



# “No more buzz”

**An extended case study of the engagement in HIV  
in the Anglican Church in Ocean View, Cape Town**

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## **Abstract**

The paper studies the degree of engagement in questions of HIV in the local Anglican Church in Ocean View, Cape Town, using a triangulation design combining participant observation, survey results and interviews. Survey results from two other parishes in the Cape Town area and from clergy in the dioceses of Cape Town and False Bay are used to extend the material and to establish wider patterns in an extended case study approach. The findings show that people in the congregation of St Clare of Assisi in Ocean View are generally aware of HIV. The “buzz” around HIV has however subsided. The congregation is not directly engaged in work relating to HIV anymore and HIV is more mentioned than talked about in the church. HIV stigma continues to pose a challenge to the response to HIV at the local level. Conceptualisations of HIV vary markedly among members of the congregation with a majority seeing HIV+ people as living positively. There is also a group that strongly associates HIV with death, dirt and filth. The results are confirmed to hold also in other parishes of the Anglican Church of Southern Africa in the Western Cape. To work towards the prevention of HIV, the local church needs to put HIV back on the agenda and continue to speak about the virus by integrating HIV perspectives into the current framework.



*To the people of St Clare of Assisi, Ocean View*



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## List of Abbreviations

AIDS	Acquired immune deficiency syndrome
ACSA	Anglican Church of Southern Africa
ART	Antiretroviral therapy
ARV	Antiretroviral
CHART	Collaborative for HIV and AIDS, Religion and Theology
FBO	Faith-based organisation
HIV	Human immunodeficiency virus
INERELA+	International Network of Religious Leaders Living with or Personally Affected by HIV and AIDS
IRHAP	International Religious Health Assets Programme
MDG	Millennium Development Goal
MSM	Men who have sex with men
PLHIV	People living with HIV
PLWHA	People living with HIV and AIDS
PMTCT	Prevention of Mother to Child Transmission
PWID	People who inject drugs
PWSS	People who sell sex
RE	Religious entity
SDG	Sustainable Development Goal
SIDA	Swedish International Development Cooperation Agency
STI	Sexually Transmitted Infection
VCT	Voluntary Counselling and Testing

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## Chapter 1 – Introduction

There was an HIV buzz, but, I don't know, this is my opinion but for me, it is quiet now. The drugs, the gangsters have kind of escalated. It's almost like, ok, we know about HIV now, so you know, carry on, live with it. It's like having high blood pressure and there is only awareness on high blood pressure day. So when it is HIV kind of memorial day you would hear about HIV and then it is just quiet again.

When world leaders agreed on a new set of goals for global development in September 2015, the sixth Millennium Development Goal (MDG), to “combat HIV/AIDS, malaria and other diseases”, was subsumed under the new third Sustainable Development Goal (SDG), to “ensure healthy lives and promote well-being for all at all ages”. While this broadening of perspective can be welcomed as a necessary acknowledgement of the complexity and interrelatedness of human health and well-being, it also harbours the risk of averting attention away from the HIV pandemic that continues to ravage around the world with an estimated 1.4 million people’s death being AIDS related in 2014.<sup>1</sup> Indeed, one of the challenges the global HIV response encounters today is to keep HIV on the agenda, in a time where there is “no more buzz” around questions of HIV.

The latest reports on HIV and AIDS are very positive about the development of the response to the pandemic. UNAIDS reported in 2015 that there was a 35% decrease in new HIV infections since 2000, a 42% decrease in AIDS-related deaths since the peak in 2004 and an 84% increase in access to antiretroviral therapy since 2010.<sup>2</sup> The optimism is shared in South Africa, which continues to be the epicentre of the pandemic with an estimated 6.8 million people living with HIV (PLHIV).<sup>3</sup> The Progress Report on the National Strategic Plan for HIV, TB and STIs (2012 – 2016) hails South Africa’s “wherewithal to take on this epidemic and to beat it”<sup>4</sup> and continues

The dark days of denialism are long gone! [...] [T]here are now more than 2.5 million South Africans on antiretroviral treatment (ART). This is a remarkable achievement and has led to a substantial increase in life expectancy.<sup>5</sup>

The Ministry of Health’s Annual Performance Plan for 2014/2015 does not even mention HIV explicitly anymore in the forewords by Minister of Health Dr. PA Motsoaledi and Director General MP Matsoso, attesting to the fact that HIV is no longer seen as the single most

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<sup>1</sup> UNAIDS, *AIDSinfo*, [website], n.d., <http://aidsinfo.unaids.org/>, (accessed 26 April 2016).

<sup>2</sup> UNAIDS, *AIDS by the numbers 2015*, Geneva, UNAIDS, 2015, p. 2

<sup>3</sup> UNAIDS, *AIDSinfo*

<sup>4</sup> South African National AIDS Council, *Progress Report on the National Strategic Plan for HIV, TB and STIs (2012 – 2016)*, Pretoria, South African National AIDS Council, 2014, p. 3.

<sup>5</sup> South African National AIDS Council, p. 3

dangerous threat to public health in South Africa. The report remarks on the “impressive strides in the implementation of HIV, TB and PMTCT<sup>6</sup> programmes” that have been made since 2009.<sup>7</sup>

However, recent statistics also show a darker side of the developments in South Africa. While the number of HIV related deaths has more than halved from 330 000 in 2010 to 140 000 in 2014, the number of new HIV infections among adults (15+) decreased by only 17.5% during the same time, to 330 000 new infections in 2014.<sup>8</sup> While fewer people are dying of AIDS-related causes, HIV continues to spread. There is therefore continued need to focus on questions of HIV prevention and to keep HIV on the agenda.

Due to the pervasiveness of the HI virus and the virus’s impact on all parts of human life, prevention necessarily needs to be carried out at many levels simultaneously; families, clinics, schools, public institutions and health organisations are all important. Another group of agents in the response to the pandemic has been religious entities (REs) in general and Christian churches in particular.<sup>9</sup> It has been argued that 30% to 70% of health services in sub-Saharan Africa are provided by faith-based organisations and institutions (FBO/FBI).<sup>10</sup> REs are contributing with care and support in both tangible and intangible ways and it is the combination of these material and spiritual aspects of religious care that distinguishes the work of FBOs from other actors’.<sup>11</sup> REs also play an important role through the effect they have on human sexuality and consequently on the level of exposure to HIV. Teachings on human sexuality and especially teachings on contraception have a direct bearing on the degree of exposure of faith communities.<sup>12</sup> REs can engage in effective education and ministry to reduce the spread of HIV, foster confidence for testing and support people throughout treatment. A necessary precondition for REs to engage with the HIV pandemic is that HIV is put on the agenda. Only where HIV is spoken of can awareness of HIV be raised and HIV prevention methods be developed.

The Anglican Church of Southern Africa (ACSA) has been recognised for its strong social commitment owing in part to the prominent role of Nobel Laureate and Archbishop Emeritus of Cape Town Desmond Tutu in the apartheid era and its aftermath. ACSA is one of the churches that have seriously engaged in questions of HIV in South Africa, both at the national and at the

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<sup>6</sup> Prevention of Mother to Child Transmission

<sup>7</sup> National Department of Health, *Annual Performance Plan 2014/15 – 2016/17*, Pretoria, National Department of Health, 2014, p. 29.

<sup>8</sup> UNAIDS, *AIDSinfo*

<sup>9</sup> Keough, L. and Marshall, K., *Faith Communities Engage the HIV/AIDS Crisis: Lessons Learned and Paths Forward*, Berkley Center for Religion, Peace, and World Affairs, Georgetown University, 2007, p. 7-9.

<sup>10</sup> African Religious Health Assets Programme, ‘Appreciating Assets: The Contribution of Religion to Universal Access in Africa’, *Report for the World Health Organization*, Cape Town: ARHAP, 2006, p. 20.

<sup>11</sup> African Religious Health Assets Programme, p. 126; G. ter Haar. ‘Religion and Development: Introducing a new debate’ in *Religion and development: Ways of transforming the world*, G. ter Haar (ed.), London, Hurst & Company, 2011, p. 20.

<sup>12</sup> See for example the discussion around condoms: W. Tyndale, ‘Religions and the Millennium Development Goals: Whose Agenda?’ in *Religion and development: Ways of transforming the world*, G. ter Haar (ed.), London, Hurst & Company, 2011, pp. 221-222.

local level. ACSA is committed to the prevention of HIV, the support of and care for PLHIV, and the eradication of HIV stigma. In the diocese of Cape Town in the Western Cape, ACSA made HIV a priority already in 2001.<sup>13</sup> The strong dedication of ACSA to break the silence around HIV and its commitment to respond to HIV and AIDS, make ACSA an interesting case for studying the long-term contribution of churches in the response to HIV and AIDS.

The main focus in this paper is on the Anglican parish of St Clare of Assisi in Ocean View, Cape Town. The current form of the parish's response to HIV and perceptions of HIV are examined through a combination of participant observation, interviews and survey responses. The emerging picture is then expanded by survey results from two other parishes in the greater Cape Town area and clergy in the dioceses of Cape Town and False Bay. This extended case study approach aims at both providing a detailed study of the local engagement and at establishing some more general insights into the current state of the response to the HIV pandemic in the Anglican Church of Southern Africa in the Western Cape.

### **1.1 Purpose and research question**

The purpose of this paper is to add to the understanding of the long-term response to HIV of the Anglican Church of Southern Africa in the Western Cape in general and in Ocean View in particular. As such the paper also makes a contribution to studies of pastoral care in South Africa and the HIV pandemic.

The research question is threefold.

- To which degree does the local Anglican Church address questions of HIV?
- How do people in local Anglican Church understand HIV?
- Which potentials and opportunities does the local Anglican Church have to respond to HIV?

All three questions are primarily raised in the current context of the parish of St Clare of Assisi in Ocean View, Cape Town. The questions are then related to a broader context and it is examined whether the results can be illustrative of the situation in other parishes of the Anglican Church of Southern Africa in the Western Cape.

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<sup>13</sup> S. Kareithi, J. Rogers and R. Mash, 'Transformation within the HIV/AIDS Context: Lessons from the Fikelela Initiative in the Diocese of Cape Town', *Transformation: An International Journal of Holistic Mission Studies*, vol. 22, no. 2, 2005, p. 107.

## 1.2 Previous research

South Africa, being the epicentre of the global HIV pandemic, is also the country that has produced most theological work on the interplay between HIV and religion.<sup>14</sup> The Collaborative for HIV and AIDS, Religion and Theology (CHART) at the School of Religion, Philosophy and Classics, University of KwaZulu-Natal, continuously works with mapping the HIV and theology field and its latest bibliography contains 3208 titles in the January 2016 version.<sup>15</sup>

The CHART publication *Religion and HIV and AIDS: Charting the Terrain* edited by Beverley Haddad (2011) provides an excellent overview over the field, ranging from the history of the HIV response to questions of public policy and the role of public statements, to the importance and impact of bible studies, systematic theology and ethics in understanding and dealing with the pandemic, to considerations of culture, stigma, sexuality and gender.<sup>16</sup> All in all, the authors find that religion has been and continues to be important in the response to HIV and AIDS. Religion has provided both tangible and intangible resources for people affected and infected by the virus and promotes better and saver lives. Still, the authors also point to the potential negative impact of religion in terms of stigmatisation, the condemnation of sexuality and the reduced use of condoms, as well as its potentially negative impact on gender relations.

The role of REs in development and public health has been recognised both within religious studies/theology and development studies. *Religion and Development: Ways of transforming the world* edited by Gerrie ter Haar (2011) introduces the topic of religion from a development studies perspective and argues for the importance of including religion and REs as partners in the development project.<sup>17</sup> An impressive mapping of REs' contribution to public health is done by the International Religious Health Assets Programme (IRHAP) at the Berkley Center for Religion, Peace & World Affairs at Georgetown University, Washington, USA.<sup>18</sup> IRHAP publications include mappings of religious health assets in Asia, Latin America and Africa and studies on epidemics such as HIV and AIDS, malaria and Ebola.<sup>19</sup> Attention has been drawn to the importance of understanding REs as possessing assets which can be employed to improve health, moving away from a perspective of needs or wants. Religious assets, networks and agency

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<sup>14</sup> S. de Gruchy, 'Systematic theological reflection on HIV and AIDS: mapping the terrain', in B. Haddad (ed.) *Religion and HIV and AIDS: Charting the Terrain*. Scottsville, South Africa: University of Kwazulu-Natal Press, 2011, p. 171.

<sup>15</sup> Collaborative for HIV and AIDS, Religion and Theology, *The Cartography of HIV and AIDS, Religion and Theology: A Partially Annotated Bibliography*, Scottsville, South Africa: University of Kwazulu-Natal, 2016.

<sup>16</sup> B. Haddad (ed.) *Religion and HIV and AIDS: Charting the Terrain*. Scottsville, South Africa: University of Kwazulu-Natal Press, 2011.

<sup>17</sup> G. ter Haar (ed.), *Religion and development: Ways of transforming the world*, London, Hurst & Company, 2011.

