The role of faith-based organisations in the care of people living with HIV/AIDS in Swaziland

A dissertation submitted to the University of Manchester for the degree of MSc Poverty and Development in the Faculty of Humanities.

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2014

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List of abbreviations

ADL – Activities of Daily Living

AIDS – Acquired Immune Deficiency Syndrome

ART – Antiretroviral Therapy

ARV – Antiretroviral

CBHV – Community Based Health Volunteer

CHBC – Community Home-Based Caregivers

CSO – Civil Society Organisation

FBO – Faith-Based Organisation

FBP – Food by Prescription

GBV – Gender-Based Violence

HBC – Home-Based Care

HIV – Human Immunodeficiency Virus

HRQOL – Health Related Quality of Life

HTC – HIV Testing and Counselling

IEC – Information Education and Communication activities

IGI – Income Generating Initiatives

KP – Key Population

M&E – Monitoring and Evaluation

MDG – Millennium Development Goal

MOH – Ministry of Health

MTCT – Mother-to-Child Transmission

NERCHA – National Emergency Response Council on HIV and AIDS

NGO – Non-Governmental Organisation

OI – Opportunistic Infection

OVC – Orphans and Vulnerable Children

PEPFAR – The U.S. President's Emergency Plan for AIDS Relief

PLWHA – People Living With HIV/AIDS

QOL – Quality of Life

RHA – Religious Health Assets

SAP – Structural Adjustment Programme

SHBC – Shiselweni Home-Based Care

SRH – Sexual and Reproductive Health

STIs – Sexually Transmitted Infections

TASC – The AIDS Information and Support Centre

TB – Tuberculosis

UN – United Nations

VCT – Voluntary Counselling and Testing

WFP – World Food Programme

Abstract

The scale and effect of the HIV/AIDS pandemic in countries such as Swaziland has emphasised the need for multisectoral collaborations. Multisectoral collaborations can utilise the strengths of different organisations in order to effectively respond to the pandemic, thereby preventing further declines in life expectancy and living standards. Hence, in contexts such as Swaziland, civil society organisations have a valuable role to play in the delivery of HIV/AIDS related prevention, care and treatment services. This includes faith-based organisations which are recognised in literature as providing a significant proportion of health related services in developing countries, particularly in sub-Saharan Africa. However, the relationship between faith and development and the role of faith-based organisations in development has been debated in the literature. Some donors and development agencies have been cautious of engaging with faith-based organisations due to fear of them proselytising or exacerbating HIV/AIDS related stigma and discrimination. However, others hold faith-based organisations to be distinctive and have a comparative advantage over secular organisations in the delivery of development related services. One reason given for their distinctiveness is the assumption that they provide a holistic approach to the care of people living with HIV/AIDS, meeting their various physical, psychological, social and spiritual needs.

This dissertation explores the ways in which faith-based organisations, in comparison to secular non-governmental organisations, meet the physical, psychological, social and spiritual needs of people living with HIV/AIDS. It will apply a needs-based quality of life framework in order to evaluate the impact that the activities of the participating organisations have on the health related quality of life of people living with HIV/AIDS. This is of importance since the provision of care and treatment for people living with HIV/AIDS not only aims to increase their life expectancy, but also their quality of life. The dissertation will specifically make reference to two case studies: Shiselweni Home-Based Care and The AIDS Information and Support Centre. Using findings from literature, secondary data and primary research conducted in the form of a qualitative questionnaire, the dissertation seeks to answer the primary research question: Are the services faith-based organisations provide for people living with HIV/AIDS more holistic in their nature than those of secular non-governmental organisations? The research found that the services both Shiselweni Home-Based Care and The AIDS Information and Support Centre provide for people living with HIV/AIDS are holistic in nature, meeting physical, psychological, social and spiritual needs. However, faith-based organisations may better be able to provide spiritual care to people living with HIV/AIDS due to their ideology and ethos.

1. Introduction

1.1   The importance of understanding the role of faith-based organisations in development

Faith-based organisations (FBOs) conduct a vast array of development related activities, including caring for people living with HIV/AIDS (PLWHA) (Parry 2003; Rakodi 2011a; Morgan et al 2014). UNAIDS (2009) notes that faith communities, and in particular faith-influenced non-governmental organisations (NGOs), are major providers of HIV/AIDS prevention, care and treatment services. In contexts where there is a large demand for public services such as these, or where governments are ineffective, FBOs can help ensure service provision is sufficient to meet the needs of the population (Trinitapoli 2006; Clarke and Jennings 2008; Clarke 2010).

There is a debate in the literature as to whether or not FBOs are distinctive and 'add value' to development, potentially holding a comparative advantage over secular organisations (James 2011; Olarinmoye 2012; Tomalin 2012). This includes in the provision of services for PLWHA (Lipsky 2011). Such propositions are grounded in an understanding that FBOs are "less donor-dependent than secular NGOs", have closer "links at the grassroots", and "an ability to deliver services efficiently and cost effectively" (Leurs 2012: 708). Hence, FBOs are assumed to increase the efficiency, effectiveness and relevance of development interventions (Hefferan et al 2009). FBOs' norms and values, including the promotion of the "spiritual and moral elements of poverty" (Clarke and Jennings 2008: 1), are also thought to provide a 'holistic' approach to development (Smith et al [n.d]; James 2011).

1.2 Background and context

In 2010 there were an estimated 34 million PLWHA worldwide (WHO et al 2011). The majority of PLWHA live in developing countries, in particular in sub-Saharan Africa (UN 2001; WHO et al 2011). This is problematic given that sub-Saharan Africa is "a region lacking in resources to deal with this epidemic" (Kopelman et al 2002: 231).

HIV/AIDS poses health and wider development challenges. It not only negatively impacts upon maternal and child health, increases susceptibility to other diseases and causes premature death, but also exacerbates income poverty and causes food insecurity (Phaladze et al 2005; UNAIDS 2010a). HIV/AIDS can also strain health systems as it diminishes human capital, causing a "shortage of highly skilled people" (Keregero and Allen 2011: 3). This is especially true in contexts such as Swaziland where the prevalence of HIV/AIDS is so high. The HIV/AIDS pandemic has also weakened some national economies, as increased morality rates and levels of sickness deplete the productive labour force (ILO 2013). This has been experienced in Swaziland (Keregero and Allen 2011) where an economic downturn has been occurring in recent years (van Wyngaard 2013). As fewer individuals are economically productive as a result of ill health, the effective dependency ratio increases. This diminishes fiscal revenues, weakening the financial capacity of governments to provide welfare services which effectively meet citizens' needs and protect human rights (Wegelin-Schuringa and Kamminga 2006; Whiteside and Whalley 2007).

Hence, HIV/AIDS has a strong bearing on the achievement of development goals, such as the Millennium Development Goals (MDGs) (UNAIDS 2010a). The pandemic can be framed as a human rights issue, with violations of human rights, including poverty and gender-based violence (GBV), increasing the vulnerability of people to contracting the HIV virus (UN 2001; UNAIDS and OHCHR 2006; Doyal and Doyal 2013). Due to the scale of the HIV/AIDS pandemic, the United Nations (UN) recognises that if goals such as MDG 6, which aims to combat AIDS and other diseases, are to be achievable objectives then a multilateral response is required (UN 2001). This accentuates the importance of non-state actors.

Swaziland is experiencing a generalised HIV/AIDS epidemic and currently has the largest HIV prevalence in the world (Whiteside and Whalley 2007; Zamberia 2011; Bicego et al 2013). Resultant, "the country's life expectancy [has] become one of the lowest in the world, with over 60 per cent of all deaths in Swaziland [being] AIDS related" (Keregero and Allen 2011: vi). In trying to respond effectively to the pandemic, the Government of the Kingdom of Swaziland have restated their commitment to a multisectoral and decentralised response, as detailed in their

extended National Strategic Framework (NERCHA 2014). This commitment was first institutionalised in 2001 when the National Emergency Response Council on HIV and AIDS (NERCHA) was set up by an Act of Parliament (UNAIDS and NERCHA 2012). NERCHA "is mandated to co-ordinate and mobilise resources for an expanded, scaled-up and co-ordinated multisectoral response to HIV/AIDS in the country" (NERCHA 2004: 1). The government seeks to capitalise on the comparative advantage of each organisation involved to maximise the effectiveness of the national response to HIV/AIDS (NERCHA 2014). This is necessary to prevent Swaziland regressing from a lower-middle income country (Whiteside and Whalley 2007). Both secular and faith-based NGOs are recognised partners and stakeholders in the national response to HIV/AIDS. They have been involved both in service delivery and the planning and budgeting process for the National Strategic Plan on HIV (UNAIDS and NERCHA 2012).

1.3   Research justification

Scholars such as Tomalin (2012), Leurs (2012) and Rakodi (2011a, 2011b) recognise that claims of FBOs' distinctiveness and comparative advantage are often not backed by sufficient evidence. In specific relation to health related service delivery – the primary focus of this dissertation – Lipsky notes that "there is little comprehensive research on the advantages that FBOs bring to the delivery of health services" (Lipsky 2011: 26). Hence, there is a need for increased "faith literacy" (James 2011: 10).

Although van Wyngaard (2013) acknowledges the importance of providing holistic care which meets the various physical, social, psychological and spiritual needs of PLWHA, the study only provides an in depth analysis of the role of Shiselweni Home-Based Care (SHBC) in the spiritual care of PLWHA. It also focuses on caregivers' experiences rather than PLWHAs experiences. In his study *Manifesting the Grace of God*, van Wyngaard (2014) provides feedback from interviews with clients and highlights some of the needs of PLWHA. However, the study does not explicitly provide an analysis of how the home-based care (HBC) offered meets the holistic needs of PLWHA. Ntshakala et al (2012) assess the needs of PLWHA in Swaziland according to different quality of life (QOL) domains. However, they do not assess whether FBOs are distinctive in their approach or have a comparative advantage in

meeting these needs compared to secular organisations. Related to the latter, despite James (2011) claiming that FBOs take a holistic approach to development, he does not evidence whether or not it is *only* FBOs which can meet the holistic needs of individuals.

In aiming to overcome the limitations of previous studies, this dissertation offers a comparative analysis of the HIV/AIDS related activities of The AIDS Information and Support Centre (TASC) and SHBC. It aims to further understand the role of FBOs in the care of PLWHA in Swaziland, critically exploring claims that FBOs "meet people's needs holistically" (James 2011: 115). Seed and Lloyd (1997: 56) state that "a holistic approach to QOL addresses the needs of the 'whole' person – physical, mental, social and spiritual". It is important to explore such claims as a holistic approach can enhance well-being and QOL (DFID 2012).

Understanding whether, and in what ways, FBOs are distinctive or have a comparative advantage is also important for the purposes of establishing multisectoral collaborations and aid distribution. Large sums of official development assistance continue to be channelled to CSOs (OECD 2013). Further understanding the role of faith in development could highlight ways in which donors and development agencies can "take advantage of the considerable contribution that FBOs can bring and at the same time mitigate the inherent risks" (James 2011: 110). Failure to do so may lead to "development shortfalls" in which the potential positive contribution of FBOs is not maximised (Marshall 2011: 49). Parry notes that despite FBOs having played a crucial role in responding to the HIV/AIDS pandemic, they remain underfunded by international donors. She argues that it is "time to rethink" this trend and consider the importance of channelling funds to FBOs in the fight against HIV/AIDS (Parry 2003: 18).

