment agenda of FBOs and secular NGOs. For example, the Rev Gift Moerane notes:

> *I think there are only two or three elements that are unique for the religious communities. The moral aspects of the teachings, the ethics of how to live your life, the dos and don'ts, that we always talk about and the whole issue of our teachings should actually make us to be distinct from other secular NGOs because we preach from the holy books, the Qur'an, the Bible, and so on, the Torah, we teach from these books and the values they are clear. So that's what makes us to be different* (Gift Moerane, Johannesburg, 12 June 2015).

In essence, my respondents asserted that the moral and ethical foundations of FBO interventions were different to those of secular NGOs. Though many referred to the humanitarian ethos and to human rights, which provide the moral and ethical foundations of the HIV and AIDS initiatives of many NGOs, they also emphasised the primacy of values conveyed in religious texts.

Rev Herbert Moyo raised a related issue commenting that churches address existential issues on the basis of those values rather than on basis of rationalism underlying standard content of HIV counselling:

> *Religion also tries to respond to issues of existentialism and HIV actually is at that level of life and death. It's about existentialism. So you need someone who can tell you about life to deal with the issues of HIV. So for me it makes much more sense to talk about HIV from a faith perspective than to just talk about HIV. If it becomes part of a ritual not to have unsafe sex it can be better respected than just don't have unsafe sex. I hope* (Herbert Moyo, Pietermaritzburg, 3 July 2015).

Bishop Kevin Dowling expressed this ethic in terms of how the message can take the form of asking "what would Christ have done" and for people to be "ambassadors of Christ" adding:

> *To take the faith dimension, whatever, how they understand the person of Jesus and the gospel message and so on, and make that come true in some way for people as far as they can, given the under-resourced situation of many churches in this country, given the fact that most of our churches comprise poor people* (Kevin Dowling, Johannesburg, 26 June 2015).

Bishop Peter John Lee emphasised the Christian gospel as the foundation of this ethic and its importance in motivating volunteer carers:

> *... it's that compassionate urge in the gospel that keeps people engaged. It gets people engaged, but all sorts of people get engaged initially. The long stay stuff very often comes out of the gospel motivation that people are exposed to daily, weekly. It's a value system being put before them. To which they respond, out of which they behave* (Peter John Lee, Johannesburg, 17 June 2015).

Petrina Pekoe, a former Hope Africa staff person, describes this in a slightly different way, highlighting that the church engages in prevention rather than just curative work:

> *The secular response is talking to the disease. The secular response in a big way is dealing with the after-effects after you've got the disease. So, it's the curative that the secular is seen to a big degree. I'm saying as a church, what the church's response can be is while they're doing curative let us then be on the other side making sure that it doesn't happen in the first place. That is what we should be preaching. That is the message we should be giving. And we really have a very, very big role. I'm not asking the priest to know about what your blood cell counts must be, etc. let's leave that to the secular or the curative. But let's talk here about raising the awareness, keeping it on the radar for everyone, making sure our young people during confirmation camps, and bible studies, etc. it is there, doing bible study around HIV and AIDS. Let's keep it as a priority and do the prevention and the education* (Petrina Pekoe, Cape Town, 13 July 2015).

In the course of articulating the premises of the response of their FBO to HIV and AIDS, respondents also expressed the difference in their interpretation of Christian scriptures to those of some other Christian FBOs. They espoused a theology of love and care as opposed to a theology of divine retribution in terms of HIV infection and AIDS-related illness being punishment by God for the individuals' sinful behaviour. Generally, respondents voiced concern about the theology and practices of some "independent" churches, in particular faith healing (the laying on of hands on an individual by a priest and prayer) of HIV and AIDS. The "orthodox" FBOs emphasise the need for HIV-infected individuals to take professionally prescribed medication and that there is no cure yet for the disease. One respondent also noted that: "*some 'orthodox' churches have also challenged churches who practice faith, healing, calling on them to acknowledge the realities of the disease*" (Gugu Madlala, Durban, 30 June 2015).