<sup>18</sup> The IRHAP developed out of the African Religious Health Assets Programme (ARHAP), founded in 2002 at the University of Cape Town, South Africa. For more information see:

<http://berkeleycenter.georgetown.edu/organizations/international-religious-health-assets-programme>

<sup>19</sup> For a complete list of publications see: <http://berkeleycenter.georgetown.edu/publications/all>

can fruitfully be drawn upon to promote health and well-being.<sup>20</sup> REs add to public health by not only providing tangible assets such as health care and support facilities, but also intangible assets such as volunteerism, education, behaviour change and the building of social capital.<sup>21</sup> Lipsky (2011) argues therefore, that FBOs are at least as good as NGOs at providing health services.<sup>22</sup> USAID has recognised the potential for REs to educate, to offer spiritual and institutional support, to provide prevention programmes and to address questions of HIV and gender-based violence in its *A Call to Act*.<sup>23</sup>

Still, the evaluation of REs' effect on public health and issues of HIV and AIDS has not been exclusively positive. Many scholars have highlighted the stigmatising effect REs have had in the HIV pandemic. Stigma in turn is generally seen to have detrimental effects on HIV prevention and the well-being of people living with HIV and AIDS (PLWHA) by leading to silence around issues of HIV and AIDS, denial and inhibiting voluntary counselling and testing (VCT).<sup>24</sup> Campbell, Nair and Maimane (2006) argue that stigma results from fear of infection coupled with poor information about HIV transmission, fear of poverty and the association of sexuality with immorality and sin. HIV is then often perceived as a punishment from God.<sup>25</sup> Also Liamputtong (2013) sees HIV and AIDS stigma as rooted in the association between HIV and AIDS with immorality, promiscuity, perversion, contagiousness, and death, coupled with a lack of appropriate knowledge about the virus.<sup>26</sup> Agreeing that stigma is always contextual and interrelated with social hierarchies, these authors highlight the importance of studying stigma at the local level.<sup>27</sup>

There are a number of studies that address questions of HIV, sexuality and stigma in the local South African context. Keikelame et al. (2010) conducted key informant interviews in 2010 in Cape Town, Durban, Pretoria and Johannesburg with leaders in the Anglican, Moravian, Methodist, and Presbyterian churches as well as with traditional indigenous and Muslim leaders. They find that stigma is a problem and that some religious leaders and organizations are

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<sup>20</sup> African Religious Health Assets Programme, 'Appreciating Assets: The Contribution of Religion to Universal Access in Africa', *Report for the World Health Organization*, Cape Town: ARHAP, 2006, p. 128; J. Olivier, J. R. Cochrane and B. Schmid, *ARHAP Literature Review: Working in a Bounded Field of Unknowing*, Cape Town, African Religious Health Assets Programme, 2006, p. 10.

<sup>21</sup> Olivier, Cochrane and Schmid, p. 11

<sup>22</sup> A. B. Lipsky, 'Evaluating the strength of faith: Potential comparative advantages of faith-based organizations providing health services in sub-Saharan Africa', *Public Administration and Development*, vol. 31, no. 1, 2011, pp. 25-36.

<sup>23</sup> B. Herstad, *A Call to Act: Engaging Religious Leaders and Communities in Addressing Gender-based Violence and HIV*. Washington, DC: Futures Group, Health Policy Initiative, Task Order 1, 2009, pp. 14-21.

<sup>24</sup> G. Paterson, 'HIV, AIDS and stigma: Discerning the silences' in B. Haddad (ed.), *Religion and HIV and AIDS: Charting the Terrain*, Scottsville, South Africa: University of Kwazulu-Natal Press, 2011, pp. 350-365; S. Mall et al., 'Changing patterns in HIV/AIDS stigma and uptake of voluntary counselling and testing services: The results of two consecutive community surveys conducted in the Western Cape, South Africa', *AIDS Care*, vol. 25, no. 2, 2013, pp. 194-201.

<sup>25</sup> C. Campbell, Y. Nair, and S. Maimane, 'AIDS stigma, sexual moralities and the policing of women and youth in South Africa', *Feminist Review*, vol. 83, 2006, pp.132-138.

<sup>26</sup> P. Liamputtong, 'Stigma, Discrimination, and HIV/AIDS: An Introduction' in P. Liamputtong (ed.), *Stigma, Discrimination and Living with HIV/AIDS: A Cross-Cultural Perspective*, Dordrecht, Springer, 2013, p. 3.

<sup>27</sup> Gillian, pp. 350, 360-361; Campbell, Nair and Maimane, p.133

propagating stigma, equating HIV with sin and punishment from God. Keikelame et al. also show that there is a difficulty among religious leaders to address questions of sex and sexuality even as FBOs have undertaken important action to fight stigma.<sup>28</sup> Visser and Sipsma (2013) show that HIV and AIDS is perceived in negative terms and connected to stigma by both HIV infected women and community members in Tshwane, South Africa, three decades into the epidemic.<sup>29</sup> Barney and Buckingham (2012) conducted a qualitative study of the interplay between spirituality and HIV and AIDS in a township in Johannesburg. They demonstrate the emergence of a complex picture: God and the church, ancestral spirits and bewitchment all contribute to the understanding of and coping with HIV and AIDS. They can be a positive resource in people's lives, but they can also be condemning, leading to stigmatisation and isolation. In agreement with Keikelame et al., Barney and Buckingham establish that there is a tendency to avoid HIV in the churches.<sup>30</sup> Looking at KwaZulu-Natal, Krakauer studies the Roman Catholic, Shembe and Zionist churches in two communities near Durban in his master thesis at the University of Oxford in 2004. Krakauer finds that churches are not directly involved in HIV prevention work, yet do include a discourse on sexuality in their teachings. The Catholic Church also engages in HIV care work. The four characteristics that shaped churches' HIV response are the churches' resources, organizational structure, cultural appeal, and discipline.<sup>31</sup> A more recent study on KwaZulu-Natal is Eriksson (2011), who studies HIV prevention methods and their effect on youth sexuality in the Roman Catholic Church, the Lutheran Church and the Assemblies of God in her doctoral thesis from Uppsala University. She shows that religious leaders struggle with breaking the silence around HIV and that HIV prevention messages are often ambivalent as sexuality is omitted in churches. Church attending young people, while seeing the church as an important institution, often understand church teachings as focussed mainly on abstinence and report that even though churches do engage in education, basic questions of HIV transmission remain unclear to them.<sup>32</sup>

Though there have been a number of studies on the understanding of HIV and stigma in South Africa, more work needs to be done. First, most studies have a clear geographic focus and there are only a few studies that address the Western Cape directly. Second, the empirical studies presented above span the time from 2004 to 2013. The understanding of HIV and HIV stigma

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<sup>28</sup> M. J. Keikelame et al., 'Perceptions of HIV/AIDS leaders about faith-based organisations' influence on HIV/AIDS stigma in South Africa', *African Journal of AIDS Research*, vol. 9, no. 1, 2010, pp. 63-70.

<sup>29</sup> M. Visser and H. Sipsma, 'The Experience of HIV-Related Stigma in South Africa' in P. Liamputtong (ed.), *Stigma, Discrimination and Living with HIV/AIDS: A Cross-Cultural Perspective*, Dordrecht, Springer, 2013, pp. 205-227.

<sup>30</sup> R. J. Barney and S. L. Buckingham, 'HIV/AIDS and spirituality in a South African township: a qualitative study', *Journal of Religion & Spirituality in Social Work: Social Thought*, vol. 31, no. 1-2, 2012, pp.51-66.

<sup>31</sup> M. Krakauer, 'Churches' Responses to AIDS in Two Communities in KwaZulu-Natal, South Africa' Master Thesis, Oxford University, 2004.

<sup>32</sup> E. Eriksson, 'Christian Communities and Prevention of HIV among Youth in KwaZulu-Natal, South Africa', Acta Universitatis Upsaliensis, *Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine 684*, Uppsala, 2011.

changes in relation to the availability of information and treatment options.<sup>33</sup> It is therefore interesting to take a new look at these topics. Finally, very few studies deal explicitly with the Anglican Church of Southern Africa. The only study in the CHART database containing the term “Anglican Church” in its title or abstract is a study by Mash and Mash (2012) on the Anglican Church’s youth peer education project *Agents of Change* at the Fikelela AIDS project in the Cape Town diocese.<sup>34</sup> To date there has been no publication specifically on the engagement in HIV in the Anglican Church in South Africa. The present study aims to address this gap.

### 1.3 Theory

In a sense, the church functions through language. Preaching and proclamation, teaching and messaging, reading and prayer are all language acts. Language informs beliefs, opinions and thought and thus shapes perception. Perception in turn entails an understanding of the world which impacts on behaviour such as HIV prevention.

This understanding of the relationship between language, perception and behaviour is based on a constructivist stance which underlies this paper – the belief that knowledge is formed by social conditions and relations. In the investigation of HIV perceptions there are no givens and no single references for truth.<sup>35</sup> Knowledge is produced in social contexts and shaped by social relations. The focus of this paper is therefore on understanding and mapping rather than on causal explanation. Mapping refers here to the laying bare or making clear of the ideas surrounding HIV.

#### ***Clarification of concepts***

The term *Anglican Church* refers throughout the entire paper to the Anglican Church of Southern Africa. The *Anglican Communion* is the wider group of Anglican churches worldwide. *Religious entities* (REs) are all organisations whose activities are informed by religion and *faith communities* the people attached to these entities. The term the *church* without further specification refers to the theological concept of the universal church, that is, the body of all believers. The *local church* indicates the embodiment of the universal church in a specific local context. Lastly, the plural *churches* denotes the grouping of individuals denominations.

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<sup>33</sup> M. Roura et al., “Just like fever”: A qualitative study on the impact of antiretroviral provision on the normalisation of HIV in rural Tanzania and its implications for prevention’, *BMC International Health and Human Rights*, vol. 9, no. 22, 2009, pp. 1-10; Mall et al. pp. 194-201

<sup>34</sup> R. Mash and R. J. Mash, 'A quasi-experimental evaluation of an HIV prevention programme by peer education in the Anglican Church of the Western Cape, South Africa', *BMJ Open*, vol. 2, no. 2, 2012, pp. 1-8.

<sup>35</sup> J.S. Jensen, ‘Epistemology’ in M. Stausberg and S. Engler (ed.), *The Routledge Handbook of Research Methods in the Study of Religion*, Oxan, Routledge, 2011, p. 42.

As indicated above, language is understood to inform the mental pictures people hold of the world. Language is not only expressive of these concepts, it is also formative, in the sense that repeated language use can shape and reshape concepts. The concept of God, for example, is formed in language and constantly reformed in language through God talk, the speaking about God. In the same way the concept of HIV is formed and reformed through *HIV talk*. For the purpose of this paper, perception is understood as more than mere sensation.<sup>36</sup> Perception entails concepts to render sensations intelligible and speakable. A bus stop is only a bus stop once a person holds the concept of a bus stop. Conceptualisation is the shaping and reshaping of concepts and complexes of concepts and is distinguished from perception by the degree of reflection entailed. A person can both perceive and conceptualise HIV as a punishment from God. However, the perception is based on concepts that are largely formed in a person's context, while the conceptualisation builds on active reflection and thought processes on the part of the concept holder. The degree of consciousness in reflection can vary, and conceptualisation here includes understanding informed by unintentional reflection which occurs in everyday life thought and conversations. As such, the distinction between perception and conceptualisation is blurry and entails a difficulty in distinguishing where perception ends and conceptualisation starts.

Importantly, both perceptions and conceptualisations of HIV can remain fragmentary and incoherent. It is possible, for example, to perceive or conceptualise HIV as a punishment from God and simultaneously as a disease that befalls the innocent. Perception and conceptualisation work in analogous ways by impacting the way in which people understand reality and therefore also the behavioural options available to them.

Understanding HIV from within a scientific, religious or cultural framework radically alters the behavioural responses. Depending on whether a person understands the cause of HIV as a virus transmission, a punishment from God or bewitchment, different prevention strategies are chosen. Also different treatment options are then considered, such as antiretroviral therapy (ART), prayer and repentance, or healing and the fighting of evil spirits.<sup>37</sup>

Perceptions and conceptualisations of HIV can translate into HIV stigma, defined as an attitude towards someone on the basis of perceived differences and the individual's deviation from social norms such as morality, purity, chastity, health and prosperity.<sup>38</sup> These attitudes are contextual, based on a complex set of social, cultural, religious, racial, gendered, sexual and historical aspects.<sup>39</sup> Stigma manifests itself in actions such as verbal abuse, gossip, and the

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<sup>36</sup> See the discussion in D. O'Brien, 'The Epistemology of Perception', *Internet Encyclopedia of Philosophy: A Peer-Reviewed Academic Resource*, [website], n.d., <http://www.iep.utm.edu/epis-per/>, (accessed 13 May 2016).

<sup>37</sup> C. Benn, 'The influence of cultural and religious frameworks on the future course of the HIV/AIDS pandemic', *Journal of Theology for Southern Africa*, vol. 113, 2002, p. 3-18.

<sup>38</sup> P. Liamputtong, pp. 1-3

<sup>39</sup> Olivier, Cochrane and Schmid, p. 47

distancing from PLWHA. When stigma is translated into behaviour it is best described as discrimination.<sup>40</sup> The discrimination experienced by PLWHA has also been called *enacted stigma*. This is distinguished from *internalised stigma*, the endorsement of negative beliefs and feelings associated with HIV and AIDS that are directed toward the self. Lastly, the expectation of stigma in the future is referred to as *anticipated stigma*.<sup>41</sup>

### ***HIV talk, HIV stigma and HIV prevention***

One of the social contexts in which concepts and understanding are formed is the local church. In South Africa the local church is often seen as an important place of information.<sup>42</sup> As such, churches play a role in the perception and conceptualisation of HIV by engaging in HIV talk – the addressing of issues connected with HIV and AIDS in language.