1.4   Research objectives and questions

This dissertation aims to develop evidenced-based conclusions as to whether or not FBOs are distinctive and have a comparative advantage in the care of PLWHA. In order to do so it will explore whether SHBC and TASC take a holistic approach to

meeting the needs of PLWHA, analysing the impact of their activities on the health-related quality of life (HRQOL) of PLWHA. In line with the research aim the following research objectives have been identified:

a. To understand the role of FBOs in the delivery of HIV/AIDS related prevention, care and treatment services in Swaziland.

b. To understand the role of secular NGOs in the delivery of HIV/AIDS related prevention, care and treatment services in Swaziland.

c. To explore whether FBOs are distinctive in their provision of services for PLWHA, in comparison to secular NGOs.

Based upon the aims and objectives of the study, the primary research question this research project aims to answer is:

Are the services FBOs provide for PLWHA more holistic in their nature than those of secular NGOs?

The following sub-questions have been identified, which assist in answering the primary research question:

1. To what extent do the services offered by FBOs improve the HRQOL of PLWHA?

2. To what extent do the services offered by secular NGOs improve the HRQOL of PLWHA?

1.5   Methodology

This dissertation adopts a case study approach. Rakodi (2011b) holds that a comparative study which identifies similarities and differences between FBOs and secular organisations is necessary in order to determine the distinctiveness of FBOs. A case study approach is therefore a suitable research method for the aims of this study. Case studies also allow the researcher to obtain conceptual validity (George and Bennett 2004). Although it can be problematic to make generalisations from a case study, the approach facilitates a deeper understanding of the role of FBOs in the care of PLWHA in Swaziland in comparison to secular organisations. Case study

findings can also help to inform the relevance of the development interventions of the organisations being studied (McGregor 2006). A case study approach is also in keeping with the qualitative nature of the research being conducted and the small purposive sampling technique used (Mayoux 2006). A qualitative approach is appropriate for the dissertation as "qualitative methods have been shown to be effective in investigating health in developing countries" (Root and Whiteside 2013: 3).

The study will focus on Swaziland. Swaziland is ranked 148 on the human development index, being classified as having low human development (UNDP 2014). Swaziland also has the highest prevalence of HIV/AIDS in the world (Hickel 2012; van Wyngaard 2013). As mentioned, Swaziland has experienced an economic downturn in recent years and therefore the government faces limited financial capacities (Whiteside and Whalley 2007; van Wyngaard 2013). Developing an understanding of the role that FBOs may play in service provision and the care of PLWHA in Swaziland is therefore of critical importance. Specifically, this dissertation focuses on Shiselweni as it is the most underdeveloped region in Swaziland. In their 2007 Poverty Reduction Strategy and Action Plan, the Swaziland Ministry of Economic Planning and Development (2007) recorded the prevalence of poverty in Shiselweni to be as high as 76%. The low incomes faced by the majority of the Shiselweni population limit their ability to access the goods and services necessary to meet their basic needs. These challenges are compounded by the region being poorly serviced, with a lack of access to transportation systems and medical facilities; "only 3.5% of households travel less than 30 minutes to the nearest health facility" (Ministry of Economic Planning and Development 2007: 67). PLWHA living in the region therefore face significant barriers in accessing sufficient HIV/AIDS related treatment, care and support. The research draws on two case studies: SHBC, a FBO, and TASC, a secular NGO. These organisations were selected as both are well-established indigenous organisations and operate HIV/AIDS related programmes in the southern Shiselweni region. SHBC has also been identified by Robin Root as a "best practices case study", for assessing the contribution of FBOs in the care of PLWHA (Root cited in van Wyngaard 2014: 6).

As well as utilising literature on the role of FBOs and CSOs in development, this dissertation also utilises the findings from primary research as there was minimal secondary data available. The qualitative questionnaire (*see Appendix 1)* provided a flexible research design which could be tailored to the research topic and facilitate flexible responses, helping to ensure the relevance of the findings (Simon 2006). The questionnaire helps to garner an understanding of the activities the organisations carry out and the types of needs of PLWHA these meet, subsequently helping answer the research questions. The questionnaire was distributed via email. Although questionnaires distributed via email often have lower response rates than other methods, such as face to face interviews (De Vaus 2002), it is the most appropriate method for use in this study. This is due to geographic and time constraints. Owing to the limited sample size and seeking the prior agreement of the SHBC and TASC to participate in the research, low response rates were not of particular concern for this study. In order to analyse the findings of the questionnaire and the comparative case study more widely, this dissertation uses an objective, needs-based approach to QOL. This approach was chosen as it helps the researcher compare and determine the impact of SHBC's and TASC's activities on the HRQOL of PLWHA.

In determining the impact of SHBC's and TASC's activities on the HRQOL of PLWHA, this dissertation is limited in its scope and remit as the researcher was unable to obtain the opinions of individual beneficiaries. This may be perceived as a study limitation because subjective definitions of QOL emphasise the importance of gaining individual beneficiaries' perceptions, as will be outlined in chapter 2. Instead, the questionnaire invited SHBC and TASC to give their perception of the impact their activities have on the QOL of PLWHA. This did, however, leave the study open to response bias as it required the participating organisations to give an honest and accurate reflection of their own work. This potential study limitation applies to the questionnaire more generally. Self-report methods can be open to response bias in that organisations may emphasise positive aspects of their organisation and activities and under-report anything that may not be perceived as desirable by the researcher (Furnham 1986; Donaldson and Grant-Vallone 2002). Response bias can undermine the validity of research findings and any theoretical conclusions drawn from them

(Donaldson and Grant-Vallone 2002). In an attempt to limit response bias the researcher ensured the questionnaire did not contain any leading questions and placed no pressure on the organisations to give a certain type of answer; situational pressure to give a socially desirable response is one factor that can motivate individuals to give a bias response (Donaldson and Grant-Vallone 2002).

The researcher recognises that historically literature has focused on the role of Christian FBOs in development, rather than FBOs of other faith backgrounds (Berger 2003). Despite this recognition this dissertation focuses on the work of SHBC, a Christian FBO. It does so as Christianity is "by far the most predominant faith" in Swaziland (van Wyngaard 2013: 229) and has the largest following of any of the major world religions (Clarke and Jennings 2008). Among the limitations of this study, therefore, is the difficulty of drawing generalisations from the findings in relation to the activities of FBOs from other faith backgrounds and traditions. The research findings will also be limited in scope and generalizability due to focusing on only one country case study and a comparison of only two organisations. However, a limited in depth case study has potential benefits. Not only are case studies useful for achieving conceptual validity (George and Bennett 2004), they also facilitate inductive reasoning and further "understanding of the important aspects of a new or persistently problematic research area" (Punch 2005: 147-148). This is important due to the contested role of FBOs in development. In consideration of the above, a comparative case study is the most suitable methodology for the purposes of this dissertation.

1.6   Structure of the dissertation

The structure of the rest of this dissertation is as follows:

- Chapter 2 – Literature Review
- Chapter 3 – Theoretical Framework
- Chapter 4 – Shiselweni Home-Based Care
- Chapter 5 – The AIDS Information and Support Centre
- Chapter 6 – Conclusion

2. Literature Review

This chapter will briefly analyse the role of CSOs in development, the relationship between faith and development, what is understood as a FBO and the similarities between FBOs and secular CSOs. It will then explore the argument that FBOs have a distinctive ability to "make international development more efficient, effective, and relevant" (Hefferan et al 2009: 6). It will do so making specific reference to HIV/AIDS. The chapter will then explore the needs of PLWHA before outlining critiques made of FBOs.

2.1 The role of civil society organisations

The end of communism and neoliberal policies of structural adjustment pursued during the 1980s, resulted in the generation of a 'third sector' and a proliferation of CSOs, including FBOs (Berger 2003; Lunn 2009; Deneulin and Rakodi 2011; Tomalin 2012). CSOs are alternative actors to the state and market, albeit with relationships sometimes existing between them. Through humanitarian relief, advocacy and service delivery, CSOs help ensure the welfare needs and rights of the poor and marginalised are realised (Mitlin et al 2007; Ibrahim and Hulme 2010). CSOs, including both secular NGOs and FBOs, have played an instrumental role both in raising awareness of the effects of HIV/AIDS and the challenges faced by PLWHA, and in the provision of prevention, care and treatment services (Rau 2006). However, the role of faith and FBOs in development has often been contested. Thus the relationship between faith and development and the role of FBOs will now be explored further.

2.2 The relationship between faith and development

In the latter part of the twentieth century into the early twenty first century, the relationship between faith and development moved from one of estrangement to engagement (Clarke and Jennings 2008; Olarinmoye 2012). This challenged the separation of religion, spirituality and faith from development theory and practice, which had occurred through processes of modernisation (Lunn 2009; Tomalin 2012).

The move from estrangement to engagement resulted from recognition that development is a multidimensional phenomenon and that cultural norms and values have a bearing on development (Lunn 2009). This more inclusive view of development recognises the influence religious values and activities can have on development processes (Lunn 2009), with religion and faith being an intrinsic part of culture (UNFPA 2008). This asserts the importance of taking FBOs and – more widely – faith in development seriously.

It should be noted that although the terms faith, spirituality and religion are often used interchangeably, they are distinctive concepts (Tanyi 2002; Cotton et al 2006; Lunn 2009). Spirituality is definable as "human's search for meaning in life", whereas "religion involves an organized entity with rituals about a higher power or God" (Tanyi 2002: 500). Faith on the other hand can be defined as "the human trust or belief in a transcendent reality (although the word faith is also applied in non-religious contexts)" (Lunn 2009: 937-938). To avoid creating confusion this dissertation will refer to spirituality when discussing the needs of PLWHA. It does so as religion and faith also involve a search for meaning in life and therefore spirituality can be used as an all-encompassing term within this context.

Estrangement

It is well noted in the literature that religion, spirituality and faith have historically not been given sufficient attention in development theory, policy and practice (Lunn 2009; Rakodi 2011b). In an attempt to try and ensure religion and politics did not make revival claims to power (Ellis and Ter Haar 2004), European colonies often tried to separate the state from religion (Ter Haar 2011). Post-colonial governments also often neglected the role of religion, faith and spirituality in development, seeking to emulate the Western trajectory of development, which saw the secularisation of the public sphere (Deneulin and Rakodi 2011; Tomalin 2012). As secularisation theory holds, "religious institutions, actions and consciousness lose their social significance over time as societies modernise" (Clarke 2007: 77). However, Berger (2003)

stipulates that the move of religion from the public to private sphere is traceable to the post-Enlightenment period.