A central way in which faith-based responses differ from secular responses is recognising that though HIV and AIDS is a health issue, a person is a spiritual being. As such, churches seek to deal with both the physical and spiritual being in their responses.

As Rev Tsepo Matubatuba describes it:

> *HIV and AIDS is a health issue primarily, because*

> *it's actually dealing with infection of the body which is actually affecting the functioning of the immune system of a person. But, a person is a spiritual being. Without dealing with the spiritual being of the person it is very difficult to deal with a physical being of a person because you need to accept that you need to do something about your health.*
>
> *Spiritual healing is mostly a prerequisite for physical healing. So that is how the church is most important because it doesn't only deal with physical. Because I remember when we started everyone wanted to really learn the medical side of how we control it, and now going out and doing home-based care, nursing people and whatever, and when you come you don't even want to mention God but actually we later were taught to mention God first and every other thing is going to follow, even the change of attitude* (Tsepo Matubatuba, Johannesburg, 19 June 2015).

Catholic Archbishop Stephen Brislin describes a related issue which is the church deals with the personal and tries to address a variety of social conditions people experience:

> *... the faith-based response is always more personal and treats people as people and tries to know the person, know the personal struggles, the family situation, the economic situation and so on. ... A government intervention I think would just deal with the practicalities, the medical side. Whereas I think the church would try at least to look at it more holistically. And that the church would certainly try to accompany the person as much as possible in dealing with various issues, so not simply a person going in to get the drugs and then going home again but that there would be more of an accompaniment, particularly through the home-based care system where we try to say that you don't just go there for a particular issue, talk to people, discuss with them, hear what their problems are* (Stephen Brislin, Cape Town, 21 July 2015).

Churches also play a role in bringing back hope after people receive their diagnosis, something Van Wyngaard (2013, p. 32) has noted in relation to the Shiselweni Home-Based Care. Rev Tsepo Matubatuba remarked this is both in practical terms by offering information about treatment and in spiritual terms by reassuring the HIV-positive person they are loved by God. This process of offering hope helps those who are HIV-positive to accept their status. He describes this as follows:

> *... the first thing when you get to know that you are infected after doing a test the first thing the reaction is that you despair, you feel that you are going to die and you also feel guilt that you feel that you have sinned or whatever. Maybe God is punishing you and whatever. So the first thing that the church does is to actually bring back hope* (Tsepo Matubatuba, Johannesburg, 19 June 2015).

Another way in which faith-based responses differ from secular responses is the way workers engage with the work and those who are HIV-positive. As Bishop Dowling explains:

> *I've been in the shacks and meeting the workers after they come to me in the middle of winter with three patients died on the floor of their shack during the night, covered with excrement and vomit and everything else, and they've cleaned the shack and now they were washing the clothes, then they gathered with me and I said to them how do you keep doing this day after day, and they all of them said their different faiths it's because I know that God has called me to this and God is sending me and I go with the power and the spirit of God to touch these people's lives with God's love and healing and compassion. And so they say we'll gather here now and we'll cry, but we'll pray and we'll sing and then we'll say now God is sending us out again and they go out to start visiting.*
>
> *It's very hard to quantify that. I mean, you can't look at impact assessment as you've covered this, this and tick off all the boxes. But it's that dimension where you experience in the recipients that something special has happened inside them simply because they've encountered that dimension in the carer. And just the whole reverence, that's the word I've always used with our carers, that the people that you care for must feel that you reverence them, that they're sacred people, there is sacred ground, holy ground on which you are privileged to walk. So that word reverence is what for me captures that quality of difference, which brings in that God dimension, the spiritual dimension, and just the way they will talk, the gentleness, the way they will spend time it doesn't matter how long, the way they will look at that person, the way they will hear what that person is saying, that it's not just the words, might enable the carer just to go a little deeper with that same reverence so that the person can gradually lose their fears and really tell it as it is. That kind of thing when the carers are motivated with that holistic spirit dimension, then what they actually do the more professional things, take on a different quality* (Kevin Dowling, Johannesburg, 26 June 2015).