Stigma in its three forms has not only direct bearing on the quality of life of PLWHA, but also on HIV prevention. Stigmatized persons often employ coping strategies such as secrecy, denial, deception and social withdrawal in order to avoid rejection.<sup>43</sup> Stigma is a barrier to voluntary testing and counselling (VTC).<sup>44</sup> With the importance of ‘knowing one’s status’ in the pandemic, obstacles for testing add to the spread of the virus as people are less likely to make the necessary prevention efforts and seek treatment. Stigma also impacts on the willingness of PLWHA to access health services and adhere to treatment.<sup>45</sup> Treatment in turn impacts on prevention in two ways. First, appropriate anti-retroviral drugs can reduce the viral load of PLHIV to such a degree that the probability of passing on the virus to a sexual partner becomes minimal.<sup>46</sup> Second, treatment is correlated with the normalization of HIV within socio-cultural contexts.<sup>47</sup> Normalisation reduces the stigma attached to HIV by altering the perception of HIV as a deviation from the norm, and thus enables people to access health service without fear of deprivations. In the absence of treatment however, PLHIV are susceptible to opportunistic diseases which negatively impact PLHIV’s health and well-being. As health deteriorates and the infection and its consequences become visible, fear of contagion and a discourse of blame set in further adding to HIV stigma and isolating PLHIV.

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<sup>40</sup> Liamputtong, p. 3-4

<sup>41</sup> V.A. Earnshaw and S.C. Kalichman, ‘Stigma Experienced by People Living with HIV/AIDS’ in P. Liamputtong (ed.), *Stigma, Discrimination and Living with HIV/AIDS: A Cross-Cultural Perspective*, Dordrecht, Springer, 2013, pp. 31-32.

<sup>42</sup> Schmid, p. 92

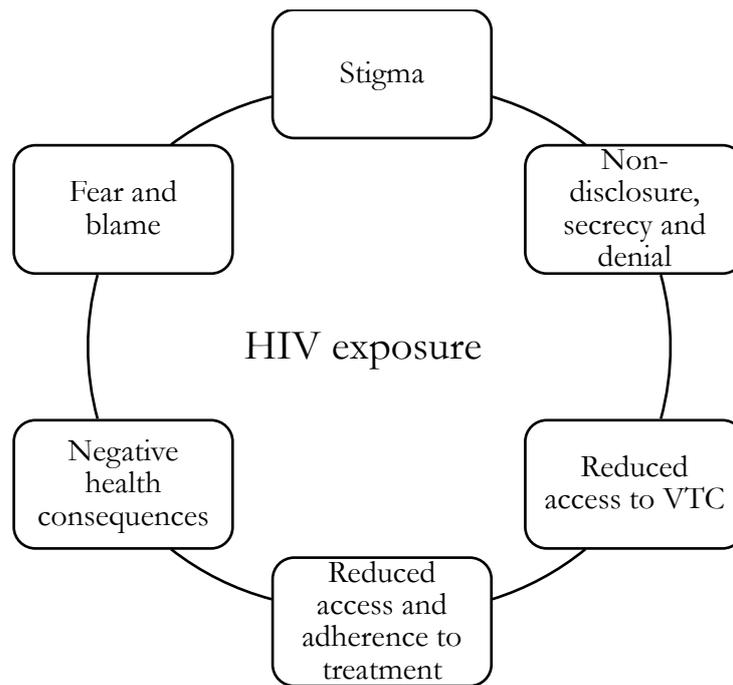
<sup>43</sup> M. Greeff, ‘Disclosure and Stigma: A Cultural Perspective’ in P. Liamputtong (ed.), *Stigma, Discrimination and Living with HIV/AIDS: A Cross-Cultural Perspective*, Dordrecht, Springer, 2013, p. 73.

<sup>44</sup> Mall et al., pp. 194-201

<sup>45</sup> P. Peretti-Watel et al., ‘Management of HIV-related stigma and adherence to HAART: Evidence from a large representative sample of outpatients attending French hospitals’, *AIDS Care*, vol. 18, no. 3, 2006, pp. 254–261; M. J. Keikelame et al., p. 67

<sup>46</sup> Messer, p. 385

<sup>47</sup> M. Roura et al., pp. 1-10.



**Figure 1: Stigma and HIV exposure**

The relation between stigma and HIV exposure is illustrated in Figure 1. Stigma is rooted in language, and specifically in the way HIV is addressed and referred to. By reducing disclosure, VTC and treatment, HIV stigma adds to the spread of the virus and leads to a deterioration in health. As people experience disease and sickness they are ostracised by the community and a discourse of blame or fault sets in, adding to the HIV stigma.<sup>48</sup>

As stigma is rooted in conceptions of the normal and the deviant, stigma can be broken by information, openness and understanding, which lead to the normalisation of HIV. The importance for REs to engage questions of HIV openly and to break the silence surrounding HIV, and especially sexuality, has therefore been repeatedly addressed.<sup>49</sup> Speaking openly about HIV and AIDS reduces stigma, increases the uptake of VTC, increases the engagement in treatment and makes it possible for people to more accurately assess their own exposure.<sup>50</sup>

Disclosure is another mechanism to bring about normalisation and public self-disclosure is found to be negatively correlated with HIV stigma.<sup>51</sup> Self-disclosing HIV+ individuals can then act as positive role models further normalising HIV and giving hope to people infected with and affected by the virus.

<sup>48</sup> Benn, p. 9; World Council of Churches, 'HIV Prevention: Current Issues and New Technologies', *Contact*, no. 182, 2006, p.23; A. Ragnarsson, H.E. Onya and L.E. Aarø, 'Young people's understanding of HIV: A qualitative study among school students in Mankweng, South Africa', *Scandinavian Journal of Public Health*, vol. 37, no. 1-2, 2009, p. 104.

<sup>49</sup> B. Herstad, p. 14; Olivier, Cochrane and Schmid, p. 46; Keikelame et al., pp. 63-70; Denis, p. 68

<sup>50</sup> Mall et al., pp. 194-201; Roura et al, pp. 1-10; Keikelame et al, pp. 67-68

<sup>51</sup> R. Smith, K. Rosetto, and B. L. Peterson, 'A meta-analysis of disclosure of one's HIVpositive status, stigma and social support', *AIDS Care*, vol. 20, no. 10, 2008, pp. 1266–1275.

## 1.4 Method

The theoretical discussion above informs the research design, choice of method and data generation. Data and theory are closely related, in that theory shapes the categories and concepts, such as stigma, used to create the material.<sup>52</sup> The study relies on a triangulation design in which both methods and data are mixed. The paper draws on participant observation, semi-structured interviews and survey answers. While data generation was concentrated in one geographic location, aligning the study with a case study approach, data was also collected in other contexts as a means to corroborate the research findings. As such, the investigation is based on an *extended case study* approach. All methods were used simultaneously (single-phase timing). While other contexts are used to establish validity and general patterns beyond the case in focus, the study does not as such involve a comparative method.

While the methods chosen are traditionally associated with both qualitative (participant observation, interviews) and quantitative (survey) approaches, the study aligns more closely with a qualitative design. The different methods do not strictly complement each other, but are rather seen to contribute to the same data set with the survey as a quantitative method also generating qualitative data. This set-up has been described as a transformation model within triangulation designs. Transformation allows the data to be mixed during evaluation and analysis and makes it possible to integrate the interview and survey data sets.<sup>53</sup>

### ***Participant observation***

The first method employed was participant observation. The degree of participation was moderate, in which participation is almost complete in activities, but the researcher does not completely participate in the culture.<sup>54</sup> Being present and participating in the congregation's services allowed direct observation of the topics addressed and the social relations in the parish of St Clare of Assisi in Ocean View. The strength of participant observation is the immediacy of the observations as well as the possibility to observe complex patterns of behaviour. In line with Harvey's (2011) recommendations, an attempt was made to be present as much as possible in the parish, to build rapport, practise *epoché*<sup>55</sup>, to be empathic and to pay attention.<sup>56</sup> Due to the importance of being present participant observation was limited to one parish. One of the

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<sup>52</sup> M. Stausberg and S. Engler, 'Introduction: Research methods in the study of religion\'s' in M. Stausberg and S. Engler (ed.), *The Routledge Handbook of Research Methods in the Study of Religion*, Oxon, Routledge, 2011, pp. 9-11.

<sup>53</sup> J.W. Creswell, 'Choosing a Mixed Method Design' in J.W. Creswell and V.L.P. Clark, *Designing and conducting mixed methods research*, London, Sage Publications, 2007, pp. 62-67.

<sup>54</sup> B. Kawulich, 'Participant Observation as a Data Collection Method', *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, vol. 6, no. 2, 2005.

<sup>55</sup> *Epoché* is the conscious bracketing out of the researcher's prior assumptions, ideologies and expectations.

<sup>56</sup> G. Harvey, 'Field research: Participant observation' in M. Stausberg and S. Engler (ed.), *The Routledge Handbook of Research Methods in the Study of Religion*, Oxon, Routledge, 2011, pp. 218-232.

limitations of participant observation is that it cannot be guaranteed that the researcher understands what s/he sees or whether the researcher understands that s/he understands.<sup>57</sup> Given different frames of reference, languages, experiences, history and knowledge any given observation can be perceived differently by the researcher from the rest of the participants. Also, if the number of observations is small, there is no assurance that the observations represent the normal or usual situation. Although this limits the usefulness of participant observation, it does not completely invalidate it as a useful method.

### **Surveys**

The second method in the study was a self-administered survey (Annex I). Following the advice by Navarro-Rivera and Kosmin (2011)<sup>58</sup>, a short survey with ten items was created and distributed in paper form in three Anglican congregations and sent electronically to 216 Anglican clergy in the dioceses of Cape Town and False Bay. To align as closely as possible with the interview method, the questionnaire contained seven open free-text questions. Four questions included a simple yes/no response and a scale item was added to indicate the perception of HIV pervasiveness. In surveys there is a potential problem with social desirability, the tendency of respondents to answer what they think is expected of them.<sup>59</sup> To guard against this, questions were phrased objectively and an emphasis was put on the opinions, thoughts and feelings of the participants.

The survey adds to the material by reaching a larger number of people. Also there is a possibility that people are more honest in self-administered surveys than in face-to-face interviews.<sup>60</sup> As such, the survey extends the interviews well. Potential drawbacks are that people still might not be honest and that questions and answers can be misunderstood by the participant and the researcher, so that answers remain unclear or ambiguous. There is also a difficulty with missing answers to specific questions.<sup>61</sup> Especially from the perspective of quantitative methods, sampling is an issue. As the survey was self-administered it cannot be assumed that it is a random sample. Rather, it is conceivable that those most (least) affected by HIV would be least likely to take the survey as they do not want to be confronted with questions of HIV and AIDS. The data set can therefore not be used for statistical analysis with the goal of generalisation. The problem is less pertinent when the material is used to add to the data gathered through qualitative interviews.

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<sup>57</sup> Harvey, p. 233.

<sup>58</sup> J. Navarro-Rivera and B.A. Kosmin, 'Surveys and Questionnaires' in M. Stausberg and S. Engler (ed.), *The Routledge Handbook of Research Methods in the Study of Religion*, Oxan, Routledge, 2011, pp. 408-409.

<sup>59</sup> Navarro-Rivera and Kosmin, p. 410

<sup>60</sup> Navarro-Rivera and Kosmin, p. 406

<sup>61</sup> Navarro-Rivera and Kosmin, pp. 398, 406

## *Interviews*

The last method was semi-structured interviews. Qualitative interviews result in complex and nuanced data and are a good means to understand people's thoughts, beliefs, ideas and conceptions.<sup>62</sup> The method of qualitative interviews is in line with the constructivist epistemological understanding of knowledge as something produced, interpreted and constructed. As interviews are best suited to generate data on HIV perceptions and conceptualisations, interviews were used as the primary method. A stratified sampling strategy was employed based on age and gender within the parish of Ocean View. Interviewees were either directly contacted or declared their willingness to participate in an interview as part of the survey. Interviews were held in accordance with an interview guide (Annex II), which specified the main questions and themes and was closely related to the survey. Relevant parts of the interviews were then transcribed and the interview material first coded and subsequently categorised to arrive at common themes and conceptions. The first set of transcriptions, coding and categorisation was made after six interviews. After that interviews were continuously transcribed and coded. In a second step, the same was done with the survey material. The categories could then be compared and combined to form a more extensive material.

To determine the sufficient size of the sample theoretical saturation was used, which occurs if interviews add nothing essentially new to the issue in question.<sup>63</sup> Davidsson Bremborg (2011) reports that if the research question does not involve comparison, the group is rather homogenous, and the domain of inquiry is well defined, twelve interviews are generally enough to reach theoretical saturation.<sup>64</sup> All three conditions apply for the present purpose. Theoretical saturation was assumed to have been reached when no new codes emerged during coding. This happened after ten interviews. It is important to remember however, that theoretical saturation remains theoretical. That is, saturation was reached within the group being willing to partake in an interview. It remains fully possible that there is a larger group of people whose opinions could not be accessed as they were unwilling to engage in the research project.

While semi-structured interviews are a potentially powerful method, there are a number of limitations. First, it remains unclear whether results can be generalised, even though this concern is lessened by theoretical saturation. Second, people might not be fully forthcoming in a face-to-face interview. Last, important questions might remain unasked, limiting the material to the interviewer's perception of the issues at hand. Still, for the present purpose qualitative interviews are a suitable method.