Engagement

It has been increasingly recognised that faith and development exist not as independent variables, but as interconnected spheres (Rakodi 2011b). Within the 1980 *World Development* issue on Religion and Development, Wilber and Jameson, in keeping with the impasse of development, claimed there was a need to rethink the dominant development paradigm of economic growth and the relationship between religion and development. In supporting such a position, Goulet referred to the work of Lebret, a social scientist and philosopher who held that "development is cultural and spiritual as well as economic and political" (Goulet 1980: 481). Despite these arguments being made in the 1980s it was not until the late twentieth, early twenty first century when the role of faith in development started to be given serious consideration. The realisation that religious adherence does not necessarily decline as countries modernise and develop (Berger 2003; Deneulin and Rakodi 2011; Marshall 2011; Olarinmoye 2012), has resulted positively in governments and donor agencies paying attention to the role of religion and faith, and specifically FBOs, in development (James 2011; Rakodi 2011b).

The World Bank *Voices of the Poor* study also emphasised the centrality of religion in many people's lives and the fact that religious organisations are part of the institutional makeup of civil society (Narayan et al 2000b). Dilulio (2002: 50) emphasises the impact religion can have on individuals' lives and societies more widely, stating: "religion can improve individual well-being and ameliorate specific social problems". The potential of FBOs has also gained increased attention since the Millennium Declaration. They are seen to hold significant potential to mobilise support for the achievement of the MDGs (Clarke and Jennings 2008; Deneulin and Rakodi 2011; Tomalin 2012). For example, in 2006 Gordon Brown "launched a £2.1 billion ($4 billion) bond to finance a global immunization programme for under-fives" against polio, measles, diphtheria and hepatitis (Clarke and Jennings 2008: 3).

Members and organisations of the faith community – including the Archbishop of Canterbury, the Hindu Forum of Britain and the Network of Sikh Organisations – responded by pledging their support and purchasing some of these bonds (Clarke and Jennings 2008). World Bank General Secretary Ban Ki Moon can be seen to be supportive of the argument that FBOs can contribute to development related aims and should be taken seriously as civil society actors. The following assertion he made in 2009 evidences this: "I have long believed that when governments and civil society work toward a common goal transformational change is possible. Faiths and religions are a central part of that equation" (Cited in Karam 2013: 91).

In recent decades faith communities and organisations have played a vital role in the abolition of apartheid and in international campaigns and movements, such as Jubilee 2000 and Make Poverty History (Berger 2003). This highlights the increasing presence of faith-based activism and advocacy (Clarke 2007; Hefferan et al 2009; James 2009) which has the potential to generate social change (Rakodi 2011b). Hence, FBOs can be seen as 'drivers of change' through which development and social justice related objectives are pursued (Wolfensohn 2011; Jakobsson 2013). FBOs are also sources of social capital, in particular bridging and linking social capital. They mobilise volunteers and financial resources and foster commitment to social justice (Furbey et al 2006; Karam 2013; Malda-Douma 2013). This can be more specifically referred to as spiritual capital (Dilulio 2002). However, these qualities of FBOs may also be attributable to secular CSOs. The similarities and differences between FBOs and secular CSOs therefore require exploration. Before doing so, however, it is necessary to define what is understood by the term FBO.

2.3 Defining 'faith-based organisation'

Even prior to structural adjustment programmes (SAPs), faith communities and FBOs played an important role in lobbying, advocating and providing services to meet the needs of the poor and marginalised (Ferris 2005; Lipsky 2011; Leurs 2012; Olarinmoye 2012). This is arguably especially true in societies where religion is an integral part of culture (UNFPA 2008), as concepts of charity are firmly embedded

within many of the world religions (Cohen 2005). The key shift that occurred as a result of SAPs was that many existing faith communities, including organised religious actors, reconceptualised themselves as FBOs in order to take advantage of the new donor interest and funding available (Leurs 2012). Resultant, FBOs are difficult to define, categorise and sometimes distinguish from secular organisations due to their heterogeneous nature (Sider and Unruh 2004; Lunn 2009; Tomalin 2012).

FBOs vary in scale, scope, goals, organisational structure, activities, funding sources, and their relationships with external agencies (James 2009; Clarke 2010; Rakodi 2011b). FBOs also derive their ethos and base their activities upon different belief systems (Clarke and Jennings 2008; Clarke 2010). Another variable includes the way faith manifests itself in the work of FBOS (Sider and Unruh 2004; Hefferan et al 2009; Clarke 2010). FBOs may, for example, only have a loose connection with a religion or may be explicitly religious in all they do (Sider and Unruh 2004). Reflective of these numerous variables there is no one definition of a FBO.

This dissertation uses the following definition: "an organisation is faith-based (or faith-related) when its mission and identity are self-consciously derived from the teachings of one or more religious or spiritual traditions" (Lipsky 2011: 25). This definition is inclusive of both formal and informal organisations. To exclude organisations not associated with an organised religion or formally registered as a non-profit organisation would "exclude much religiously inspired development work with which donors might usefully engage" (Tomalin 2012: 693). As Clarke (2013) recognises, not all FBOs are NGOs. It also helps to overcome the concern of Jeavons (2004) that the term FBO implies a Christian religious tradition; the definition recognises that FBOs may not always be influenced by a single religious or spiritual tradition. This is especially relevant in contexts such as Swaziland, where a plethora of spiritual and religious traditions and practices exist (van Wyngaard 2013).

2.4   Similarities between FBOs and secular NGOs

Similarities can be drawn between FBOs and secular NGOs. These include their ability to mobilise volunteer and financial resources, having links to the grassroots, being not for profit and being self-governing entities (Ferris 2005; Rau 2006; Rakodi 2011b; Leurs 2012; Olarinmoye 2012). Having grassroots connections is beneficial for increasing the effectiveness and relevance of development interventions, as organisations are able to respond to the real instead of perceived needs of poor and marginalised communities (Ferris 2005; Ibrahim and Hulme 2010; Leurs 2012). Common ground also lies in their commitment to reduce poverty, promote human development and pursue social justice (Marshall and Van Saanen 2007; Ter Haar 2011). It is significant that the Millennium Summit was the month after the Millennium World Peace Summit of Religious and Spiritual Leaders. The latter saw religious and spiritual leaders come together to discuss and emphasise the importance of urgently addressing global inequities (Marhsall and Van Saanen 2007). The Millennium Declaration has therefore been understood by some to be "an agreement with quasi-religious or spiritual significance" (Clarke and Jennings 2008: 2). In consideration of the similarities discussed, generalised assumptions of FBOs' distinctiveness are problematic. Indeed some studies, such as that by Smith et al [n.d: 20] find "few distinctive differences between FBOs and secular organizations", including in their "commitment to holistic services". Hence, it is necessary to further critically explore claims of FBOs' distinctiveness.

2.5 The distinctiveness of FBOs

As mentioned in chapter 1, some scholars hold FBOs to have a comparative advantage over secular organisations. However, as various types of FBOs and secular NGOs exist, it is arguably not possible to make such sweeping generalisations (Tomalin 2012). Rakodi (2011b) suggests it is more appropriate to ask questions about the distinctiveness of contributions made by FBOs in development. This dissertation will now outline some reasons why FBOs may be understood to have a distinctive ability to increase the efficiency, effectiveness, and relevance of international development, with specific relation to the HIV/AIDS pandemic.

Efficiency

It is significant that FBOs provide up to 40% of health care services in sub-Saharan Africa (PEPFAR 2012), including notable levels of HIV/AIDS related services (UNAIDS 2009; Doyal and Doyal 2013). This evidences the role of FBOs in filling gaps in government service provision (Parry 2003; PEPFAR 2012). The positive roles FBOs undertake in fighting HIV/AIDS include: the provision of voluntary counselling and testing (VCT); caring for orphans and vulnerable children (OVC); working to prevent mother-to-child transmissions (MTCT); providing home-based care (HBC) and conducting awareness and educational campaigns (PEPFAR 2012). Although many secular NGOs also provide such services, FBOs are commended in literature for their ability to mobilise significant volunteer and financial resources to ensure such action is sustained (Ferris 2005; James 2009; James 2011; Tomalin 2012; Karam 2013). Supportive, the World Council of Churches generates and allocates billions of dollars a year for development purposes (Ferris 2005). This ability results from religious practices of tithing and supporting charities, and the ethical values of compassion, justice and reconciliation (James 2009).

Effectiveness

Due to the presence of faith institutions in many poor rural communities, FBOs often exist in the most rural hard to reach communities (James 2009). Some case studies have shown that this increases the effectiveness of FBOs in improving the access of rural communities to HIV/AIDS prevention and mitigation programmes (Leurs 2012). The centrality and longevity of the presence of faith institutions in many communities also means that poor and marginalised communities often trust FBOs more than their secular counterparts (James 2009; Marshall 2011; Rakodi 2011b; Olarinmoye 2012; Tomalin 2012). The latter can be understood to make FBOs distinctive in comparison to other grassroots organisations.

The effectiveness of FBOs in responding to the HIV/AIDS pandemic can also be attributed to their belief and values systems. Key to prevention efforts, FBOs may

promote values and behaviours which minimise the number of sexual partners people have, and hence reduce the risk of spreading HIV/AIDS. These include abstinence, marriage and faithfulness (Dixon 2010; Lipsky 2011; Rakodi 2011b; Leurs 2012). However, it is important to remember that not all FBOs have the same value systems. As will be outlined later, some FBOs have been criticised for promoting stigma and discrimination or condemning the use of condoms (Marshall and Van Saanen 2007). In addition, alongside behavioural approaches, structural determinants of the spread of HIV/AIDS require sufficient attention. Demonstrative, in Swaziland neoliberal economic policies have increased unemployment, subsequently increasing labour migration amongst men and transactional and commercial sex amongst women (Hickel 2012).

Relevance

One way FBOs can increase the relevance of development is to meet the needs of individuals holistically (James 2011). As Parry (2003) notes, part of the services some FBOs provide is the spiritual care of PLWHA; they do not merely focus on the physical, psychological and socioeconomic needs of PLWHA. This increases the relevance of HIV/AIDS prevention and care programmes as not only is poverty multidimensional but religion, faith and spirituality play a central role in the lives of millions of individuals (Berger 2003; Deneulin and Rakodi 2011; Olarinmoye 2012). The needs of PLWHA will now be briefly explored, before being returned to in more detail in chapter 3. This dissertation will then explore some critiques of FBOs.

2.6   The needs of people living with HIV/AIDS

ART therapy has extended the life expectancy of HIV positive individuals (Grossman et al 2003), reducing immortality by up to 80% (WHO 2002). Resultant, there is concern with both the length and quality of life for PLWHA (Seed and Lloyd 1997; Phaladze et al 2005; Pei-Chen Fan et al 2011; Ntshakala et al 2012). It is widely accepted that the goal of providing treatment, care and support to PLWHA is not just to decrease mortality and morbidity or prevent the further spread of HIV infection,

but to improve the QOL of PLWHA (UNAIDS and WHO 2000; Grossman et al 2003). It is significant that the WHO defines health as not just the absence of disease but "a state of complete physical, mental and social well-being" (WHO 1997: 1). Hence, the needs of PLWHA extend beyond their physical health needs to their psychological health and levels of social support. However, it is important to remember that an individual's QOL can also be determined by spirituality. As Seed and Lloyd (1997) recognise in their definition of holistic, individuals have spiritual needs. Spirituality can act as important coping mechanisms for PLWHA, thereby positively impacting upon their mental, emotional and physical health (Cotton et al 2006; Tsevat 2006; Ridge et al 2008; Dalmida et al 2009). It can also positively increase the levels of social support received by PLWHA (Tuck et al 2001). The inclusion of physical, psychological, social and spiritual domains in the needs of PLWHA is supported by O'Boyle and Waldron (1997: S22) who state that the central tenets of palliative care are as follows "control of pain, of other symptoms, and of psychological, social and spiritual problems" (O'Boyle and Waldron 1997: S22). It is also supported by the WHO (1997), who identify spiritual as a QOL domain, and Cicely Saunders' concept of total pain. The latter theorises that there are four sources of pain, each of which impacts the health and palliative care of individuals: physical, emotional, spiritual and social (Howard 2001).