In terms of clergy, their buy-in was viewed as useful for a variety of reasons. Clergy are influential, often being the person with the highest level of education in the community. Clergy are important resources for their congregants. If clergy have the right information they may contribute positively to social development and HIV response. Clergy have a readily available audience. The result can be parishes with leaders who are sensitive to the issue of HIV and AIDS are more likely to be active in responding. As Linda Vava notes:

> *For me, I would say the faith-based message, it's a more approachable way or medium that is easily from the community's peoples once you see a Bishop or the Bishop at the church that person is the most honourable person. So, most of the communities if it's coming from the Bishops and they always believe the Bishop is everything, your reverend is the person who if he is saying something it is easily, as someone who is very honourable, so once the message is coming from the church level it is easily to reach many it's easily to be absorbed within the community. So I think for me it's better* (Linda Vava, Cape Town, 17 July 2015).

Specific roles of pastors and priests were identified including preaching, pastoral support, and counselling. One respondent commented that the association of HIV with sex means some view it as not being clean enough to preach on. This may explain respondents' comments that clergy were not putting it in their sermons: clergy may speak in the community of HIV and AIDS but not preach on it, or that one respondent could not remember more than a passing reference to HIV and AIDS. However, another respondent noted the development of a specific resource for preaching by the World Council of Churches called Preaching in Times of HIV and AIDS which enables pastors and priests to preach on the topic of HIV and AIDS. One respondent commented on the need for pastors and priests to talk about being faithful, family values, and living together. Another respondent suggested pastors need to find new ways of speaking about HIV and AIDS to combat a perceived message fatigue amongst congregants. Another area of activity by priests and pastors is that of pre-marital counselling in which they talk about testing and fidelity. However, another respondent asked how clergy could counsel someone if they were uncomfortable with their own sexuality.

Rev Herbert Moyo describes the special characteristics of pastors which are different from other secular actors:

> *There is authority, there is respect, there is availability of the minister, there is trust. In pastoral care there is this idea that ministers are pastoral figures, they also represent the presence of God in themselves. And what they say is at times taken with that understanding that they represent the prayers of God. The common language in community is men of God or women of God. When the man of God speaks, when the woman of God speaks, people listen. ... So I would say there is need for continued teaching on HIV through faith based organisations or through the clergy. It produces better results than when it is taught from a secular perspective* (Herbert Moyo, Pietermaritzburg, 3 July 2015).

Clergy also play an important role in providing pastoral support, including to those who are ill, as noted by Patterson who as mentioned earlier explains: "an average 40% of respondents in 18 African countries had contacted a religious leader about a problem at least once during the last year" (Patterson, 2011, p. 210). As Bishop Dowling notes, pastors are able to provide a very specific form of pastoral care in the laying on of hands and prayers for those who are ill:

> *I think also while the person is dying to enable pastors, as I've done so often, to touch the sick person, lay hands on them, pray with them and the family so that people see that you're not going to get, it's not a fearful thing to touch this sick person who is dying of AIDS. There's so many little things that are so important. Especially for the sick person to feel a person's hand on them. ... That time, transition to death and after death, I think the faith communities have a very special role there. And the way the pastor is, and the way he speaks, and bringing those very important values before the assembled people can be a powerful teaching moment* (Kevin Dowling, Johannesburg, 26 June 2015).

One of the ways in which priests and pastors could become better able to respond to HIV and AIDS relates to their seminary training. Respondents noted that seminary training is inadequate and that there is a need for training and education of clergy. One respondent commented that HIV is only mentioned in the section on pastoral care, while another noted that seminary must cover social issues such as HIV and AIDS.