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<sup>62</sup> A. Davidsson Bremborg, 'Interviewing' in M. Stausberg and S. Engler (ed.), *The Routledge Handbook of Research Methods in the Study of Religion*, Oxon, Routledge, 2011, pp. 310-311.

<sup>63</sup> Davidsson Bremborg, p. 314.

<sup>64</sup> Davidsson Bremborg, p. 314

While each method has its particular limitations and drawbacks, the mixed methods approach allows for the different strength of the associated methods to be combined in the generation of data. The detailed and complex understanding of interviews is extended with the inclusion of a larger group of individuals through the survey, and the potential of distortions partially corrected by participant observation. The triangulation approach is therefore well fitted to generate the material for this study.

### ***Reliability, validity, and generalizability***

Stausberg and Engler (2011) suggest reliability, validity, and generalizability as criteria for evaluating research.<sup>65</sup> As these are traditionally associated with quantitative research, other criteria suggested for qualitative research include credibility, authenticity, confirmability and transferability as well as accountability, caring, dialogue and reflexivity or objectivity, impartiality, honesty, reflexivity and self-criticism.<sup>66</sup> Even as reliability, validity, and generalizability are associated with the positive research paradigm, they can still inspire a discussion within other research paradigms and are therefore used here.<sup>67</sup>

Reliability addresses the issue of whether measurements are consistent or stable. Participant observation is susceptible to differences in perception, understanding and interpretation and is therefore only limitedly reliable. Reliability is better in interviews, though also face-to-face interviews are not totally reliable. The same question asked in two different settings, by two different persons or at two different points in time can generate different answers, even if the differences could be expected to be small. Surveys are generally seen as reliable methods being least dependent on the person and the context of the researcher. The use of mixed methods in triangulation is then enough to establish reliability.

Validity concerns the question of whether one measures what one thinks one measures. In line with the constructivist theoretical underpinning, methods are understood to be performative in that methods in themselves create a specific description of reality rather than making a stable pre-existing description available.<sup>68</sup> An interview or survey question creates a mental image that literary puts a thought in a person's mind. It is possible that the person would never have produced that thought or made that connection if it wasn't for the question. The concept of validity becomes therefore complicated. If there is no stable reality out there to be captured, validity needs to be recast. For the present purpose, validity denotes the extent to which methods

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<sup>65</sup> Stausberg and Engler, p. 7-9

<sup>66</sup> Stausberg and Engler, p. 7-9; Jensen, p. 49

<sup>67</sup> N. Golafshani, 'Understanding Reliability and Validity in Qualitative Research', *The Qualitative Report*, vol. 8, no. 4, 2003, pp. 597-607.

<sup>68</sup> M. Stausberg and S. Engler, 'Introduction: Research methods in the study of religion\'s' in M. Stausberg and S. Engler (ed.), *The Routledge Handbook of Research Methods in the Study of Religion*, Oxan, Routledge, 2011, p. 5.

are able to establish an acceptable representation of the concepts under investigation. With this definition of validity surveys become the least valid as it cannot be guaranteed that the survey contained the most relevant questions or that questions were understood as intended. Semi-structured interviews establish validity by allowing the interviewee and the researcher to take the interview to the salient issues. Also participant observation is valid in this regard, as observation can be focussed to attend to the necessary performances.

Lastly, generalisability is foremost a goal of quantitative studies. The present paper does not attempt to establish general patterns of thought for a larger population. Nonetheless, the triangulation approach of an extended case study, drawing on data from several sources, allows for the corroboration of the case study findings with a wider context and thus gives an indication of HIV perceptions and conceptualisations even beyond Ocean View.

### ***Reflexivity***

Within especially feminist methodologies it has been recognised that the researcher has power as the author and possessor of special knowledge.<sup>69</sup> This becomes particularly challenging when a researcher aims to represent others. Here the researcher's own views and sensitivities become a concern.<sup>70</sup> Calls for greater reflexivity on the part of the researcher have therefore proliferated.<sup>71</sup>

When I was in South Africa to collect the material for this study I was a 29-year old German man living and studying in Sweden. I come from a middle-class background and had been married to a woman just a little longer than half a year. All this mattered when I met people in Ocean View and other parishes. My position as a white European set me into the context of South African history with apartheid being acutely remembered. In many regards I remained an outsider who was allowed to enter for a short while into the lives of the people I met. I have tried my best to be open and to bracket out my own understanding and conceptualisation in an attempt to represent the material as truthfully as possible. Yet, I acknowledge that all my representations are shaped by my position and context and are therefore not objective in a strict sense.

### ***Ethical considerations***

This study is based on the belief that language matters. Considered use of language can strengthen the response to HIV and AIDS, while inconsiderate language might add to stigmatisation. Care has therefore been taken to follow the UNAIDS recommendations for

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<sup>69</sup> M.J. Neitz, 'Feminist methodologies' in M. Stausberg and S. Engler (ed.), *The Routledge Handbook of Research Methods in the Study of Religion*, Oxan, Routledge, 2011, pp. 57.

<sup>70</sup> W.C. Roof, 'Research design' in M. Stausberg and S. Engler (ed.), *The Routledge Handbook of Research Methods in the Study of Religion*, Oxan, Routledge, 2011, pp. 75-77.

<sup>71</sup> Stausberg and Engler, pp. 7-9; Jensen, p. 49; Neitz, p. 55

language use.<sup>72</sup> The only deviation from the UNAIDS guidelines is the term people who sell sex (PWSS) which is used instead of sex worker.<sup>73</sup>

An application for the field study was accepted by the Faculty of Theology at Uppsala University as part of the Swedish International Development Cooperation Agency's (SIDA) Minor Field Study programme. Consent for the participant observation, interviews and paper surveys was obtained from the rector of each parish. Interview and survey participants were informed about the objectives of the study and the use and confidentiality of their data. It was also stressed that participation is voluntary and can be withdrawn in part or in full. Interviewees were also informed that an anonymised version of the transcript of their interview can be made available for the validation of research findings.

Since the paper addresses potentially sensitive issues, some questions were not directly asked in interviews, such as questions relating to the participants' HIV status, sexuality or medical history. Instead, participants were given the opportunity to disclose as much information as they felt comfortable with. Even though this can possibly limit the material, it was deemed necessary out of respect for the dignity and integrity of the participants.

This study entails the telling of another's story and attention has therefore been paid to questions of representations. An attempt is made to on the one hand be honest and to describe the material as it is and on the other hand to focus on potentials and opportunities, assets and agency, instead of concentrating on wants and shortcomings. As such, it is hoped that people cannot only see themselves in this account, but also that the description can add to the response to HIV and AIDS on the local level.

Lastly, scholarly research should add value to the community. The material presented here is as much that of all participants as it belongs to the researcher. To meet this requirement all participants in this study were offered to receive an electronic copy of the paper upon completion.

## 1.5 Material

The material was collected during an eight weeks SIDA financed Minor Field Study in the greater Cape Town area between March 18 and May 17, 2016. The material consists of three distinct parts: participant observation, survey answers and face-to-face interviews.

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<sup>72</sup> UNAIDS, *UNAIDS Terminology Guidelines*, 2015, p. 3

<sup>73</sup> See the discussion in S. Ditum, "Why we shouldn't rebrand prostitution as "sex work", *New Statesman*, 1 December 2014, <http://www.newstatesman.com/politics/2014/12/why-we-shouldnt-rebrand-prostitution-sex-work>, (accessed 13 May 2016).

### ***Participant observation***

During the field study material was gathered through participant observation in the parish of Ocean View: St Clare of Assisi. The observations consist of eight services held in the congregation on Sunday mornings (8.00 o'clock), Wednesday morning (9.30 o'clock) and Wednesday evening (19.00 o'clock). One of the Wednesday morning services was a healing service. Healing services are held on the first Wednesday every month. Sunday morning services were usually 90 minutes long, while other services were generally about an hour. Attendance at the Sunday morning service was between 290 and 360 people. Wednesday morning attendance was 70 on average and 50 on Wednesday evenings. After each occasion observations were written down in a field study diary to ensure rich descriptions.

### ***Survey answers***

The second part of the material consists of survey answers. The survey consisted of 10 items, most of which were open free-text questions (see Annex I). Question 1 asked participants for rudimentary personal information, while questions 2-4 aimed at establishing whether HIV was perceived as being an issue in the congregation and in people's lives. Questions 5-7 inquired whether HIV was talked about. Lastly, questions 8-10 targeted HIV perceptions and conceptualisations. An electronic version of the survey was sent to 216 clergy in the dioceses of Cape Town and False Bay. A paper version was distributed in three parishes in the greater Cape Town area; St Clare of Assisi, Ocean View, Christ Church, Constantia and Christ the Saviour, Letegeur.

In total 73 respondents completed the survey. The majority of surveys came from Ocean View (32). The sample sizes from Constantia, Letegeur and the online survey were roughly similar with twelve, fifteen and fourteen returned surveys, respectively. The total sample comprises clergy (15), lay leaders (13) such as lay ministers, parish councillors, wardens, confirmation instructors and Sunday school teachers, and parishioners (24). The remaining respondents did not report their role in the congregation. The female/male ratio was 47 to 24 which could be explained by the fact that generally more women attend church. Age was fairly evenly distributed ranging from 15 to 94 years. Splitting ages into intervals of ten, each age group up to 80 years was represented by at least three responses. The average age was 50 years. All in all, the survey material is spread over a number of dimensions and can therefore be believed to represent a variety of opinions and experiences.

## *Interviews*

Lastly, a series of face-to-face semi-structured interviews was conducted to obtain a deeper insight into the understanding of and attitudes towards HIV. A total of 10 interviews were held with clergy, lay leaders and parishioners from the parishes of Ocean View: St Clare of Assisi, Lentegur: Christ the Saviour and Constantia: Christ Church. Interviews were on average 54 minutes long. The interviews were held at the local Anglican Church (4), at people's private homes (5) or office (1). One interview was held as a group interview with three participants. Three of the interviews were done in connection with the survey and aimed to elaborate on the survey answers. One interview was conducted with a key informant from Fikelela AIDS project, a diocesan organisation of the diocese of Cape Town specialising in questions of HIV and AIDS. All but one interview were audio-taped. Subsequently the relevant parts were transcribed through repeated listening, coded and categorised. The interview participants aged between 33 years and 63 years. In total seven women were included and five men. Most participants were from the parish of St Clare of Assisi. All interviewees, besides the coordinator of the Fikelela AIDS project Mrs Beverly Hendricks, remain anonymous and are only identified by short alphanumeric strings. Interview transcripts can be requested from the author for reasons of research validation.

## *Limitations*

While the triangulation method ensures that the material is rich in variation, it needs to be iterated that the material cannot necessarily be seen to be representative of the entire population. Both the survey and the interviews were based on a form of self-selection in which participants voluntarily engage in the research project. It is conceivable that there remains a group of people whose opinions and experiences could not be accessed and who stay invisible in this study. Specifically, the more in line with general expectations an individual's sentiments are, the more comfortable is the individual to disclose her or his beliefs. It is thus plausible that more distinctive attitudes are harder to record and continue to escape the current research project.

Another limitation relates to language and culture. Interviews and surveys were held in English which is neither the author's native language nor generally that of the participants. While the use of a common language made understanding possible, problems of translation and interpretation remain. These are compounded by differences in cultural references which necessarily impact on interpretation. It can therefore not automatically be assumed that what was said is what was understood.

## 1.6 Disposition

After this introductory chapter follows a brief background in chapter 2. The background elaborates on the history of the HIV and AIDS response in South Africa in general before turning to the response of the Anglican Church. Chapter 2 closes with a short description of the different neighbourhoods that form part of this study. The remainder of the paper is thematically structured. Chapter 3 addresses the local Anglican Church's engagement with HIV and is largely descriptive in nature. Questions of HIV awareness, HIV talk and HIV works are addressed in order. The next chapter takes a closer look at the perceptions and conceptualisations of HIV. The focus is here on the identification of specific groups being especially exposed to HIV, on questions of responsibility and blame and lastly on stigma. Chapter 5 on the potentials and opportunities of the local church to respond to the HIV pandemic draws some practical implications from the analysis. The focus is on assets and agency and the ways in which the church can contribute to diminish HIV stigma with its implications for HIV prevention. Finally, chapter 6 concludes.

## Chapter 2 – Background

The official response to the HI virus was slow in South Africa. While HIV began to spread in the late 1980s and throughout the 1990s, the end of apartheid and the political turmoil it entailed had political leaders focussed on other political and social issues. President Mbeki, in office 1999–2008, denied the impact HIV had on South Africa and refused to scale up treatment programmes. A first roll out of antiretrovirals (ARVs) was only possible after considerable pressure from the world community in 2004.<sup>74</sup> Since then the government has worked on an active response to the pandemic. Treatment was rolled out on a larger scale under president Zuma, reaching about 2.3 million people in 2013, an increase from only roughly 350 000 in 2007.<sup>75</sup> Controversy over the political response to HIV remains however, with president Zuma being strongly criticised for his remark that showering can reduce the risk of contracting HIV.<sup>76</sup>

The main mode of HIV transmission in South Africa remains heterosexual intercourse.<sup>77</sup> Key determinants of transmission are condom use, knowledge of HIV and AIDS, HIV testing, early sexual debut, male circumcision, the number of sexual partnerships, and HIV stigma and

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<sup>74</sup> M. Visser and H. Sipsma, 'The Experience of HIV-Related Stigma in South Africa' in P. Liamputtong (ed.), *Stigma, Discrimination and Living with HIV/AIDS: A Cross-Cultural Perspective*, Dordrecht, Springer, 2013, p. 206.