2.7   Critiques of FBOs

An understanding of the criticisms made of FBOs is necessary for an appreciation of the reasons why some donors, government and international development agencies may be cautious in engaging with FBOs (Olarinmoye 2012). Although this dissertation will now assess some generalised critiques made against FBOs it should be remembered that FBOs are heterogeneous.

FBOs have often been treated with caution as faith identities can be "divisive" and "dangerous" (Marshall 2011: 41). They hold the potential to cause conflict between different faith groups, subsequently leading to violence, poverty and displacement (Narayan et al 2000a; Lunn 2009). 9/11 evidenced the "rise of religious identities"

(Tomalin 2012: 691) and demonstrated "the power of religious faith to motivate extreme action" (James 2011: 114) which can prevent progressive social change and egalitarian democracy (Rakodi 2011b). Many donors also fear that evangelical FBOs will not respect the traditional spiritual and religious beliefs of the communities and individuals they are assisting, or give preference to individuals from the same faith tradition (Berger 2003; Ferris 2005; James 2011; Rakodi 2011b).

For the purposes of securing donor funding, some FBOs have therefore downplayed their "religious identity and motives" (Tomalin 2012: 690) or separated faith-based and non-faith-based elements of their programmes (James 2009). Hence, FBOs may compromise their distinctiveness, making it more difficult to distinguish them from secular organisations (James 2009). This is problematic given that one of FBOs' greatest perceived advantages is their ability to meet both the spiritual and material needs of individuals (Narayan et al 2000a). It is therefore imperative to understand the ways in which faith beliefs and motives penetrate and influence FBOs and whether they will be either conductive or a hindrance to development (James 2011; Rakodi 2011b).

In relation to HIV/AIDS, faith communities and FBOs have been critiqued for their role in exacerbating the stigma and discrimination experienced by PLWHA (Parry 2003; Progressio 2011; Nilsson and Moksnes 2013). They have done so through perceiving HIV/AIDS to be a consequence of sinful and promiscuous behaviour, including same gender, pre-marital or extra-marital sex (World Bank 1997; Kopelman 2002; Trinitapoli 2006; Doyal and Doyal 2013). This is known as the "punishment theory of disease" (Kopelman 2002: 231). Stigma and discrimination are problematic as they increase the reluctance of PLWHA to access health services thereby negatively affecting their health and QOL (Holzemer and Uys 2004; UNAIDS 2010b). However, FBOs may also challenge stigma and discrimination; some faith leaders and organisations have spoken out against HIV/AIDS being seen as a consequence of sinful behaviour (Keikelame et al 2010; Marshall 2011). FBOs' active participation in service delivery for HIV/AIDS patients also helps to tackle stigma and discrimination

through their display of compassion and indirect message that PLWHA are still worthy of care and support (Parry 2003; Progressio 2011).

The role of FBOs in the prevention of HIV/AIDS also comes into dispute when condom use is raised. Condom use is the final element of the 'ABC' strategy promoted by PEPFAR, standing for 'Abstinence, Be faithful, and Correct and consistent condom use'. Although some Churches and FBOs promote the use of condoms (Dixon 2010), Benagiano et al (2011) highlights that the Roman Catholic Church and some associated organisations have condoned the use of 'artificial contraception'. Although perceptions on the matter have now on the majority changed in the Roman Catholic Church, some individuals still maintain their conservative Catholic position (Benagiano et al 2011).

Other FBOs promote patriarchal norms and values (Seguino 2011), which can problematically manifest in GBV and diminish the ability of women to ask their sexual partners to use sexual protection measures (Jewkes et al 2003). In such cases, the values promoted by some FBOs may be seen as an obstacle to the promotion of human rights and gender equality (Rakodi 2011a; Rakodi 2011b). In order to prevent females contracting HIV it is therefore vital that FBOs, alongside other CSOs and government agencies, promote gender equality and women's empowerment (Parry 2003; James 2011). This includes economic empowerment in order that women do not remain in abusive relationships for means of economic security (UNAIDS 2010a).

2.8 Conclusion

The literature review has shown that CSOs, including FBOs, play a vital role in the provision of HIV/AIDS prevention, treatment and care services. Although similarities can be drawn between secular and faith-based CSOs, FBOs are held to have distinctive qualities, such as their ability to meet the holistic needs of individuals, which positively contributes to the QOL of PLWHA. However, FBOs may also face criticism. Discerning both the advantages and criticisms of FBOs can enable development actors to capitalise on their strengths whilst managing potential

weaknesses. This dissertation therefore aims to facilitate a comparison between the services SHBC and TASC offer PLWHA, allowing evidenced conclusions as to whether FBOs offer a more holistic approach than NGOs in the care of PLWHA.

3. Theoretical Framework

This chapter will define QOL and more specifically HRQOL, before outlining four domains of the needs of PLWHA: physical, psychological, social and spiritual. As will be outlined, these domains not only reflect the definition of holistic offered by Seed and Lloyd (1997) but also definitions of HRQOL.

3.1 Defining and measuring QOL and HRQOL

QOL is a multidimensional concept with no one definition (O'Boyle and Waldron 1997; Bowling 1999; Phaladze et al 2005; Costanza et al 2008; Van Rensburg 2009). The WHO takes a subjective and relative approach to measuring QOL, defining it as "individuals perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO 1997: 1). Costanza et al (2007) define QOL as "how well human needs are met or the extent to which individuals or groups perceive satisfaction or dissatisfaction in various life domains" (Costanza et al 2007: 269). The latter part of the definition, similar to that of the WHO, takes a subjective approach to QOL. However, the former part highlights an objective approach, measuring QOL according to a pre-set category of human needs. As recognised by Bowling (2001) and McKenna and Doward (2004), one of the theoretical approaches most frequently used in assessing QOL is a needs-based approach.

Needs may be relative or universal (Doyal and Gough 1991; Lister 2010). In relation to the former, phenomenologists argue that needs are socially constructed (Doyal and Gough 1991). However, this dissertation recognises that some needs are objective and universal (Phillips 2006), including those enshrined in the Universal Declaration of Human Rights (UNAIDS 2006). This dissertation does however acknowledge that needs may be satisfied differently in different cultures; for example the basic need of adequate nutrition may be satisfied by different foodstuffs (Doyal and Gough 1991; Fraser 1998).

In taking an objective, needs-based approach to QOL this dissertation offers a thin instead of thick conceptualisation of human needs (Fraser 1998; Phillips 2006). It does so as the researcher is unable to obtain subjective perceptions from PLWHA. In addition, subjective opinions and preferences can be problematic for the formation of policy, expressing wants not needs (Doyal and Gough 1991; Lister 2010). Needs, not wants, require satisfying to prevent individuals being 'harmed', therefore implying a sense of duty and obligation on others (Lister 2010). Doyal and Gough (1991: 55) define harm as negative outcomes for individuals' autonomy and survival, and therefore "dramatically impaired participation in a form of life". Need satisfaction is thus central to the promotion of social justice. The existence of the 'happy poor' is also worth mention, with some individuals living in poverty reporting high levels of subjective well-being (Phillips 2006). Problematically, this may be an expression of 'adaptive preferences' (Alkire 2009). For these reasons a personal or experiential approach to QOL may be discredited (Phillips 2006). Hence, this dissertation still finds it appropriate to take an objective needs-based approach. This is despite recognition that some scholars hold subjective wants to be central to human flourishing or critique needs-based approaches for imposing Western conceptions of basic needs (Fraser 1998).

This dissertation specifically focuses on the HRQOL of PLWHA. QOL involves a broader range of dimensions, for example, housing and environmental factors such as pollution, traffic and the climate (WHO 1997; Bowling 2001; Grossman et al 2003). HRQOL on the other hand focuses on the impact of disease on an individual's health, and any treatment and care services they receive (Bowling 1999). It does not just focus on the absence of disease but incorporates positive elements of health status (Bowling 2001). Echoing the WHO's definition of health, HRQOL is a multidimensional concept and is definable as "the social, emotional and physical well-being of patients" (Bowling 1999: 2). However, Bowling's definition of HRQOL can be critiqued for excluding spirituality. As mentioned, spirituality can positively impact upon PLWHA's health. In taking an objective needs-based approach, this dissertation therefore defines HRQOL as 'how well individuals' social, psychological, physical and spiritual needs are met'. In doing so it acknowledges that both medical and non-medical

aspects influence individuals' HRQOL (McKenna and Doward 2004), combining a disease-specific and domain-specific approach to QOL (Bowling 1999; Bowling 2001).

Table 1 outlines the needs of PLWHA according to the HRQOL domains identified. It also outlines how these needs correspond to the two universal primary needs identified by Doyal and Gough (1991): autonomy and physical health. Autonomy involves individuals having the ability and confidence to formulate beliefs and make rational decisions (Doyal and Gough 1991). They argue that it is the fulfilment of these two universal and objective human needs which prevents harm and promotes individuals' participation in society. They therefore take a functionalist approach to QOL, "which relates to the ability to perform activities of daily living (ADL) and fulfil role obligations" (Bowling 2001: 6).

Table 1: The needs of PLWHA

HRQOL Domain	Needs of PLWHA/Satisfiers	Primary need
Physical	Access to safe water and sanitation	Physical health
	Adequate nutrition	
	Accessibility of quality health and social care	
Psychological	Psychological support	Autonomy and physical health
Social	Social support	Autonomy and physical health
	Sexual and reproductive health services	
Spiritual	Spiritual care	Autonomy and physical health

As there is no agreed upon list of the needs of PLWHA, the needs listed were identified through an assessment of the literature on QOL and HRQOL of PLWHA and those with chronic illnesses. The list also combines elements from well-established and utilised QOL and HRQOL measurement tools, some of which are specific to HIV/AIDS. These tools include the WHO-HIV BREF (WHO 2002), the SF-36, the FAHI (Grossman et al 2003), and the HIV-QOL Questionnaire (HIV-QL31) (Grossman et al 2003). Facets common to these tools include: physical function and needs, including access to health and social care and nutritional intake; psychological health; level of independence, including ability to engage in ADL; social relationships; disease symptoms; and management (WHO 2002; Grossman et al 2003). Of the above only the WHO-HIV BREF includes a facet of spirituality/religion/personal beliefs. This is

problematic as scholars such as Soper hold spirituality to be central to human flourishing (Soper 1993). Furthermore, as outlined, meeting the spiritual needs of PLWHA can positively benefit their physical and psychological health. This dissertation will now explore in more detail the needs of PLWHA.