One of the most unique activities of churches, and particularly clergy, is that they bury the dead. As Rev Paul Germond describes, burying the dead was a major activity of the churches at the height of the epidemic before antiretrovirals (ARVs) were readily available:

> *The church took enormous strain dealing with just the load of burials. The overload on the Saturday because Saturday is a big burial day in the townships, and Wednesdays were taken up with burials as well. That really if there was a labour of love in the HIV AND AIDS crisis from the churches side was to bury people* (Paul Germond, Johannesburg, 23 June 2015).

Germond also notes the potential for funerals and burials to play an important role in addressing stigma:

> *One thing the church does is bury people. And so the spirituality of death and the theology of death become really important. And I think that the ability of the church to contribute at that level is really important. And you see a lot of people turn to God and to the church in their last days. I think that's one reason the church spends so much time with dying people is that's when a lot of people face the fact that they want to resolve this part of their lives and they feel that's an important thing to do. And so I think certainly the church here in Africa that has been absolutely critical in the face of the HIV AND AIDS pandemic. And I think that has actually changed people's attitudes towards HIV AND AIDS, the fact that it's okay to be buried by the church. If the church buries you then you can't be that bad a person. Then that undermines some of the stigma. And I think a lot of that has happened* (Paul Germond, Johannesburg, 23 June 2015).

Bishop Dowling elaborates on the way in which disclosing HIV-positive status of the deceased at funerals could counteract stigma:

> *If at a funeral for example it could be a wonderful teaching moment in a good sense if the family can face that issue, that why did this person die. Years ago you could see it: young people dying, utterly strange in terms of the culture. It's just completely wrong that a young person has died, twenty one year old, nineteen year old, what caused this? And then there's the other stuff which is not healthy at all, witchcraft and so on, but if that moment if it can be used and I think communities are coming to the awareness that this has affected so many people we all know why. So it can be spoken about.*
>
> *It's a wonderful teaching moment to enable that whole group in burying this person. We know why this person has died. What additional suffering did they go through besides their sickness. And deal with the stigma and discrimination issue head-on.*

> *What is this moment calling us all to as we gather around this gravesite? It could be a beautiful moment to enable people to look at my attitudes, look at my judgements that I'm making, and so on and also to get the correct information, non-judgemental information about everything to do with this disease* (Kevin Dowling, Johannesburg, 26 June 2015).

Discussion

Based on the comments of the church leaders, clergy and lay people interviewed, three significant aspects of the churches' response to the disease emerged. First, the response is grounded in the foundations of religious institutions including their texts, the gospel message (in the case of Christian churches and FBOs), and religious discussions of the existentialist nature of life and death.

Second, churches and FBOs have institutional advantages that make their responses possible, including the respect afforded to religious leaders such as clergy and bishops, the vast number of volunteers who are part of the churches network, and the fact that churches play a key role in the funerals and burial of those who succumb to AIDS-related illnesses. Documenting and analysing these institutional advantages helps move the discussion beyond what Olivier (2014) refers to as merely anecdotal evidence.

Third, the approach of the churches is one grounded in faith and spirituality. This includes the notion that faith gives hope to those who are diagnosed with HIV, the way in which religious beliefs and faith sustain volunteers through the challenging work of helping those who are HIV-positive and/or ill with AIDS-related illnesses, and finally the way in which faith and spirituality are embedded in the actual responses to those with HIV, particularly those who are dying of AIDS-related illnesses. With reference to the first point, interviewees' comments reaffirm the evidence of Van Wyngaard (2013) that faith and spirituality are important for patients. With reference to the second point, the description by Bishop Dowling of his conversations with volunteers makes clear that their motivation is faith-based but also that their faith maintains them through this difficult work. Olivier and Clifford (2011, p. 372) comment that "... less is known about the internal, religious-specific aspects that motivate or sustain volunteers in comparison with individuals who are not religiously motivated". However, the evidence from Bishop Dowling and others goes some way to documenting the motivation and sustenance of religious volunteers. In relation to the third point, Olivier and Clifford (2011) question the presumption that religion-based activities are infused with spiritual elements. However, the discussion thus far indicates that spirituality and religious beliefs are indeed embedded in the activities of churches and church organisations.