<sup>75</sup> South Africa National AIDS Council, p. 18

<sup>76</sup> n.a., 'SA's Zuma 'showered to avoid HIV'', *BBC News*, 5 April 2006, <http://news.bbc.co.uk/2/hi/africa/4879822.stm>, (accessed 7 May 2016)

<sup>77</sup> National Department of Health, *The 2011 National Antenatal Sentinel HIV & Syphilis Prevalence Survey in South Africa*, Pretoria, Department of Health, 2012, p. ii.

discrimination.<sup>78</sup> The latest available statistics show positive trends for ART availability, the HIV incidence rate, and mother-to-child transmission.<sup>79</sup> While the HIV prevalence rate is still increasing, the increase has been attributed to the longer life expectancy of PLHIV on ART.<sup>80</sup>

Religious entities (REs) were quicker than the government to respond to the pandemic. While the early religious literature emphasised HIV as a punishment from God and advocated a return to a moral way of life, REs and especially the mainline churches have since abandoned that stance.<sup>81</sup> Instead, churches started to publicly call for engagement in the HIV pandemic, statements that have positively influenced the perception of HIV and AIDS.<sup>82</sup> Also the Anglican Church of Southern Africa (ACSA) issued a number of statements as part of the Anglican community. The Anglican Communion across Africa affirmed on August 22, 2002 that

We are living with AIDS. As the body of Christ, confronted by a disaster unprecedented in human history, we share the pain of all who suffer as a result of AIDS. Faced by this crisis, we hear God's call to be transformed. We confess our sins of judgement, ignorance, silence, indifference and denial.<sup>83</sup>

The statement commits the Anglican Church to “breaking the silence in order to end all new infections”, to “educating ourselves at every level within the Church”, to “confronting poverty, conflict and gender inequalities”, to “ending stigma and judgement”, and to “holding ourselves accountable before God and the world”.<sup>84</sup> This commitment is iterated by other statements from within the Anglican Communion that assert the importance of fighting stigma and stress that “AIDS is not a punishment from God”.<sup>85</sup> ACSA takes up the sentiment in the wider Anglican community in its mission statement where the importance of acting is stressed and the concern with health and the response to HIV and AIDS, malaria and tuberculosis is part of the priorities in the mission statement.<sup>86</sup>

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<sup>78</sup> Shisana, O. et al., *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012*, Cape Town, HSRC Press, 2014, p. 3-5.

<sup>79</sup> South African National AIDS Council, pp. xiv-xv, 4

<sup>80</sup> South African National AIDS Council, p. 4

<sup>81</sup> Denis, pp. 60-61; Manda, D.L., ‘Comparative ethics and HIV and AIDS: Interrogating the gaps’ in Haddad, B. (ed.) *Religion and HIV and AIDS: Charting the Terrain*. Scottsville, South Africa: University of Kwazulu-Natal Press, 2011, pp. 201-202.

<sup>82</sup> Olivier, Cochrane and Schmid, p. 41; Fredriks, M., ‘Statements by religious organisations on HIV and AIDS: Intersecting the public realm’ in Haddad, B. (ed.) *Religion and HIV and AIDS: Charting the Terrain*. Scottsville, South Africa: University of Kwazulu-Natal Press, 2011, p. 121.

<sup>83</sup> Anglican Communion across Africa, *All Africa Anglican AIDS Planning Framework "Our Vision, Our Hope" The First Step*, [website], 2001, <https://www.oikoumene.org/en/resources/documents/other-ecumenical-bodies/church-statements-on-hivaids/anglican-communication-africa>, (assessed 8 May 2016).

<sup>84</sup> Anglican Communion across Africa

<sup>85</sup> Council of Anglican Provinces in Africa, Statement from CAPA AIDS board meeting, [website], 2002, <https://www.oikoumene.org/en/resources/documents/other-ecumenical-bodies/church-statements-on-hivaids/anglican-provinces-in-africa>, (accessed 8 May 2016).

<sup>86</sup> Anglican Church of Southern Africa, *The Church*, [website], <http://www.anglicanchurchsa.org/view.asp?pg=about>, (accessed 8 May 2016).

Beyond public statements the Anglican Church made HIV and AIDS a priority area in the 2001 synod meeting and Fikelela AIDS Project was established as a specialized office in the Cape Town diocese the same year. Fikelela aims at mobilizing the Anglican Church through the forming of local HIV and AIDS Task Groups. The HIV and AIDS groups were to put HIV and AIDS onto the local church agenda and encourage participation by church members thus empowering the local congregations to actively respond to the pandemic and making churches HIV friendly.<sup>87</sup> Another area in which Task Groups were involved was partnering up in the care and support of those infected with and affected by the virus in a range of activities such as visiting children, providing food packs, starting support groups, church-based orphan care and provision of home-based care services.<sup>88</sup> In April 2005, 92 congregations had established HIV Task Groups out of 136 parishes that were part of the diocese of Cape Town.<sup>89</sup> In addition, Fikelela also established an emergency children's centre at Khayelitsha to cater to orphans.<sup>90</sup>

In 2005 Fikelela also commissioned a study on the sexual behaviour of Anglican youth (aged 12 – 19 years) in the Western Cape. The results showed that Anglican youth are engaging in sexual activities at a similar rate as the wider population. 31% of respondents said that they were sexually active. Of these 65% did not use contraceptives during their first sexual encounter and 66% had more than one sexual partner compared to 48% in the larger population. 90% expressed that their first sexual experience was with a member of own peer group. For the Anglican youth fear of contracting HIV and the use of condoms were not major issues. The study also demonstrated that youth found the Anglican Church's message on sex and sexuality to be ineffective as it was delivered by elders, focussed on prohibitions and upheld marriage.<sup>91</sup>

In response to the study findings, Fikelela started the *Agents of Change* peer-educators programme. The programme entails the training of young people to become peer educators and role models.<sup>92</sup> Peer educators and supporting facilitators from Fikelela then teach a 20 sessions life skills programme in the local congregations focussing on issues of identity, sexuality, drugs and alcohol usage, pregnancy, sexually transmitted infections (STI) and HIV and AIDS.<sup>93</sup> The *Agents of Change* programme has been shown to raise the age of sexual debut for young people

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<sup>87</sup> Kareithi, Rogers and Mash, p. 107

<sup>88</sup> Kareithi, Rogers and Mash, p. 107

<sup>89</sup> The diocese of Cape Town was split in 2005 into three distinct dioceses; the dioceses of Cape Town, False Bay and Saldanha Bay. Fikelela is seated at the diocese of Cape Town but continued to support all dioceses up to 2007. Today Fikelela's main focus is the diocese of Cape Town, while some programmes such as the *Agents of Change* continue to be run in all three dioceses and congregations in any diocese in the Western Cape can contact Fikelela for support and advice.

<sup>90</sup> Kareithi, Rogers and Mash, p. 108

<sup>91</sup> R. Mash, R. Kareithi and B. Mash, 'Survey of sexual behaviour among Anglican youth in the Western Cape : scientific letter', *South African Medical Journal*, vol. 96, no. 2, 2006, pp.124, 126-127.

<sup>92</sup> Fikelela AIDS Project, *Agents of Change*, [website], 2015, <http://fikelela.org.za/agents-of-change>, (accessed 8 May 2016).

<sup>93</sup> Fikelela Aids Project, *Agents of Change: Peer Education Manual*, Cape Town, Fikelela AIDS Project, n.d., p. 1.

and to increase the use of condoms, whereas no effect could be demonstrated on the number of sexual partners or on secondary abstinence, abstinence by people who have been sexually active.<sup>94</sup>

Fikelela also produced material on human sexuality to be used in confirmation classes, material for the establishment of the HIV and AIDS Task Groups in local congregations and for the integration of HIV and AIDS in worship.<sup>95</sup>

### ***Local contexts***

The apartheid policy of racial segregation and forced removal has resulted in clearly distinguished, patently demarcated and largely homogenous neighbourhoods throughout South Africa. With the Group Areas Act of 1950 the government claimed the power to decide where each racial group could live and own property. During the 1960s and 70s neighbourhoods all throughout the country were declared as either white, coloured or black and people were forcibly removed and relocated. To meet the needs of segregated housing, new neighbourhoods were created. In 1968 one of these new neighbourhoods where Coloureds were moved to was established 40 km south of Cape Town centre on the Cape Peninsula and called Ocean View. People classified as Coloured were subsequently forcibly removed from the newly white declared areas such as Simon's Town, Noordhoek and Red Hill.<sup>96</sup> The memory of the forced removals is still strong among the people in Ocean View.

Ocean View is a small community, geographically isolated by the surrounding mountains. Public transport is limited and access to the larger Cape Town area therefore difficult. According to the latest census in 2011, the total population was 13 569 with an average house hold size of 4.4. The population continues to be predominantly Coloured (91%). 25% of those aged 20 years and older have completed Grade 12 or higher. Unemployment is at 21% of the labour force (aged 15 to 64) and 48% of households have a monthly income of R3 200 or less.<sup>97</sup> Only 11.4% of households have a monthly income of more than R12 800.<sup>98</sup>

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<sup>94</sup> R. Mash and R. J. Mash, 'A quasi-experimental evaluation of an HIV prevention programme by peer education in the Anglican Church of the Western Cape, South Africa', *BMJ Open*, vol. 2, no. 2, 2012, pp. 1-8.

<sup>95</sup> Fikelela AIDS Project, *Survivor Africa: A Human Sexuality Workbook for the Youth of the Anglican Church*, Cape Town, Fikelela AIDS Project, n.d.; Fikelela AIDS Project, *Mobilising your Church: How to be salt and light in the HIV/AIDS pandemic*, Cape Town, Fikelela AIDS Project, n.d.; Fikelela AIDS Project, *Worship and HIV/AIDS*, Cape Town, Fikelela AIDS Project, n.d.

<sup>96</sup> S. Moses, 'Does space and place matter? Perspectives from growing up in a Cape Town neighbourhood created under apartheid' CSSR Working Paper No. 136, University of Cape Town, Cape Town, Centre for Social Science Research, 2005, p. 5.

<sup>97</sup> South Africa has established an upper-bound poverty line which was R620 per person and month in March 2011. With an average household size of 4.4, R3 200 is just above the poverty line which ensures that households can purchase enough food and non-food items. See Statistics South Africa, *Poverty Trends in South Africa: An examination of absolute poverty between 2006 and 2011*, Report No. 03-10-06, Statistics South Africa, Pretoria, 2014, pp. 7-8. A monthly household income of R12 800 or more makes a household generally well-off in the South African context.

<sup>98</sup> Statistics South Africa, *City of Cape Town – 2011 Census Suburb Ocean View*, Pretoria, Statistics South Africa, 2013.

In recent years Ocean View has experienced a proliferation of gang-related violence which is mainly linked to drugs. Killings are many and during the time of this study there was at least one killing most weeks. As Ocean View is a small community the shootings affect everyone with a number of victims being related to members of St Clare of Assisi. The people in Ocean View see unemployment as the main challenge, closely followed by drugs and alcohol, violence and safety. Other challenges are the quality of education, the access to public facilities and health.

Lentegeur in Mitchell's Plain is another predominantly coloured neighbourhood with 91% identified as Coloured. Located in the Cape Flats the neighbourhood is much larger with a 2011 population of 310 485. In other regards Mitchell's Plain is similar to Ocean View. The average household size is 4.57 and 35% of inhabitants have finished secondary school. 38% of households have a monthly income of R3 200, 21.3% of households have an income of more than R12 800 per month, making the neighbourhood slightly wealthier than Ocean View. The unemployment rate in 2011 was 24%.<sup>99</sup>

Similar to Ocean View, parishioners and lay leaders in Christ the Saviour perceive the main challenges in the lives of people in their congregation to be drugs, unemployment, safety and violence. Also the congregation in Lentegeur experienced problems with gangsterism and shootings, even if the situation has calmed down somewhat during the last months.<sup>100</sup>

Constantia stands in stark contrast to Ocean View and Mitchell's Plain. The population of 12 454 is predominantly White (75.3%) and 84% of residents aged 20 years and older have completed secondary schooling. Unemployment is low at only 4% of the labour force. 71% of households have a monthly income of R12 800 or more and just 17% of households have a monthly income of R3 200 or less with an average household size of 3.03.<sup>101</sup>

### **Chapter 3 – Words, Works and Silences**

A necessary condition for the prevention of HIV is the acceptance of HIV as a real concern impacting one's life, that is, HIV awareness. Only when individuals are convinced that HIV affects them personally do they see a need to adapt behaviour to reduce the exposure to HIV. This chapter looks first at the general level of HIV awareness in Ocean View and beyond and considers then the questions of HIV talk and HIV works, the speaking about and practically engaging with HIV and AIDS. Lastly, the chapter looks at wider mentions of health and the practise of healing.

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<sup>99</sup> Statistics South Africa, *City of Cape Town – 2011 Census Suburb Mitchells Plain*, Pretoria, Statistics South Africa, 2013.

<sup>100</sup> GI43, interviewed by Simon Hallonsten, Spring 2016, Cape Town, South Africa, 00:23:06-6 to 00:24:26-5.

<sup>101</sup> Statistics South Africa, *City of Cape Town – 2011 Census Suburb Constantia*, Pretoria, Statistics South Africa, 2013.