3.2 Physical needs of PLWHA

Access to safe water and sanitation

Although access to safe water and sanitation is a human right of all individuals, it is a key physical need of PLWHA. HIV/AIDS related symptoms such as fever and diarrhoea increase the need for access to clean water and sanitation facilities. Such facilities also minimise the risk of those with weakened immune systems contracting secondary infections (Magrath 2006; Keregero and Allen 2011). Due to social and cultural gender norms, it is usually a female's responsibility to fetch water. In resource poor rural settings women may have to travel long distances to collect water. This may eventually be prevented due to ill health (Haddad and Gillespie 2001; Wegelin-Schuringa and Kamminga 2006). Thus increasing ease of access to clean water will help to ensure women and their families have access to clean water regardless of the stage of HIV/AIDS progression. The above concerns are of particular relevance for PLWHA in rural Shiselweni given that access to safe water in Swaziland is characterised by regional inequality, with "access to safe drinking water at 87 per cent in urban areas and 51 per cent in rural areas" (Keregero and Allen 2011: 4).

Adequate nutrition

Adequate nutrition is a universal right and health need (Fraser 1998). It is also central to the HRQOL of PLWHA. Insufficient nutrition increases individuals' susceptibility to HIV infection and re-infection (Whiteside and Whalley 2007), and increases the likelihood of MTCT (Haddad and Gillespie 2001). It also further weakens PLWHAs' immune systems, increasing susceptibility to opportunistic infections (OIs) (Grossman et al 2003; WHO 2003; Baingana et al 2005; WFP et al 2008). Malnourishment also

undermines ART effectiveness, increases its side effects or causes HIV to progress to AIDS faster (Uwimana and Struthers 2007; Whiteside and Whalley 2007; WFP et al 2008; Root and van Wyngaard 2011). Adequate nutrition can avert some of these potential negative outcomes by improving adherence to ART, delaying disease progression, reducing fatigue and increasing PLWHAs' physical strength (Grossman et al 2003; WHO 2003; WFP et al 2008; Mukherjee 2008). This is significant as the WHO-HIV BREF identifies energy and fatigue as central to QOL (WHO 2002). Through promoting adherence and hence physical health, adequate nutrition promotes PLWHAs' physical ability to engage in paid employment, thereby reducing poverty and food insecurity (WFP et al 2008). As Phaladze et al (2005) emphasise, poverty and malnutrition are inherently linked. Along with recognition that poverty limits individuals' access to health care (Khamarko and Myers 2013), this justifies why the questionnaire questions the impact of TASC's and SHBC's activities on PLWHAs' income. However, it should be noted that the nutritional needs of PLWHA may vary, dependent upon factors such as age, stage of disease progression and whether nutritional deficiencies are already present (WHO 2003).

Accessibility of quality health and social care

The accessibility and quality of health and social care is an important aspect of individuals' HRQOL (WHO 1997). Access to health facilities, services and medicines is also a human right, as enshrined in Article 12 of the International Covenant on Economic, Social and Cultural Rights which outlines the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health" (WHO and WPCA 2014: 9). Apart from access to ART, palliative care which assesses and controls pain and other symptoms being experienced can positively impact HRQOL (WHO and WPCA 2014). This includes managing side effects of ART (Kennedy et al 2004). Those PLWHA with fewer or no symptoms are also better able to perform ADL (Uwimana and Struthers 2007). Access to medical treatment is of central concern for PLWHA, given that as HIV weakens the immune system they are more susceptible to contractcting OIs (Fallowfield 1990; Whiteside and Whalley 2007; Doyal and Doyal 2013). It is problematic that structural inequalities, including TRIPS trade agreements,

and a shortage of trained health care professionals, mean that antiretroviral drugs and analgesics remain inaccessible to millions of people living in resource poor settings, including Swaziland (Uwimana and Struthers 2007; Harding et al 2010; Hickel 2012). A distinction between formal and informal health care sectors is useful here (Zamberia 2011; Ntshakala et al 2012). Formal health care, based on Western medicine, may be inaccessible to PLWHA in low income and rural settings (Keregero and Allen 2011; Ntshakala et al 2012). In addition, the scale of both the HIV/AIDS and tuberculosis (TB) pandemic in Swaziland is burdening formal public health systems, with need outweighing capacity (Whiteside and Whaley 2007). In such contexts PLWHA may turn to traditional healers and family for treatment and care (Ntshakala et al 2012).

3.3 Psychological needs of PLWHA

Psychological support

Diagnosis of a chronic illness such as HIV/AIDS can negatively affect individuals' psychological health; hence psychological pain is encompassed with the concept of total pain (Howard 2001). Substance abuse, anxiety, stress, depression and low self-esteem are all potential effects of living with HIV/AIDS (Fallowfield 1990; Kuyken et al 1994; Baingana et al 2005). Improving positive feelings, mitigating negative feelings and increasing self-esteem all help to improve HRQOL (WHO 2002). Stigma and discrimination may exacerbate the psychological distress of PLWHA (Fallowfield 1990; Baingana et al 2005; Doyal and Doyal 2013). Psychological distress can outplay in behaviours which hinder treatment and efforts to prevent disease transmission. These include: not accessing treatment and support, non-compliance with prescribed medication regimes and engagement in high risk behaviours (Baingana et al 2005; Kennedy et al 2004 Zamberia 2011). Non-adherence to ART regimes is problematic for both individuals' and the public's health. Not only does it negatively affect the viral load of PLWHA, it can also lead to drug resistant strains of the HIV disease developing (Kalichman et al 1999; Hegazi et al 2010). Hence, psychological support is central to palliative care (Uwimana and Struthers 2007).

3.4 Social needs of PLWHA

Social support

When individuals' health is negatively affected by a chronic illness such as HIV/AIDS, they may become increasingly dependent on others. This can result in distress, or what has been termed 'social pain' for the individual (Howard 2001). Hence, to promote PLWHAs' HRQOL sufficient levels of social support are needed (Grossman et al 2003). Social support is definable as "the perception or experience that one is loved and cared for by others, esteemed and valued, and part of a social network of mutual assistance and obligations" (Khamarko and Myers 2013: 2–3). Social relationships are thought to have a causal impact on health (House et al 1981).

Building on the earlier work of House et al (1980), Khamarko and Myers (2013) list four types of social support: informational, instrumental, emotional and appraisal. Each of these can impact the HRQOL of PLWHA. Firstly, informational support provides PLWHA with information and guidance to help them manage their health, including how to correctly take ART medication (Khamarko and Myers 2013). Secondly, instrumental support involves the provision of material, financial or personnel resources. This could include HBC or the provision of food. Thirdly, emotional support involves PLWHA having a social network which provides them with encouragement and affection, thereby improving their psychosocial health (Khamarko and Myers 2013). Fourthly, appraisal support involves the extent to which individuals are socially integrated into society and the number of social relationships they have (Khamarko and Myers 2013). Stigma and discrimination can negatively affect the social support available to PLWHA. It may even result in PLWHA being denied access to health care and employment (ILO 2003; Doyal and Doyal 2013). Hence, stigma and discrimination carry a double burden: causing potential job loss and thus, for example, food insecurity, whilst diminishing levels of social support available (Tsai et al 2011). Social capital, definable as "the strength of associational life, trust, and norms of reciprocity", may thus deteriorate (Haddad and Gillespie 2001: 490) and the physical and psychological health of PLWHA be negatively affected (ILO 2003). Doyal and Gough (1991) recognise that social isolation may cause

low self-esteem and increase depression and anxiety, diminishing autonomy. Hence, social support helps improve both ART adherence and autonomy (Kennedy et al 2004). The idea that social exclusion can induce depressive symptoms and suicidal thoughts is supportive of Durkheim's earlier study findings on suicide (House et al 1988).

The social relationship facets listed in the WHO-HIV BREF are supportive of the social support dimensions outlined above (WHO 2002): personal relationships, social support and social inclusion. The WHO-HIV BREF also includes sexual activity (WHO 2002). As will now be outlined, sexual and reproductive health (SRH) services are central to improving the HRQOL of PLWHA.

Sexual and reproductive health services

Doyal and Gough do not include sexual relationship in their list of intermediate needs; those things needed for the satisfaction of basic needs. They claim "some people manage to live healthily and autonomous lives without inter-personal sex" (Gough 2003: 11). However, this dissertation has chosen to include SRH services as sexual relationships can negatively affect the HRQOL of PLWHA. SRH services are central not only to preventing STIs, reinfection or the spread of HIV/AIDS, but also promoting the SRH rights of female PLWHA (Baingana et al 2005; GNP+ et al 2009). Hence, in order that PLWHA are able to participate in safe sexual relationships, access to SRH services is required. Both education on safe sexual practices and the provision of contraception, i.e. condoms, is needed to prevent the spread of HIV and sexual transmitted infections (STIs) (GNP+ et al 2009).

In specific relation to the needs of female PLWHA, globally women are overrepresented amongst the HIV positive population. Not only does their physiology increase their susceptibility to contracting the virus, women's SRH rights are also often undermined in patriarchal societies and they may have minimal control over their SRH choices (Baingana et al 2005; GNP+ et al 2009). Thus, addressing gender inequality and promoting the SRH rights of female PLWHA is vital for preventing HIV/AIDS transmission and addressing human rights abuses, such as GBV.

3.5 Spiritual needs of PLWHA

Spiritual support

Spiritual pain relates not only to fears about the future but also to a loss of hope, meaning and purpose in life. This may result from individuals being diagnosed or living with a chronic illness (Howard 2001). Spiritual beliefs and practices can help chronically ill individuals find a sense of meaning, purpose and hope. This has been evidenced to improve both the physical and psychological health of chronically ill individuals, and thus their QOL (Harrison et al 2001; Cotton et al 2006; Tsevat 2006; Dalmida et al 2009). In relation to psychological health, Cotton et al (2006) found that PLWHA who were part of an organised religion and used their religious beliefs and practices as a positive coping mechanism were more likely to have "greater optimism, greater self-esteem, greater life satisfaction" (Cotton et al 2006: S5). Supportive, the Fetzer Institute (2003) notes that involvement in religious services, prayer and reading the Bible can improve the emotional well-being of individuals. Ridge et al (2008) also find in the study of PLWHA in the UK, that prayer can reduce anxiety. In relation to physical health, Cotton et al (2006) found that individuals who are part of an organised religion where more likely to avoid negative coping behaviours, such as drinking large amounts of alcohol. This is relatable to the values and behaviours that certain religious groups may promote (Fetzer Institute 2003).

The spiritual needs of PLWHA may therefore be met through informal practices such as prayer and meditation or by involving PLWHA in organised religious activities (Doyal and Doyal 2013). It can also be concluded from the above that spiritual care is thus an important part of the care of PLWHA, specifically palliative care (Kellehear 2000; Sepúlveda et al 2002; WHO and WPCA 2014). In recognising the impact spirituality can have on QOL, the WHO identifies it as a key QOL domain (WHO 1997). It is therefore problematic that the basic needs approach which rose to prominence in the 1970s originally neglected spirituality "as a major component of what gives meaning and a sense of purpose to many people's lives" (Deneulin and Rakodi 2011: 46).