Conclusion

This article has outlined the ways in which religious leadership, both clergy and lay leaders, perceives religious responses to HIV and AIDS to differ from secular responses, including secular organisations and government-run programmes. The perspective of religious leaders is not an objective reality. However, it highlights a cultural phenomenon in civil society responses to HIV and AIDS — spirituality — which is a premise of FBO interventions, and how this premise has overtly informed the longstanding HIV and AIDS interventions of these organisations in many African countries.

Acknowledging that in some respects, secular organisations have advantages in their programmes, for example, a greater capacity to speak of sex, sexuality, and gender relations, it is nonetheless the case that a decline in funded faith-based responses to HIV and AIDS has the potential to negatively affect the overall HIV and AIDS programming in South Africa, not simply in terms of the number of programmes available but also in terms of the quality of those programmes. This dependence on foreign aid is noted by (Burchardt et al., 2013), though they refer to civil society organisations overall, rather than religious organisations specifically. One specific area of work which is of grave concern is that of monitoring and adherence as government staff neither have the time nor the capacity to engage in these kinds of activities to the same degree as has been the case with church organisations and their staff and volunteers. In other words, people living with HIV and AIDS cannot expect the same level of ongoing monitoring and care from government ARV services as has been the case in the past through church HIV and AIDS programming. As Bishop Dowling describes it:

> *The government now claims that they have over 3 million on ARVs, the most of any country in the world. Fine but as we all know, with the government service extremely stretched in terms of personnel. In the area where I am, we know this because of our partnerships and links with the professional nurses in the government clinics and hospitals and so on.*
> *I really fear we are facing a catastrophe three or four years down the line. Because what is happening is that because of the minimal personnel resources both professional nurses, involved nurses and others, there isn't a sufficient number of these people to do proper care. So people are coming to clinics and the place is crowded even in the afternoon you're going to clinic and you'll still have a couple of hundred people who are still waiting to be seen. So all a nurse can do, and it's not to blame her in any way, all she can do is simply say here are your drugs for the next three months and then they're on their own* (Kevin Dowling, Johannesburg, 26 June 2015).

A further area which is of concern is whether churches will continue to engage in education and awareness-raising activities. Though rising HIV-infection rates suggest that there are problems, if not failures, with education and awareness-raising work, there is still a need for them both in hope of changing behaviour and to de-stigmatise the disease. Some of the major educational programmes of the churches and church organisations will no doubt fall by the wayside when funding is reduced. This does not mean that individual churches and congregations will not continue to engage in this work. However, there can be little doubt that funded programmes that develop curricula for use in sex education and prevention work, fund coordinators to facilitate this work, and train congregations to undertake this work can have a greater impact than one-off efforts by

individual clergy, volunteers, and congregations. A further major barrier churches face is an overall complacency about HIV and AIDS which has set in amongst the general public. However, the main institutional structures will continue to exist and provided clergy and lay people remain concerned about the disease there is still the possibility of continued education and awareness-raising activities.

Some forums for participation already exist between government and churches, for example, the National Interfaith Council of South Africa. However, this forum is concerned with a wide variety of issues, not just HIV and AIDS. Other more localised or provincial forums through which government and churches coordinate exist, however, respondents from this study described these forums for participation as somewhat limited in terms of their capacity to encourage genuine collaboration on government health programmes. Cardinal Wilfrid Napier noted another problem with church–government collaboration, commenting that when the collaboration is successful government wants to take all the credit (Wilfrid Napier, Durban, 7 July 2015).

What can be done to ensure the capabilities built up by the church are not lost as programmes close and/or shift to the government health programmes? This will take recognition by the South African government of the value of FBOs in responding to HIV and AIDS and an effort to improve the collaboration which already exists and build on this to find new ways of collaboration. While a difficult task, it is no doubt one which will reap great benefits.

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