## HIV awareness

For the present purpose HIV awareness is defined as the acceptance of HIV as a personal concern. As such, HIV awareness is distinguished from knowledge of HIV which relates to the mere acknowledgement of the virus somewhere else. The concept of HIV awareness centres on the need to 'bring HIV home' through talk or practical engagement. The difference between awareness and knowledge also entails an understanding of 'us' and 'them', which HIV awareness relating the virus to 'us' while mere knowledge about HIV sees the virus as something that affects others.

When asked about the main challenges in the lives of members in their congregation, very few people feel that HIV is one of the main challenges. Indeed, no one included HIV or AIDS as a main challenge in the list of current issues in the survey results from Ocean View. The same holds for the answers obtained from Lenteguur and Constantia. Only amongst Cape Town and False Bay clergy was AIDS mentioned as a main challenge, and that once. During interviews two respondents indicated that HIV was a main challenge. This attests to the fact that few people are immediately concerned with HIV and is in line with the fact that there is no one who is publicly known to be HIV+ in any of the three congregations. However, also interviewees who did not mention HIV as a main challenge still generally contend that HIV is an issue in Ocean View and Lenteguur. This suggests that HIV is perceived as a concern, but not as one of the most pressing issues.

Looking at the survey results it becomes clear, that perceptions of the seriousness of HIV vary markedly between respondents. In total the survey respondents did mildly disagree with the statement that *I feel that HIV is an issue in my congregation* (average 2.94), while there was agreement with the statement that *I feel that HIV is an issue in my community* (average 4.13) and strong agreement with the statement *I feel that HIV is an issue in South Africa* (average 5.24). This indicates that HIV is generally accepted as a concern, but more of others than of one's own congregation. In St Clare people felt that HIV was more of an issue than in the total sample mildly agreeing with the statement that HIV is an issue in the congregation (average 3.72).

Perceptions of the importance of HIV as an issue are not homogenous and further analysis displays a polarisation within the answers. 18 respondents from Ocean View (56%) felt that HIV was at least as much an issue in the congregation than what it was in the community, and 23 answers (72%) suggest that HIV is seen at least as much a worry in Ocean View than what it is for the rest of the country. These answers suggest that there is little differentiation between *us* and *them* amongst a large group of survey respondents when it comes to HIV. People who think that HIV is at least as much an issue in their congregation as in their community are also generally more concerned with HIV in their congregation. These replies stand in stark contrast to

the 20% (6 responses) who strongly disagree with HIV being an issue in the congregation in Ocean View. There is then a minority in the local Anglican Church that does not see HIV as an issue 'at home' and can be described as unaware of HIV. The same pattern is observed for the parishes in Constantia and Lentegeur.

Another indicator for HIV awareness is the self-reported number of people who have had an HIV test. In total, 76% of respondents reported having had an HIV test. The percentage in Ocean View and amongst clergy is close to the total sample, 75% and 73% respectively, while it is somewhat lower in Constantia (64%) and much higher in Lentegeur (93%). Even though the reasons for getting an HIV test are many, from routine check-ups in antenatal care to compulsory HIV tests in certain lines of work, the large extent to which people have had HIV tests shows that many people have come into close contact with HIV issues and are thus in a position to accept HIV as a real concern in their personal lives, making them aware of the virus. This is confirmed in the interview material in which respondents stress the anxiety that an HIV test entails as one is necessarily forced to consider whether one could have contracted the virus.

According to the survey roughly two thirds of the people reported talking about HIV to their family members. Most often parents or grandparents would engage their children or grandchildren to make them aware of HIV (18)<sup>102</sup> and focus on questions of prevention (16). Families also address issues of sexuality (10), with a majority concentrating on the importance of using condoms (7), abstinence (4) and faithfulness (2). Furthermore, people iterate the importance of knowing one's status and that of one's partner (3) and to get tested together with a new partner before engaging in sexual activities. Lastly, the need to accept and support PLHIV is stressed (10). Families in which HIV is not spoken of generally feel that their family is not affected (4), that it simply does not come up (5) or that it is uncomfortable to speak about it (1). The results are similar across the four contexts and confirmed by the interview material. This highlights the same variation as above with a majority of people addressing the topic of HIV in their families, while a minority avoid the topic making it harder for family members to be HIV aware.

In sum, many people of St Clare of Assisi are aware of HIV. People have gotten tested and see HIV as also affecting the congregation. Many families address HIV and in that way 'bring HIV home'. At the same time, there is a part of the congregation that does not see HIV as an important issue and avoids the topic even if they know about HIV. Also, while HIV is seen as a concern it is not seen as one of the most pressing issues. Consequently, HIV does not receive as much attention with implications on HIV awareness. The same holds for the parishes of Christ the Saviour and Christ Church, as well as for clergy in the dioceses of Cape Town and False Bay.

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<sup>102</sup> Numbers in parenthesis give the frequency of each response.

## HIV talk

One possible way to increase awareness of HIV is to talk about the virus. Addressing issues of HIV in language forces people to engage HIV and makes the virus 'real'. The Anglican Church has been committed to breaking the silence around HIV and to address the issue of HIV stigma. Yet, assessments of the degree to which the local Anglican Church addresses questions of HIV vary markedly.

In Ocean View 19 out of the 32 survey respondents (59%) reported that HIV is talked about in the congregation. If one assumes that HIV talk can only address questions of HIV if it is noted and thus adds the four participants who answered that they do not know whether HIV is spoken of to the 9 voices saying that HIV was not addressed, it appears that roughly half of the people see the parish to engage in HIV talk. This finding is confirmed in the other three contexts.

The divergent assessments are rooted in different ideas of what constitutes HIV talk. From the interview material it becomes clear, that HIV is mostly addressed during December around and on World AIDS day on December 1. HIV is also mentioned in services and particularly in the sermon at times. When HIV is talked about it is most often to raise awareness and to promote acceptance of and compassion towards PLHIV. This indicates that HIV is brought home and discussed as an issue that affects the lives of people in the congregation. However, survey respondents in Ocean View and Constantia also reported that HIV was at times talked about as a concern chiefly for other people.

During the period of participant observation, HIV was mentioned twice in St Clare. Once in connection with the introduction of the researcher and the research project when HIV+ individuals were offered confidential counselling. The other time was in intercession on Mother's day, May 9, 2016, when prayer included all mothers infected with HIV. However, the message does not appear to be clear and HIV might be mentioned more than what it is talked about.

In the beginning when this thing started to surface we heard about people who got the virus. You know they have been infected with the virus. But you don't know who it is. That time it was a hush-hush, you don't talk about these things. So it is still hush-hush. We don't know. We don't know. Nobody talks about it.<sup>103</sup>

Survey participants see the silence around HIV in Ocean View to be rooted in the sensitive nature of the topic. People are afraid to address the issue, because of stigma, taboo and ignorance. There is also the feeling that HIV is not relevant as it affects others, a sentiment shared by respondents from Constantia, Lentegeur and clergy. One of the apparent omissions in the local Anglican Church is that HIV is not publicly self-disclosed. There is agreement among interviewees from Ocean View, Lentegeur and Constantia, that people do not feel comfortable

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<sup>103</sup> ON57, interviewed by Simon Hallonsten, Spring 2016, Cape Town, South Africa, 00:22:28-1 to 00:22:58-0

disclosing their status publicly in the local church. This adds to the feeling that HIV is an issue that chiefly pertains to others.

To summarize, there is disagreement about whether HIV is talked about in the congregation in Ocean View. Roughly half of the people feel that HIV is addressed, the other half deems HIV to be omitted. When the topic of HIV is touched, it remains unclear to which degree it is addressed, that is, whether HIV is talked about or merely mentioned. It is clear however, that HIV is not publicly self-disclosed and that there is still reluctance to address questions of HIV amongst at least parts of the congregations. The findings from Ocean View are confirmed in Lentegeur, Constantia and among clergy.

### **HIV work**

The situation regarding practical HIV work is similar to that of HIV talk. 50% of survey respondents in Ocean View said that their congregation engaged in HIV related work, while 16% reported that their congregation did not have any practical HIV involvement and the remaining 34% stated that they didn't know. Again, these findings are similar also in Constantia, Lentegeur and among the clergy.

Among those who knew of some HIV related work in their congregation, most people mentioned the HIV Task Team in St Clare. The description of the kind of work that the congregation was involved in varied ranging from counselling (4), to care (3) and support (2), to food support (2), prayer (1), fundraising (1), outreach work (1), child care (1) and awareness raising (1). The situation in Christ the Saviour was similar, while the congregation of Christ Church engaged primarily in outreach work and fundraising. Clergy in the dioceses of Cape Town and False Bay reported the same kind of activities in their various congregations. From this it appears that most congregations have engaged in some kind of practical HIV related work. However, not all of these projects could be sustained.

### ***The HIV Task Team in Ocean View***

The HIV task team in Ocean View was formed 2008 with the purpose to provide counselling, support and care for people and families infected with and affected by HIV. The team also provided food support for PLHIV. However, no one from the congregation ever came to disclose their status and to receive counselling. There are different accounts of the reasons for the difficulty of engaging the HIV pandemic. Some interviewees have suggested that it was difficult to know how to communicate the offer to HIV+ church members, while others maintain that the group did not have the necessary counselling experience and was therefore reluctant to provide counselling. Most people emphasise that the HIV Task Team was up for the

task, but that no one took up the offer, either because there was no need or due to an unwillingness to disclose one's status. The team subsequently decided to broaden the scope of the commitment in social issue and got involved in three general foster homes. In 2014 it was decided to rename the group to Task Team, thus dropping the HIV.

The experience from Ocean View is mirrored in both Lentegour and Constantia. Also Christ the Saviour had an HIV Task Team which was eventually discontinued as members became involved in other projects, even though the Women's Ministry continues to engage in food support for PLHIV. The same happened to the HIV projects at Christ Church. The fact, that of the 92 HIV Task groups that were active in 2005 only 37 continued to be active in 2015, shows that this is a more general phenomenon.<sup>104</sup>

### **Health, healing and HIV**

While HIV was not directly addressed in St Clare more than the two instances mentioned above, there is an active healing practise and involvement in questions of health and social issues. Sermons and prayer address questions of unemployment, violence, and drugs. One sermon was devoted to the topic of judging with the clear message: Do not judge other people. The sermon on St Joseph the Worker's day (May 1, 2016) revolved around John 5:8 "Stand up, pick up your mat, and walk!", emphasising that there was healing, even if you have been sick for a long time. The speaking of social challenges, health and healing demonstrate that the parish of St Clare is aware of the current social problems in the community and in the congregation and engages in a discourse of hope and healing.

During each service special prayers are held under which people can come up to the altar rail and the priest prays for them. Parishioners tell the priest about their specific need for prayer and the priest then generally informs the congregation, though it also happens that the issue is not publicly addressed but stated in terms of "what your heart wants". Special prayers are held for people celebrating their birthdays and anniversaries, but also for travels and health related issues such as pain, disease or operations. The prayer often includes a medical understanding of healing, where prayer is made for medication to work, for doctors to make the right decisions or for operations to go well. Every first Wednesday of the month a special healing service is held in which special prayers also contain the anointing with oil of inflicted body parts.

While some interviewees expressed concern about healing involving the replacement of treatment and medication with prayer, healing was generally seen to be spiritual, giving peace of

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<sup>104</sup> Kareithi, Rogers and Mash, p. 108; Fikelela AIDS Project, *HIV Task Teams*, [website], 2015, <http://fikelela.org.za/task-teams->, (accessed 12 May 2016).

mind rather than being physically healed, though it was thought that physical healing was expected by at least some members of St Clare of Assisi.

You know, some people got something here and they trust no one. And all over the sudden while she [the priest] is praying and they go to this healing service and they find that ok, I can perhaps trust that person, talk to that person and then they will come to you and then they say: I am feeling better now. I was sitting with this all in my mind all the time. I don't know who to share it with. I got some people that are sharing stuff with me. But I mean, then they are feeling better. So for them, they feel like they are getting healed now.<sup>105</sup>

Whereas the healing practises and the speaking of pressing social problems in St Clare do not directly address HIV, they are closely related to issues of HIV. The question of judging as well as the topic of hope and healing addressed in the sermons are clearly relevant and can thus provide comfort and resources to PLHIV.

### **Evaluative conclusion**

When HIV just started, like many years ago, when Fikelela started and the training went on, there was a lot of training, there were a lot of workshops, there was a lot of information. I think even in the schools children were taught about HIV. I feel that there is quiet now. I don't know if the drugs have taken over. But there isn't that much awareness being done. People used to have marches before, people used to have workshops before, that is, kind of quiet now.<sup>106</sup>

There was a banner saying *HIV friendly church* in the Anglican Church in Ocean View. Today the banner is gone, and no one really knows why it is gone or appears to have missed it much. The banner was removed when the church interior was redecorated and has simply not come up again. It was not a conscious decision by anyone, rather something that just happens.