3.6 Analytical Framework

Figure 1 shows the relationships that need to be analysed through the case studies in order to answer the primary research question: *Are the services FBOs provide for PLWHA more holistic in their nature than those of secular NGOs?*

Figure 1: Analytical Framework
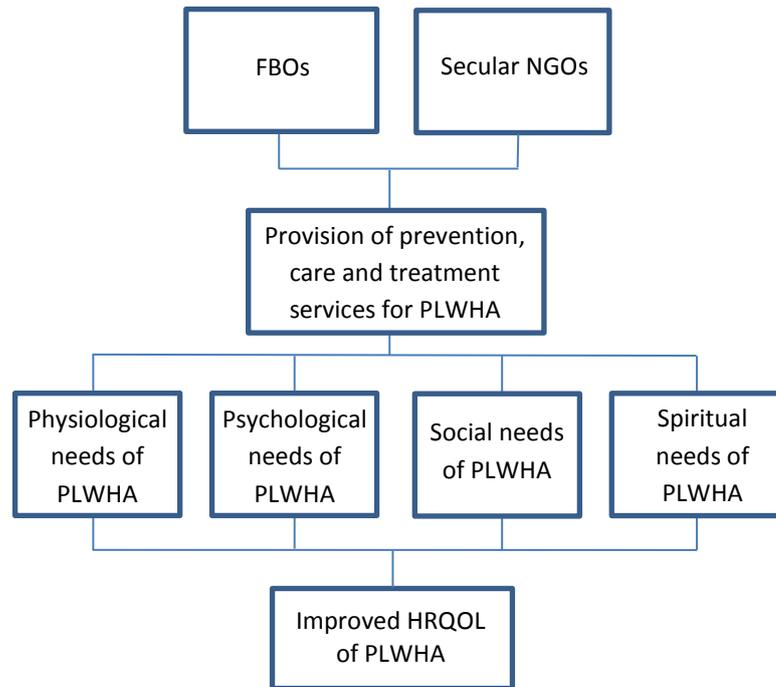
4. Shiselweni Home-Based Care

This chapter will utilise the analytical framework outlined in chapter 3 to analyse the activities of SHBC, helping answer the following sub-question: *To what extent do the services offered by FBOs improve the HRQOL of PLWHA?*

4.1 Background of SHBC

SHBC is a registered NGO in Shiselweni (Root and van Wyngaard 2011). It was established in 2006 as a ministry of the Swaziland Reformed Church, aiming "To become the hands and feet of Christ in the communities surrounding the church" (van Wyngaard 2013: 229). Hence, a Christian ideological foundation motivates their social action (Root and van Wyngaard 2011; Root et al 2014). As detailed in the questionnaire findings, SHBC provide HBC to PLWHA and individuals with physical disabilities or other medical conditions, including TB and diabetes. They aim to meet the needs of clients holistically (van Wyngaard 2013). Currently, 1009 volunteers provide HBC to over 3800 clients (van Wyngaard 2014). Volunteers conduct home visits in pairs and submit monthly reports to a community coordinator, detailing visits and the health of clients. Community coordinators then submit a monthly report to the regional coordinator who passes the information to Pastor van Wyngaard. This monitoring and evaluation (M&E) system ensures caregivers receive appropriate training and support, promoting quality of care (Root and van Wyngaard 2011; Root and Whiteside 2013).

4.2 Physical needs of PLWHA

Access to safe water and sanitation

As the questionnaire findings highlight, many individuals in Shiselweni lack access to clean water and sanitation. Access to water is constrained by recurring droughts (van Wyngaard and Joubert 2012). Many individuals collect water from contaminated rivers and streams, causing diarrhoeal disease. The questionnaire findings emphasise

that, as is typical of low-income housing, many SHBC clients do not have access to running water and hence use pit latrines, contaminating underground water sources. SHBC have responded to the challenges PLWHA face in accessing clean water by sinking a borehole in both Dwaleni and Matsanjeni. These are deep enough to prevent water contamination from pit latrines (van Wyngaard and Joubert 2012). The questionnaire findings also report SHBC digging a water hole in Dwaleni, filtering underground water through river-sand. In addition, CHBC teach clients to purify water by boiling it or adding Sodium Hypochlorite. SHBC's future aim is to secure donor funding to install wash basins into clients' homes, providing a direct source of clean water (van Wyngaard and Joubert 2012).

Adequate nutrition

As detailed in the questionnaire, SHBC do not currently provide regular food parcels to clients. Instead, to prevent vitamin deficiency they distribute multivitamins. SHBC are only able to distribute food to clients when in receipt of food donations from development agencies, such as the World Food Programme (WFP). They report currently seeking donor support to enable them to supply a powder, containing approximately fifty different vitamins and minerals, once daily to 2000 of their most nutritionally deficient clients. Rather, SHBC currently distribute food parcels quarterly to caregivers as a way of thanking and recompensing them (van Wyngaard 2006a). This may also prevent 'burn out' amongst caregivers; caregivers may be poor or HIV positive, requiring nutritional support (Root et al 2014). However, as highlighted in questionnaire findings, caregivers often voluntarily share their food with clients.

Accessibility of quality health and social care

The 2006–2007 Swaziland Service Available Mapping recorded 27 health facilities in Shiselweni for 24,1365 inhabitants. Shiselweni falls below national averages for doctor to inhabitant ratio, nurse to inhabitant ratio, and midwife to inhabitant ratio (MOHSW et al 2008). The questionnaire details only 4 medical facilities with beds, 13 doctors and 99 nurses in Shiselweni. Limited human resources result not only from

mortality rates but also staff absenteeism; medical professionals may stay home to care for sick family members or may feel overburdened, migrating to find alternative employment (Whiteside and Whalley 2007). The poor health care infrastructure is problematic given the high demand for HIV/AIDS related services. Challenges are further exacerbated by the TB pandemic (Whiteside and Whalley 2007). In such contexts, FBOs such as SHBC help increase accessibility to health and social care (Root 2011). This is of particular relevance given that there is an "estimated one church per 183 Swazis" (Root and van Wyngaard 2011: 1).

As the questionnaire and Root et al (2014) emphasise, the provision of HBC is particularly beneficial for individuals too sick or poor to travel to a clinic or pay for treatment. CHBC volunteers are trained to provide the following basic medical services: basic first aid, palliative care, basic nursing care, infection control, and management of chronic diseases such as HIV/AIDS (Root and van Wyngaard 2011; van Wyngaard 2014). For the treatment of wounds, CHBC are equipped with antiseptic and bandages. CHBC also distribute 'Rehydrat' to clients suffering from diarrhoea, preventing dehydration by replacing lost minerals and electrolytes. In regards to pain relief, SHBC stipulate in the questionnaire that caregivers provide clients with a maximum of four over-the-counter analgesic tablets per visit. This maximum dosage both prevents overdoses and helps ensure clients visit a local health clinic if symptoms are persistent. Clients are also advised to visit a local health clinic or access services provided by other agencies when their medical needs fall outside the remit of SHBC, including for VCT or the distribution of ARV drugs. This emphasises the importance of multisectoral collaborations.

4.3 Psychological needs of PLWHA

Psychological support

Mental illnesses, such as depression and anxiety, may be experienced by PLWHA. This can diminish their cognitive and emotional capacity, negatively affecting their autonomy (Doyal and Gough 1991). SHBC report that they do not offer a professional counselling service. However, caregivers provide PLWHA with someone to confide in.

Studies by Root (2011) and Root et al (2014) highlight that the 'AIDS talk' between caregivers and clients can help clients come to terms with their diagnosis and feel accepted, positively impacting their psychological health. Reflective, SHBC reported that clients often state feeling suicidal prior to receiving support from caregivers.

4.4 Social needs of PLWHA

Social support

1. Informational support

The questionnaire findings detail that during training, caregivers are equipped with knowledge on:

- What is HIV/AIDS?
- How is the virus transmitted? / HIV/AIDS primary prevention
- What are ARVs? / Antiretroviral treatment regimens
- Treatment adherence
- Why is HIV different to other viruses?
- How does the body defend itself?
- Why do so many people with AIDS also contract TB?
- Palliative care
- What causes trauma and how do we handle it?
- HIV testing
- Confidentiality protection
- Positive (secondary) prevention
- HIV/AIDS data collection and reporting
- Qualities of a good care supporter
- Orphan programmes

Hence, caregivers can act as "HIV/AIDS educators", passing some of this knowledge to clients, their families and the wider community (Root and van Wyngaard 2011: 6). This can equip families so they too can respond to the needs of PLWHA (Root and van

Wyngaard 2011; Root et al 2014). Doyal and Gough (1991) stipulate that learning which is culturally and contextually appropriate can enhance individual autonomy. It is thus plausible that caregivers can strengthen PLWHAs' autonomy by increasing their knowledge about HIV/AIDS prevention and treatment available (Doyal and Gough 1991). SHBC report that in educating clients, caregivers encourage ART uptake and adherence and teach PLWHA good personal hygiene practices, helping prevent OIs. These findings are synonymous with those of Doyal and Doyal (2013) who hold sub-optimal adherence to be a consequence of PLWHA not having enough information about ART. This is especially true for complex regimens, which can be difficult to understand and adhere to (Kennedy et al 2004). Hence, increasing PLWHAs' knowledge on positively managing HIV beneficially increases their self-efficacy (Root 2011) , definable as ''the degree to which a person feels that he or she has control over important aspects of his or her life'' (Root and Whiteside 2013: 7–8). Significantly, the questionnaire findings highlight that caregivers can encourage adherence when family members or others are trying to dissuade PLWHA from taking medication due to cultural beliefs which hold traditional medicines to be more effective (Root and van Wyngaard 2011). Hence, caregivers can correct misconceptions, such as the belief that ARV drugs are "unsuitable for Africans" (Doyal and Doyal 2013: 71) or cause people to become sicker (Root and Whiteside 2013). Caregivers can also support parents to ensure HIV-positive children receive ARV syrup twice daily at the correct time (Root et al 2014).

2. Instrumental support

UNAIDS and the WHO (2000) stipulate that social support should include providing food and helping individuals with ADL. In relation to ADL, the questionnaire findings detail that caregivers wash PLWHA who are weak or bedridden. When doing so, they use the same soap hospitals use in pre-operation preparations, killing germs and preventing OIs. Caregivers may also collect water, prepare food, or help feed or toilet clients (van Wyngaard 2006a; Root and van Wyngaard 2011). SHBC also sometimes provide financial support to individuals so they can afford transportation to a clinic (Root 2011). As SHBC and Kennedy et al (2004) report, when clients cannot afford public transport to an ART distribution centre, this discourages ART adherence.

Khamarko and Myers (2013) also mention that financial support is beneficial for ART adherence, improving health outcomes. In consideration of the above, the instrumental support caregivers provide promotes the physical health of PLWHA.

3. Emotional support

Through a supportive and confidential relationship, CHBC provide clients the opportunity to "express grief about being diagnosed" (Root 2011: 12). As both the questionnaire findings and Root and van Wyngaard (2011) highlight, the caregiver–client relationship can help normalise a HIV diagnosis, limiting its potential negative psychological impact. Even though clients may have already accessed formal counselling from a health centre, many report that the relationship with their caregiver is beneficial due to the frequency of visits and the rapport that this generates. Resultant, they may feel more able to be open with caregivers than medical professionals (Root and Whiteside 2013).