The story of the banner is illustrative for the engagement with HIV in the Anglican Church in Ocean View and the wider dioceses of Cape Town and False Bay. When HIV was a “buzz” there was large involvement and HIV was considered to be an important issue. However, as time passed, other issues became important and HIV was replaced from the top of the agenda until it shifted further and further down. Today, people generally know that HIV exists, but it also appears as far removed. With gangsterism, substance abuse and shootings rife in Ocean View other concerns have taken over. HIV is brought up on World AIDS day and is referred to at times in the service, but far from the centre of attention. It appears that HIV is still mentioned, but not often talked about. The basic pattern is repeated in practical HIV-related work. Many congregations such as St Clare responded actively to the pandemic and started HIV Task Teams. The difficulty to address HIV and the immense effort needed to sustain a focussed working

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<sup>105</sup> SJ11, interviewed by Simon Hallonsten, Spring 2016, Cape Town, South Africa, 00:47:49-0 to 00:48:46-7

<sup>106</sup> GI43, 00:27:12-6 to 00:27:50-2

group have however left many of these initiatives fade out and task teams to commit themselves to other issues.

At the same time, many people still see HIV as an issue that impacts on the life of the congregation and the community. People speak about HIV with their family members and the church has retained its involvement in the social issues of the day. HIV is a topic, but not one that receives a lot of attention. The church is still HIV friendly, but it appears to have forgotten to tell people that it is.

## **Chapter 4 – The living dead and the positively living**

The previous chapter discussed the degree to which the local Anglican Church is involved in questions of HIV. Both HIV talk and works are important in breaking the silence and making people aware. For engagement in HIV to add to HIV prevention it is however not only important that HIV is on the agenda. It equally matters what is said and how HIV is understood, that is, how HIV is perceived and conceptualised. Two of the conceptualisations which render the infection intelligible can be described as *the living dead* and as *the positively living*. As a living dead, an HIV positive person is seen to carry a sure death sentence, to be close to the grave or to be barely alive. The living dead are associated with hopelessness, resignation, shame, guilt and ultimately death. The dead are excluded from the community of the living, roaming around as ghosts, the theme of horror stories and fairy tales. The conceptualisation of the living dead entails a clear distinction between us, the living, and them, the almost dead, and lies at the bottom of HIV stigma. Understanding HIV+ people as positively living on the other hand, breaks with the divide between them and us, focusses on messages of life and hope and attaches positive value to the positive person. HIV is not seen as a radical alteration of a person's life, but as a new condition under which that same life continues. The conceptualisation of positively living breaks the stigma around HIV and makes it possible for people to continue living long, happy lives amidst their family and friends.

In Ocean View both conceptualisations coexist. For some, HIV is directly linked to death, to being contagious, to unemployment, carelessness and isolation. Others see HIV as a chronic condition that requires life-long treatment and a greater need to take care of oneself, but is definitely not a death sentence. The same divide is observed in Lenteguur, Constantia and amongst clergy. The conceptualisation of HIV as death is stronger in Ocean View and Lenteguur than what it is in Constantia and amongst clergy, where the majority see HIV as a chronic condition.

To examine these conceptualisations in more detail, this chapter looks first at the understanding of HIV risk groups and considers then questions of responsibility and HIV

stigma. The chapter closes with a discussion on the difference between risky behaviour and risky environments.

### **HIV risk groups**

HIV is clearly associated with certain groups, lifestyles and contexts. What all of these groupings have in common is that they describe a group of people who are either seen to have HIV or are seen to be especially at risk of becoming HIV+. The identification of specific risk groups creates a potential divide between groups exposed to HIV and groups that are considered safe.<sup>107</sup>

During interviews people linked HIV most often to people who sell sex (PWSS) and to promiscuity. The sexual nature of HIV transmission is emphasised. Other groups seen as most likely to be exposed to HIV are drug users, often because drug use is seen to lead to unprotected and imprudent sex. A connection is also made between PWSS and drug users. Prostitution is understood to be related to poverty, which together with homosexuality, lack of education and unemployment leads to people being exposed to HIV. Importantly, many interviewees perceive people to see HIV to only happen to others; the poor, unemployed and badly educated who sell sex, use drugs and are generally promiscuous.

At the same time, other people perceive everybody as being exposed to HIV and understand the virus to affect all people. A third assessment relates HIV to innocent victims of rape, abuse or unfaithful spouses. Also children are seen to be the innocent victims of HIV.

The survey results confirm the interview findings. In the parish of St Clare of Assisi people exposed to HIV are most often perceived to be drug users (4), those engaging in unprotected sex (3) and those being unaware of the virus (2). The results from the parish of Christ the Saviour and Christ Church are similar with respondents focussing on people engaging in unprotected sex (4), drug use (3) and promiscuity (3) in Christ the Saviour and unprotected sex (4) and unfaithful partners (2) in Constantia. The clergy deviate from this pattern to some degree with the three groups being seen as most exposed to HIV being young women (3), the poor (2) and youth (2).

The identification of HIV risk groups also entails a conflation of HIV+ people with specific lifestyles.

A lot of people start to become killers. They don't worry about themselves. They don't wash. They become very negligent towards themselves. And also they live a careless life. They don't worry about the people around them. Especially, with the mothers that are HIV positive they do not worry about their children. And they just become worse. They start selling themselves on the street. They don't see themselves as something that is valuable. They see themselves dirty and filthy.<sup>108</sup>

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<sup>107</sup> Schmid, p. 96

<sup>108</sup> CH97, interviewed by Simon Hallonsten, Spring 2016, Cape Town, South Africa, 01:00:20-1 to 01:01:05-8

Not only are the deviant, the criminal, the other, the dirty and filthy, the socially dead, perceived as being exposed to HIV, being HIV+ is in turn also construed as leading to criminality, carelessness, dirt and filth. There is a conflation of cause and effect with certain lifestyles leading to HIV infection and an HIV infection leading to certain lifestyles. In this way the sexually deviant, the dirty and filthy become one with the virus which is at the same time removed from the group of the good, normal people.

### **Responsibility and blame**

Many interviewees commented on the availability of HIV information and education, as well as HIV treatment and support. HIV help and medication is perceived as being available free of charge and as being accessible in Ocean View. Availability leads to the thought that no one has an excuse not to know. Also condoms are freely available in a number of places. There is however the feeling, that people do not want to listen to education, that especially young people are not taking the opportunity and that even though everyone knows about HIV prevention and the importance of using condoms, people refuse to follow the advice. It is by a lifestyle of clubbing and drugs that people are being infected. With the available education HIV is seen as a choice. In other words, HIV+ people have to blame themselves and accept the consequences for their actions. Responsibility is shifted to the infected person and blame is assigned to those who should have known better.

### **HIV Stigma**

Interview participants are well aware of HIV stigma and many see it as a big challenge in the HIV response also within the local Anglican Church in Ocean View. Stigma is identified as being rooted in a lack of education and knowledge and ultimately in fear in general and the fear of contagion particularly. The anticipated stigma is mainly related to people gossiping and thus singling out HIV+ members of the community. People are afraid of rumours and are therefore not willing to self-disclose their status. Anticipated stigma is strong in St Clare with participants expecting people to avoid sitting next to an HIV+ person, not wanting to hold the hand of an HIV+ person during the peace and refusing to drink from the chalice if they expect that an HIV+ drank from it. The label "being HIV" thus leads to ostracism and social isolation, the removal of the infected person from the group of the (fully) living.

Interviewees feel that it is because of stigma that people are scared of HIV and embarrassed if they are diagnosed with it. The anticipated stigma is also reported to lead to denial, secrecy and

non-disclosure, which results in the dictum that “nobody got HIV, nobody is HIV positive in our church”<sup>109</sup>. The refusal to disclose might even be especially strong within the church.

It’s more stigma than anything else, acceptance than anything else. It is very hurtful to be hurt by the people you truly love. So I would rather give my status to someone outside of the church, because of the relationship I have with you, then with someone inside in the church based on the relationship I have with you. It’s more traumatising to be hurt by someone you love than by someone you do not know.<sup>110</sup>

## **Evaluative conclusion**

HIV stigma leads to denial, secrecy and non-disclosure with negative impact on testing, treatment and the quality of life. Stigma is formed and reformed in language, the way in which questions of HIV are addressed and framed. The association of HIV with certain groups or lifestyles entails the possibility of HIV conceptualisations that potentially add to stigma and create a false sense of security. Especially as cause and effect are conflated and specific circumstances or behaviour becomes one with the virus. The difficulty is to distinguish between correct perceptions of key populations at higher risk and harmful conceptualisations of HIV as pertaining only to specific subgroups. A number of groups are usually identified to be more exposed to HIV. These include men who have sex with men (MSM), people who inject drugs (PWID), people who sell sex (PWSS), prisoners, transgender people, women, children and young people and adolescents.<sup>111</sup> Identifying people who are at higher risk of being exposed to HIV can help to foster a better response to the pandemic and inform political prioritisations in mitigating the risk of exposure. It is thus correct and can even be helpful to perceive HIV as being more common amongst MSM. However, conceptualising HIV as a virus that befalls MSM is problematic as it singles out a specific group as vulnerable based on a perceived difference and entails a false sense of security for those not identifying as members of that group. The same holds for all conceptualisations of HIV as affecting (only) specific groups of people. Especially among people who feel that HIV affects only others there is a need to address the conceptualisations of HIV.

Once it is accepted that group membership in some of the key populations at higher risk of exposure is voluntary such as MSM, PWID or PWSS, it is easy to blame HIV+ people for their infection. The understanding of HIV as a consequence for one’s own irresponsible actions works in the same way. Both put the responsibility and the blame on the HIV+ person and add to HIV stigma. The problem is compounded by the perceived relationship between HIV and irresponsible behaviour such as promiscuity, unfaithfulness and unprotected sex. The focus remains on risky behaviour rather than on people living in risky environments.

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<sup>109</sup> SJ11, 00:38:01-3 to 00:38:11-6

<sup>110</sup> CH97, 00:37:22-3 to 00:37:50-4

<sup>111</sup> AVERT, *Key affected populations*, [website], 2016, <http://www.avert.org/professionals/hiv-social-issues/key-affected-populations>, (accessed 11 May 2016).

In the Anglican Church in Ocean View people express willingness to address HIV stigma and a number of people see HIV as a threat to all people with some people being in need of greater protection and support than others. HIV is perceived as a chronic condition, which puts certain constraints on a person's life, but which does not lead to either social or physical death. Some people thus conceptualise HIV+ people as positively living.

At the same time, other people see HIV as clearly linked to specific groups, to the others, and thus not to us. HIV is perceived as being linked to risky behaviour such as unprotected sex, using drugs or having multiple sexual partners. Blame is levied on those being infected as they are supposed to have known better. The identification of HIV with the deviant, the dirty and filthy removes HIV+ persons from the group of the people living normal lives and involves a conceptualisation that can be described as the living dead. Both conceptualisations are present in Ocean View and become at times entangled and mixed as in the case of HIV+ mothers and children, where mothers are seen as fallen *living dead* and children as innocent *positively living*. The same tendencies are found in the local Anglican Church in Lentegeur and Constantia.

Even if there is an opening in the conceptions of HIV, stigma remains life and well. To move beyond HIV stigma the perception of HIV needs to move from being related to risky behaviour to being associated with risky environments. Only when HIV is not seen as a choice or as a consequence of imprudent individual behaviour, can HIV conceptualisations change through the practise of HIV talk and work.

## Chapter 5 – Potentials and Opportunities

But if we want to have 2030 to be a generation without AIDS we need to work harder. We need to equip and be there as a constant support. It can't be a hit and run. It's got to be a constant message, a constant in your face approach, and that is what we are not doing anymore. It is just taking a back seat, it will go away. It's not going anywhere. So I think we need to start at the beginning again with basic education, implementing value systems, implementing respect, we have allowed far too many negatives to creep in and now we are out of control. And I say that in a positive way, because that is my reality.<sup>112</sup>

The response to the pandemic needs to be “a constant in your face approach”. Only by continuously engaging issues of HIV and AIDS can the awareness of the pandemic be sustained and people live in recognition of the fact that HIV affects them personally. Continuous HIV talk can normalise the infection, reduce stigma, increase the uptake of VTC and treatment and work towards the prevention of HIV.

Interviewees in Ocean View, Lentegeur and Constantia see the local Anglican Church to be an important part in people's lives with church leaders being role models both within the

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<sup>112</sup> Beverly Hendricks, interviewed by Simon Hallonsten, Coordinator of Fikelela AIDS Project, May 2016, Cape Town, South Africa, 00:24:48-8 to 00:25:47-9.

congregation and the wider community.<sup>113</sup> People in these parishes have therefore the possibility to make a tangible contribution towards the prevention of HIV.

This chapter looks first at the potentials and then at the opportunities the parish of St Clare of Assisi and other similar parishes have to engage with questions of HIV. Potentials and opportunities are closely related to the focus on agency and assets in that they focus on the possibilities people have of transforming their own lives.<sup>114</sup> Potentials are resources that can be dynamically drawn upon and developed in the HIV response. Opportunities denote concrete contextual situations which open spaces of transformation. As such, potentials and opportunities are not givens; it is something that people continuously develop.

## Potentials

The congregation of St Clare is a tight social group which offers strong support to its members. Interviewees report on the support the members of St Clare receive from each other, both through direct care and through prayer. Public recognition of challenges during special prayer and healing services enables the sharing of difficulties in the group and makes it possible for people to find support and understanding. In the case of HIV with its associated stigma and psychological stress these support networks can play a crucial role.

The local Anglican Church in Ocean View can also draw on established structures both tangible and intangible. As part of the Anglican Church the congregation has at least some financial resources, buildings and staff. Clergy are highly trained and during participant observation they appeared to be committed to issues of social justice. The congregation is entrenched in the community and can draw upon a rich set of experiences and best practises in the engagement of HIV. The larger structure of the Anglican Church with its specialised offices such as Fikelela AIDS project makes it possible for the local Anglican Church to draw on the resources of the larger church organisation and to receive support in the shaping of the local response.