4. Appraisal support

As mentioned, stigma and discrimination often result from HIV/AIDS being deemed a consequence of socially undesirable behaviour (Fallowfield 1990). This discourages HIV status disclosure (van Wyngaard 2004). Both questionnaire findings and Root and van Wyngaard (2011) also note that PLWHA may refuse help from a CHBC for fear of their community finding out their status. Problematically, they may continue engaging in high risk behaviours, such as unprotected sex (van Wyngaard 2006b). Both enacted stigma and internalised stigma thus exist as barriers to health seeking behaviour (Progressio 2011; Doyal and Doyal 2013). Denial may also take place at the community or country level, with those not affected by HIV/AIDS denying the impact the disease has. This also limits the levels of support made available to PLWHA (van Wynaard 2004; van Wyngaard 2006b). The questionnaire findings stipulate that SHBC try to tackle denial by helping PLWHA to disclose their HIV status to family members or sexual partners. This encourages acceptance of the existence of HIV/AIDS, can encourage others to seek VCT (Root and Whiteside 2013) and ultimately increases levels of social support available to PLWHA (Kennedy et al 2004). However, Root and

Whiteside (2013) report that families may ridicule PLWHA for their status disclosure. Status disclosures must thus be done in a productive manner. Positively, SHBC can prevent post-disclosure discrimination through increasing HIV/AIDS related knowledge.

However, psychosocial reasons are not the only reasons for PLWHA not seeking social support. PLWHA may not wish to exacerbate the material burden of family members living in poverty. Doing so may cause hostility towards them (Doyal and Doyal 2013). Kin networks may also have disintegrated, resulting from sickness or mortality (Root 2011). In such contexts, religious health assets (RHA), such as the material, psychological and social support provided by CHBC, are important sources of social capital.

Sexual and reproductive health services

As SHBC detail in the questionnaire, SRH services fall outside their scope. However, caregivers distribute condoms and facilitate PLWHA disclosing their status to sexual partners. Hence they try to encourage PLWHA to engage in safe sexual relations (Root and van Wyngaard 2011). The questionnaire also reveals that SHBC promote women's SRH rights by teaching women "to stand up for certain rights, such as insisting that a condom be used if either or both of the spouses are HIV". This is of importance since in patriarchal societies, such as Swaziland, social norms can limit the ability of women to negotiate safe sexual practices (van Wyngaard 2004; van Wyngaard 2006b). The questionnaire also reveals that SHBC promote women's SRH rights through their partnership with NATICC – a faith-based NGO based in Nhlangano, the capital of Shiselweni. SHBC provide clients a toll-free number for NATICC which they can ring if subjected to GBV. NATICC then refer individuals, as appropriate, to the Swaziland Policy Family Protection Unit. This once again highlights the positive impact multisectoral collaborations have in tackling HIV/AIDS.

4.5 Spiritual needs of PLWHA

Spiritual support

The WHO HIV-BREF highlights the following spirituality related QOL facets specific to PLWHA: Forgiveness and Blame, Concerns about the Future, and Death and Dying (WHO 2002). In relation to the former, PLWHA may struggle with "disillusionment with a 'loving' God who could allow this to happen" (van Wyngaard 2013: 231). Family or community members may also blame PLWHA for their status, inducing guilt. SHBC recognises that spiritual care can help to overcome this disillusionment and sense of despair (van Wyngaard 2013). Clients report "having a more positive outlook on the meaning of life", feeling "revived", "uplifted", "more motivated" or loved and accepted by God (van Wyngaard 2013: 237). Such outcomes positively impact upon client's psychological health, decreasing anxiety and depressive symptoms whilst increasing their inner strength and hope. Hope here refers to "coming to peace and finding meaning in life despite the existing circumstances" (van Wyngaard 2013: 232). It can also promote physical health by encouraging ART adherence (van Wyngaard 2013). This sense of acceptance and positive outlook also links to individuals' concerns about the future. In relation to death and dying, those who believe in an afterlife may have less fear of death (van Wyngaard 2013).

Although SHBC caregivers do not have to be professing Christians (van Wyngaard 2013), most caregivers are. In their questionnaire response, SHBC attribute this to Swaziland being a predominately Christian country. The questionnaire findings reveal that, when available, caregivers are given a Bible in siSwati in their first aid backpacks. Caregivers may offer to read passages from this to clients. The questionnaire also stipulates that caregivers, on average at least once a month, may offer to pray with clients. It is commendable that caregivers do not force prayer or Bible readings upon clients (Root 2011; Root and van Wyngaard 2011). As the questionnaire emphasises, their sole aim is not proselytization, but to practically demonstrate God's love. SHBC can be understood to achieve this aim; in previous studies clients report spiritual principles and Christian beliefs being communicated through caregivers' provision of practical and psychosocial support (Root and Whiteside 2013; van Wyngaard 2013).

4.6 Conclusion

This chapter has demonstrated that SHBC helps to improve the physical and psychological health of PLWHA, improves PLWHAs' levels of social support and provides spiritual care to PLWHA. This helps to avoid harm for PLWHA, meaning they are better able to participate in family and community life. Hence, the holistic approach taken by SHBC can be understood to improve the physical health and autonomy of PLWHA and positively impact the HRQOL of PLWHA.

5. The AIDS Information and Support Centre

This chapter will utilise the analytical framework outlined in chapter 3 to analyse the activities of TASC, helping answer the following sub-question: *To what extent do the services offered by secular NGOs improve the HRQOL of PLWHA?*

5.1 Background of TASC

TASC is a secular NGO, registered in 1990. Its mission statement is as follows:

> We strive to reduce the spread of HIV and AIDS in Swaziland through the development and delivery of prevention and education activities. We strive to lessen the impact of HIV and AIDS through appropriate and innovative approaches to treatment, care and support (TASC 2012: 3).

TASC deliver HIV/AIDS prevention, treatment, care and support services in both urban and rural areas, including Shiselweni (TASC 2013). They aim to take a holistic approach in the services they provide (TASC 2013). TASC's questionnaire response identifies their primary stakeholders to be: PLWHA, OVC, economically vulnerable grandmother-headed households, grassroots community based health volunteers (CBHVs), and the general public who utilise HTC and health promotion services.

5.2 Physical needs of PLWHA

Access to safe water and sanitation

According to questionnaire findings, TASC recognise that some PLWHA have difficulty accessing safe water and sanitation. They mention that the use of pit latrines is common in rural areas and where there is no access to clean water individuals may use river or pond water or roof-harvested rain water. Despite acknowledging the challenges some PLWHA face in accessing safe water and sanitation systems, the TASC response does not mention any ways in which they are trying to overcome these.

Adequate nutrition

Literature notes that the provision of food is beneficial for ART adherence (Khamarko and Myers 2013). The questionnaire findings highlight that in recognising malnutrition is problematic for ART adherence, TASC's ART clinics carry out a nutritional assessment with each client. TASC also provides a Food by Prescription (FBP) service for those PLWHA taking ARVs. This FBP service is made possible through TASC's partnership with the World Food Programme (WFP) and Ministry of Health (MOH). In helping PLWHA achieve food security, TASC reports encouraging the formation of support groups and joint livelihoods activities, including home growing. Home growing not only increases nutritional intake, but the sale of produce creates a revenue stream, increasing tangible assets (Landon-Lane 2004). This is of particular relevance given that more than 80% of the Swazi population are engaged in subsistence agriculture (Swaziland National Vulnerability Assessment Committee 2006). As Tsai et al (2011) outline, food insecurity is not only intrinsically linked to poverty but also to levels of social support. When individual PLWHA are too ill to cultivate land or engage in wage labour, support groups can help mitigate potential negative impacts of a livelihood shock by providing financial support to purchase food, food parcels, or encouraging the sharing of meals. It is thus positive that TASC, as will shortly be outlined, encourage the formation of support groups.

Access to quality health and social care

TASC hold health to be a "birth right for everyone", hence aiming to improve the accessibility of health care (TASC 2008a). This includes, as mentioned in their 2013 annual report, increasing access to non-judgemental HIV prevention, care and treatment services for vulnerable and hard to reach groups, known as 'key population' (KP) groups. This is commendable as KP groups, including sex workers, men who have sex with men and intravenous drug users, are disproportionately affected by HIV/AIDS and have previously been left out of many interventions (TASC 2013; WHO 2014).

As detailed in the questionnaire findings and TASC's organisation profile (TASC 2012), TASC operate a mobile outreach programme to help increase the accessibility of health care. This involves the use of both a mobile clinic and CBHVs, targeting 24 remote grassroots communities in the regions of Manzini, Lubombo and Shiselweni. CBHVs provide care and psychological support to PLWHA (TASC 2013). They also refer PLWHA to an ART clinic as necessary (TASC 2008b). Positively, the use of CBHVs has increased the number of people attending HTC centres, increased ART adherence and improved the health and nutritional status of clients (TASC 2013). Similar to SHBC, TASC's CHBCs keep a record of each patient's medical condition. This is useful for M&E purposes (TASC 2008b). The mobile clinics carry out medical and health care assessments of clients, treat minor ailments and OIs and help manage pain. In preventing OIs, including TB, TASC also provides pre-ART care (TASC 2013). In specific relation to TB, the questionnaire also highlights that they provide isoniazid preventative therapy to PLWHA on ART. A portable CD4 analyser is also used by the mobile clinic meaning that results are obtainable in 30 minutes instead of waiting up to two weeks for results from the National Referral hospital (TASC 2013).

In trying to overcome financial barriers to treatment, TASC provide all their services free of charge and dispense government funded ART free of charge (TASC 2013). However, TASC highlight in their questionnaire response that despite the presence of the mobile outreach centres, PLWHA still have to travel on average 8km to access a satellite centre, costing on average E20 (equivalent to £1.17) per person per visit. Given the high poverty rates in Swaziland this may be unaffordable. They also report that PLWHA may incur costs for medication required other than ART. Hence, poverty is a barrier to PLWHA accessing necessary medication and can subsequently increase suffering (Phaladze et al 2005). Problematically, in their questionnaire response, TASC note that lack of donor funding and government support in the form of personnel, mobile units, supplies and medicines, is making it difficult to continue providing adequate levels of care to both urban and rural populations. Drug shortages are of particular concern to TASC given the promotion of the test-and-treat approach; there is a risk that the approach will increase the demand of ARV drugs to a level that outweighs current supply.

5.3 Psychological needs of PLWHA

Psychological support

In their questionnaire response TASC report that counselling is one of their main focuses. Not only do trained counsellors offer counselling to PLWHA, but CBHVs also provide psychosocial support to PLWHA. TASC provide HTC which can help HIV positive individuals to feel like they are still able to live a normal life. It can also enable them to feel comfortable to disclose their status to, for example, their sexual partner or family members (TASC 2013). TASC also report in their questionnaire response, that in the future they plan for their centres to offer a wellness programme to PLWHA. This will include meditation.