Lastly, the Anglican Communion has adopted a reasoned stance on human sexuality focussing on the need of responsibility in sexual encounters and seeing sexuality as a gift from God.<sup>115</sup> Focussing on positive messages around human sexuality and emphasising what is good practise has a greater potential of transforming individual sexual behaviour than strict moralistic prohibitions and a stress on the forbidden.<sup>116</sup> This view is shared by the members of the local

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<sup>113</sup> HQ28, interviewed by Simon Hallonsten, Spring 2016, Cape Town, South Africa, 00:06:31-9 to 00:07:22-2; JZ80, interviewed by Simon Hallonsten, Spring 2016, Cape Town, South Africa, 00:09:04-6 to 00:10:26-4;

<sup>114</sup> S. de Gruchy, 'Of Agency, Assets and Appreciation: Seeking some commonalities between Theology and Development', *Journal of Theology for Southern Africa*, vol. 117, 2003, pp. 20-39.

<sup>115</sup> Anglican Communion across Africa

<sup>116</sup> Mash and Mash, p. 5

Anglican Church where the importance to use condoms (12) is as much stressed as the role of abstinence (12) in HIV prevention.

## **Opportunities**

Perhaps the greatest opportunity the local Anglican Church in Ocean View has is to address HIV and AIDS in the church, doing HIV talk. Both interviewees and survey respondents mention HIV awareness and education as important prevention methods. Most respondents focus however on the need to adjust individual behaviour. After condoms and abstinence, honesty about one's status is seen as the most important prevention method (8), followed by testing (5), safe sex (3) and faithfulness (3). Most people then see the opportunities to prevent the spread of HIV to be directly related to minimising risky behaviour.

During interviews people expressed a larger set of ways in which the local Anglican Church can respond to the pandemic. Interviewees think it important that HIV is addressed both in the family and in the church, where it should be incorporated in other events. Also the need to keep HIV on the agenda and to remind people of HIV is stressed. Many interviewees also mention the importance of public self-disclosures. Public self-disclosures have the benefit of bringing HIV home, demonstrating that the virus is also present in the local context and thus increasing awareness and adding to the prevention efforts.

To be effective in reducing stigma, interviewees think that public self-disclosure should come from people who are similar to the people of the local Anglican Church. Only when people feel "that could have been me" does public self-disclosure raise awareness and reduce stigma. At the same time people need to feel comfortable, accepted and understood to feel confident in disclosing their status. Public self-disclosure also requires support and trust. It becomes also easier for PLHIV to publicly self-disclose if the HIV prevalence rate and the general awareness are higher. It is therefore that disclosure is more frequent in the black community.

I think because it is common now. It is common. Virtually every family is affected by HIV and AIDS. Every family is affected by it. And so people are not seeing the need to hide it. Because hiding it means death. It will lead you to death because you have nobody to support you. You have nobody to hear you out. And you will be stressed and that will kill you.<sup>117</sup>

## **Evaluative conclusion**

The local Anglican Church in Ocean View has both potentials and opportunities to respond to HIV. A challenge is that many of the ways to address the pandemic still focus on individual risky behaviour. While it is important that people engage in safe sex practises, use condoms, get

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<sup>117</sup> HQ28, 00:35:42-4 to 00:37:00-3

tested and know their status and that of their sexual partners, the emphasis remains on the individual who has to adapt her or his behaviour. The structural dimension of HIV remains then unaddressed and less focus is put on tackling risky contexts. Dealing with individual behaviour also assigns the responsibility to the individual and can therefore add to stigma when HIV is seen as a consequence of imprudent action.

To concentrate on the structural aspects of the pandemic, interviewees suggest that HIV perspectives could be integrated into the current structures and find a place in sermons, prayers and special prayers. Awareness can also be raised by having specialised HIV services apart from World AIDS day. HIV and sexuality can be addressed with youth during confirmation classes or in Sunday school, equipping young people to protect themselves from the virus. Also taking up HIV related work within the congregation again is a way to increase the awareness around HIV and keep HIV on the agenda.

As Anglican clergy rotate between parishes there is also the opportunity to draw on a variety of the life experiences clergy bring with them from their own personal history and the various parishes they have worked in. This sharing of experiences makes it possible for the local Anglican Church to draw on the experiences and coping mechanisms developed in the various contexts the church operates in. For the congregation in Ocean View this becomes especially interesting as parts of the black community, which has been hardest hit by the pandemic in South Africa, have had to cope with stigma and denial to a greater extent.

A paramount way to create awareness of HIV is to have people publicly self-disclose their status. The value of public self-disclosure is that it enables support for and understanding of PLHIV. Being able to be open and honest about one's status also increases the access and adherence to treatment and facilitates keeping a lifestyle conducive to physical and mental well-being of people living positively, not least when it comes to nutrition.

There is however a typical catch-22 dilemma in which public self-disclosure requires general awareness and acceptance, and general awareness and acceptance are brought about by public self-disclosures. To break the circle awareness and compassion need to be raised in other ways to enable people to come forward. This is done by actively engaging in HIV talk and work. The parish of St Clare of Assisi and similar parishes in the Western Cape have the potentials and opportunities to keep responding to the HIV pandemic. What is required is to put HIV back on the agenda.

## Chapter 6 – Conclusion

A lot of progress has been made in the global response to the HIV pandemic. In South Africa politicians are generally enthusiastic about the latest developments and the UN has called for sustained work to make 2030 a generation without AIDS.<sup>118</sup> Yet, while a great deal has been done and accomplished the response at the local level has begun to subside. HIV is not a “buzz” anymore and has been replaced from the top of the list of current social challenges.

The local Anglican Church in Ocean View, Cape Town, continues to mention HIV in services, sermons and prayer. However, also here HIV is receiving less and less attention. Groups that were dedicated to HIV related work have taken up other tasks and HIV awareness campaigns are chiefly concentrated around World’s AIDS day. The same tendencies are seen in other parishes in the dioceses of Cape Town and False Bay.

At the same time HIV denial and secrecy continue in the local Anglican Church in Ocean View, Lentegeur and Constantia, with churches having no self-disclosed HIV+ members. Even though there are varied perceptions of HIV with some focussing on HIV as a threat to all and advocating acceptance, support and compassion, HIV continues to be strongly associated with specific groups and lifestyles such as drug users, PWSS and the promiscuous. While the identification of key populations at greater risk of exposure to HIV is in itself positive, it can potentially lead to a conceptualisation of HIV as a virus that befalls only certain groups thus adding to stigma and creating a false sense of security for those not identifying as part of a key population. There is also a beginning discourse of blame in which HIV is seen as a choice or the consequence of risky behaviour. Blaming HIV+ individuals for their status increases stigmatisation, denial and secrecy.

The parish of St Clare of Assisi and similar parishes are important actors in their communities and have both potentials and opportunities to address HIV stigma. General awareness can be increased by incorporating HIV in the existing church activities and taking up the HIV related work that was done in the congregation. Addressing the existing HIV stigma will require a reconceptualization of HIV as being the result not of risky behaviour, but of risky environments.

Normalisation of HIV can also make it possible for HIV+ people to publicly self-disclose their status. This can potentially enable acceptance, care and support for PLHIV and make it possible to live positively. Self-disclosure can also further add to awareness and normalisation breaking the silence around HIV and making the church once more HIV friendly. In the end this

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<sup>118</sup> M. Prigg, 'The world is heading for a 'generation free of AIDS' by 2030, UN chief claims', *Mail Online*, 14 July 2015, <http://www.dailymail.co.uk/sciencetech/article-3160439/Goal-end-AIDS-epidemic-2030-ambitious-realistic-UN-chief.html>, (accessed 12 May 2016).

will require that HIV is put once again on the church agenda, that there is a “constant in your face message”<sup>119</sup> and that HIV once again becomes a “buzz”.

Yes, I think that is important. It is very important to keep speaking about it. Because once we begin to think, it’s no longer a problem we will find ourselves in danger again.<sup>120</sup>

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<sup>119</sup> Beverly Hendricks , 00:24:48-8 to 00:25:47-9

<sup>120</sup> HQ28, 00:38:30-5 to 00:38:45-1

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## **Interviews**

Hendricks, B., interviewed by Simon Hallonsten, Coordinator of Fikelela AIDS Project, May 2016, Cape Town, South Africa.

## Annex I – Survey

### Minor Field Study in Theology Opinion Survey

Dear Sir or Madam,

My name is Simon Hallonsten. I am studying Theology at Uppsala University, Sweden, hoping to be ordained for the (Lutheran) Church of Sweden. To finish my undergraduate studies I am currently carrying out a research project in the greater Cape Town area, looking into the perceptions of HIV in the Anglican Church. The study was made possible through a research grant from The Swedish International Development Cooperation Agency (SIDA). I would be very thankful if you took some time to complete this survey. The questionnaire takes **approximately 10-15 minutes** to complete.

#### Important note – Please read:

This survey is an opinion survey and **I am interested in what you think** and feel. **There are no correct answers** to the questions and this is not a test of what you know. Please answer all questions honestly. If you do not have an answer to any particular question you can skip that question.

**All information you provide will be treated as confidential.** The records may be inspected for purposes of research validation. The results of this survey will only be reported in anonymized or aggregated form. The information you provide will help to record perceptions of HIV and attitudes towards HIV in the Anglican Church in the greater Cape Town area and contribute to a better understanding of the opportunities and potentials for the Church to engage in questions of health and wellbeing.

**Your participation in this study is voluntary.** By completing and leaving this questionnaire in the assigned box at the entrance of your church you are voluntarily agreeing to participate. You are free to decline to answer all or any particular question you do not wish to answer for any reason. **Please return the survey no later than May 8, 2016.**

If you have any question about the study or the survey, please contact

Simon Hallonsten

[jansimon.hallonsten.8879@student.uu.se](mailto:jansimon.hallonsten.8879@student.uu.se)

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Thank you very much for taking the time and for your contribution to this research project!

Kind regards



Simon Hallonsten

**1. Background information**

Parish:

Age:

Role in the parish:

Sex:

Female

Male

Other

**2. In your opinion, what are the main challenges in the lives of members in your congregation (for example access to public facilities, education, safety, unemployment, health, alcohol or substance abuse, violence etc.)**

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**3. Please indicate how much you agree with the following statements**

*I feel that HIV is an issue in my congregation*

Strongly disagree    1    2    3    4    5    6    Strongly agree

*I feel that HIV is an issue in my community*

Strongly disagree    1    2    3    4    5    6    Strongly agree

*I feel that HIV is an issue in South Africa*

Strongly disagree    1    2    3    4    5    6    Strongly agree

**4. Have you ever had an HIV test?**

Yes

No

Don't know/Don't want to say

**5. Do you know of any HIV related work that your congregation does or has done?**

Yes

No

Don't know

If yes, please briefly describe that work

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**6. Do people speak about HIV in your congregation?**

Yes

No

Don't know

If yes, what do you say? If not, why do you think that is?

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**7. Do you speak to your family members about issues of HIV?**

Yes       No

If yes, what do you say? If not, why is that?

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**8. Who do you think is most at risk of being infected with HIV?**

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**9. From your point of view, how do we best prevent HIV infection?**

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**10. In your opinion, what are the consequences of being infected with HIV?**

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**Thank you!**

Thank you very much for completing this survey. All information you provide will be treated as confidential. Please remember that your participation in this study is voluntary. By completing and submitting this questionnaire you are voluntarily agreeing to participate and consent that the information you have provided may be used in anonymized or aggregated form.

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**May I contact you for a possible follow up interview?**

Yes       No

**Do you want to receive a copy of the thesis by email?**

Yes       No

If yes, please provide your contact details.

Phone number:

Email address:

*Important note! Your contact details are not part of the material gathered and will only be used to contact you for a potential interview or to send you a copy of the thesis upon completion.*

## **Annex II – Interview Guide**

### **Introduction**

- Thank you for taking the time for this interview
- Background
  - Uppsala University, bachelor in Theology
  - SIDA financing
- Purpose
  - Understand the perceptions of HIV in the Anglican church
  - Survey in Ocean View, Christ Church Constantia and others
  - Interviews for deeper understanding
- How is the information used
  - Thesis
  - Publication
  - Benefit to the church
- How much time do you have?
- Confidentiality
  - Information is only used in anonymized & aggregated form
  - Direct quotes are only used after consent
- Not here to judge
- Ok to record?
- Information stored in two versions
  - Available for review for research validation
- Stop at any time
- Decline to answer any question
- Do you want to receive a copy of the thesis once it is completed?
- Any questions?

### **Background**

- State my name, date and place
- Full name and age
- Parish
- Role in the parish
  
- Can you tell me a little about yourself?
  
- How did you get here?

## Questions

- From your experience what are the main challenges for people in your congregation?
  
- Is HIV an issue
  - In your congregation
  - In your community
  - In general
  
- Do you know of any HIV related work that your congregation does or has done?
  
- Do people speak about HIV in your congregation?
  - Why?
  - What do they say?
  - Do you think that is good/bad?
  - What are the consequences?
  
- Do you speak to your family members about issues of HIV?
  - Why?
  - What do they say?
  
- Who do you think is most at risk of being infected with HIV?
  
- From your point of view, how do we best prevent HIV infection?
  
- How would you describe the consequences of being infected with HIV?
  
- Healing
  
- Thank you, Any questions?