5.4 Social needs of PLWHA

Social support

1. Informational support

When asked to detail any ways in which they help to increase the knowledge and awareness amongst PLWHA of how HIV/AIDS is spread and the treatment that is available, TASC mentioned both their mobile outreach programme and the distribution of information, education and communication (IEC) materials. IEC materials include the production and distribution of flyers, booklets, posters and newsletters. TASC also train IEC promoters, lay counsellors and community based peer educators (CBPEs), thereby maximising the reach of their messages. HIV positive individuals are not exempt from undertaking training to become either lay counsellors or CBHV. TASC state in their questionnaire response, those HIV positive individuals who have come to terms with their diagnosis can encourage other HIV positive persons and educate members of the wider population. TASC also operate a toll free HIV and health helpline (TASC 2012), promote safe sex practices and educate PLWHA and their families on how to use home-based care supplies correctly and good hygiene practices in order to prevent OIs (TASC 2008c). TASC report in the

questionnaire that the above activities encourage early health seeking behaviour. Evidencing this, TASC has experienced large numbers of people presenting for HIV testing (TASC 2008a; TASC 2013). The informational support also informs PLWHA how to take medication correctly, encouraging ART adherence (TASC 2013). This improves PLWHAs' health status and their ability to engage in ADL (TASC 2013). TASC also provide life skills sessions at their rural catchment areas, with the aim of increasing the financial security and improving the livelihoods of OVC and grandmothers through the establishment of Income Generating Initiatives (IGIs) (TASC 2013).

2. Instrumental support

During home support visits, peer educators distribute HBC materials such as soap, disposable nappies, gloves and disinfectants (TASC 2008b; TASC 2013). They demonstrate to PLWHA and their families how to use these supplies correctly and inform them of good hygiene practices to prevent OIs, demonstrating a link between informational and instrumental support (TASC 2008c). Peer educators also help critically ill PLWHA with ADL, such as washing laundry, cleaning and cooking (TASC 2008b). TASC also provide instrumental support to OVC and carers, who may be HIV positive, and live in rural impoverished households. They provide school supplies, household items such as blankets and personal hygiene items, medical supplies to alleviate minor ailments, and food supplies and supplements (TASC 2008d; TASC 2013). If the OVC is physically disabled, carers are also provided with disposable nappies, soap, disinfectants and gloves (TASC 2013). This OVC support, however, is limited in its reach with only 25 OVC from selected households receiving this support in 2013 and 1,101 OVC receiving life skills education in 2013 (TASC 2013).

3. Emotional support

In addition to the counselling services TASC provide, PLWHA can also receive emotional support through support groups (TASC 2013). Emotional support is also provided to PLWHA through HTC sessions, run by TASC trained HTC counsellors, and through home visits from TASC trained peer counsellors (TASC 2013).

4. Appraisal support

TASC report in the questionnaire, that health education can help tackle stigma and discrimination. It does so by addressing misconceptions of how HIV/AIDS is transmitted and the perception that HIV positive individuals are to blame for their status; traditional beliefs may hold that HIV is a punishment from God or ancestors for sinful behaviour or is a result of someone being possessed by bad spirits. Health education can therefore "improve tolerance and attitudes towards those infected and affected by HIV/AIDS", promoting social integration (Kanduza 2003: 82). TASC also mention in their questionnaire response that in helping to tackle stigma and discrimination, they ensure PLWHA are represented on their Governing Board and not discriminated against in employment opportunities that arise with the organisation. In promoting the levels of support received by PLWHA TASC report that they encourage the establishment of social support groups. They also empower PLWHA to disclose their HIV status to family members, sexual partners and perhaps members of the community. As mentioned, although this can increase levels of social support available to PLWHA, it must be done sensitively to avoid PLWHA being subjected to stigma and discrimination. In their questionnaire response they state that they are "mindful of the repercussions of such an exposure".

Sexual and reproductive health services

When asked if they offer sexual and reproductive health services to PLWHA and, if so, what types of services they offer, TASC highlighted their provision of prevention of mother-to-child transmission services, condom distribution and promotion, and the referral of clients to other SRH facilities as necessary. TASC also "works in linkage with other service organisations such as SWAGAA [Swaziland Action Group Against Abuse] which specialise on gender related issues especially when it pertains to GBV and its contribution to HIV spread" (TASC 2013: 18). TASC positively reports a decrease in the number of GBV cases in communities in which they have worked (TASC 2013). In specific relation to KPs, TASC aims to increase their access to SRH services and thereby meet their SRH rights. They do so by targeting them in the provision of non-biased HTC, HIV/AIDS treatment related services, and the provision of condoms to prevent transmission, reinfection, STIs and unplanned pregnancies

(TASC 2013). TASC also report in the questionnaire that health education can promote the SRH rights of women. The questionnaire findings emphasise that due to patriarchal norms, females often have to seek permission from their parents, husband or mother- or father-in-law to access health services, such as HTC. Hence, through helping educate communities on the health care needs and rights of female PLWHA, TASC can tackle gender inequality.

5.5   Spiritual needs of PLWHA

Spiritual support

When asked if members of their staff or volunteers refer to any religious texts or spiritual principles in counselling and support sessions with beneficiaries, TASC stated that church ministers who they sometimes engage during retreats for PLWHA sometimes use the Holy Bible to address psychosocial issues. They hold the use of biblical texts to be useful for addressing messages such as equality, acceptance, non-discrimination and non-judgement of others. During times when church ministers are not engaged, TASC engages clinical psychologists, psychiatric nurses or specifically trained counsellors for addressing psychosocial issues. For example, meditation is made available to TASC clients through private sessions with a trained counsellor. Meditation, like prayer, is a form of non-organised spiritual activity and can help PLWHA cope with their diagnosis and illness (Cotton et al 2006). UNICEF (2003) notes that guided meditations – just like prayer and the reading of passages from sacred texts – can give PLWHA an inner source of strength. Meditation, like prayer, can also promote positive thinking, thereby mitigating negative rumination and potentially alleviating depressive symptoms and anxiety (Ridge et al 2008). In reference to the WHO HIV-BREF domain of 'concerns about the future', meditation may thus positively impact upon PLWHAs' thinking about the future, helping them to accept their diagnosis and have a more positive outlook.

It is worth mentioning that meditation is closely tied to the practice of 'mindfulness'. Mindfulness involves "concentration, awareness of the present moment, as well as openness and curiosity to whatever is experienced at the time" (Ridge et al 2008:

415). Segal et al (2002 cited in Ridge et al 2008: 415) make the observation that "In the West, mindfulness has become separated from spirituality to a degree. As such, many people use such meditation techniques without reference to their spiritual antecedents". It is not clear from the primary research whether meditation practices used by TASC refer to spiritual antecedents or not. However, it is very possible they do, given that spirituality and religion are integral to Swazi culture (van Wyngaard 2013).

5.6 Conclusion

This chapter has demonstrated that TASC provide a range of services which help to improve the physical health and autonomy of PLWHA. Not only do their activities promote the physical and psychological health of PLWHA, they also aim to increase the levels of social support received by PLWHA. This can help to improve both the socioeconomic and health status of PLWHA, promoting their participation in family and community life (TASC 2013). However, TASC offer limited spiritual care to PLWHA. Spiritual care is limited to the occasional use of Bible readings, as and when church ministers are engaged in retreats for PWHLA, and the practice of meditation. It is not clear whether the meditation offered by TASC makes reference to spiritual antecedents or is secular in nature like Western practices of mindfulness.

6. Conclusion

This dissertation explored the extent to which the services delivered by SHBC and TASC meet the physical, psychological, social and spiritual needs of PLWHA, and hence their impact on HRQOL. In doing so the dissertation aimed to answer the following primary research question: *Are the services FBOs provide for PLWHA more holistic in their nature than those of secular NGOs?* This chapter will summarise the research findings, outlining how they help to answer the research questions. It will then outline the policy implications of these findings and make suggestions for further research.

6.1   Sub-research questions

6.1.1   To what extent do the services offered by FBOs improve the QOL of PLWHA?

In promoting the HRQOL of PLWHA, SHBC utilise both tangible RHA, including material and health care, and intangible RHA, including "spiritual encouragement" and "knowledge giving" (Root 2011: iii). In relation to the physical health of PLWHA, the provision of HBC increases the accessibility of health care services, especially for those too ill or poor to travel to community centres and health facilities. According to questionnaire findings SHBC is also increasing ART uptake and adherence, improving access to clean water, and helping PLWHA to manage HIV/AIDS related symptoms. Although SHBC does not currently regularly distribute food parcels to clients, they mention in their questionnaire response that by improving the health of PLWHA they indirectly enable them to earn a sustainable income. This helps to alleviate poverty, a major cause of food insecurity (UNAIDS 2010a; Tsai et al 2011). When asked what they perceived the impact of their activities to be on the QOL of PLWHA, SHBC also mentioned that the death rate amongst clients has decreased at double national rates. In relation to the psychological health of PLWHA, the case study found that although SHBC caregivers are not trained counsellors, the caregiver–client relationship can help decrease anxiety and depression for PLWHA, a finding supported by Root (2011). The case study also demonstrated that HBC can increase

levels of social support received by PLWHA. The questionnaire highlights one way in which they do so is through tackling denial and stigmatisation. In specific relation to informational support and the cognitive element of PLWHAs' autonomy, the research findings highlight that SHBC caregivers educate clients on medication adherence and the prevention of OIs. Finally, questionnaire findings highlighted that caregivers often offer to pray or read the Bible with clients. This spiritual care can positively impact upon clients' physical and psychological health (Cotton et al 2006; Tsevat 2006; Dalmida et al 2009; Van Wyngaard 2013). In conclusion, SHBC are helping to meet the holistic needs of PLWHA. This helps avoid harm for PLWHA, increasing their ability to participate in family and community life.

6.1.2 To what extent do the services offered by secular NGOs improve the QOL of PLWHA?

TASC's provision of mobile clinics and HBC increases the accessibility of health care, especially for PLWHA living in rural regions such as Shiselweni. In relation to the physical needs of PLWHA, the questionnaire found that the FBP service helps increase the nutritional intake of PLWHA, encouraging ART adherence. It also revealed that TASC help prevent and treat OIs, and help PLWHA manage other symptoms. To help improve the psychological health of PLWHA, TASC offer counselling and psychosocial support. TASC is also increasing the levels of informational, instrumental, emotional and appraisal support available to PLWHA, including KPs. In specific relation to informational support, both TASC's 2013 annual report and questionnaire response emphasised that peer educators and IEC activities increase PLWHAs' health knowledge. In promoting the SRH rights of female PLWHA, through community health education TASC challenge patriarchal norms and traditional beliefs which negatively impact females' access to health care and social support. Finally, in relation to the spiritual needs of PLWHA, the questionnaire highlighted that TASC offer meditation to clients. However, as mentioned, it is not clear whether the meditation is secular in nature or refers to spiritual antecedents.

When asked what they perceived the impact of their activities to be on the QOL of PLWHA, TASC mentioned the following: health status improvements, increased life

expectancy, decreased mortality rates, improved mental health, reduced reinfection and the spread of HIV, and reduced stigma and discrimination. They also claim to promote the 'economic freedom' of PLWHA. As mentioned, tackling stigma and discrimination and improving the physical health and autonomy of PLWHA can increase their ability to engage in IGIs or wage labour. In conclusion, TASC's activities can be understood to positively impact clients' HRQOL.

6.2 Are the services FBOs provide for PLWHA more holistic in their nature than those of secular NGOs?

The research findings highlight that both SHBC and TASC help meet the physical needs of PLWHA, including by increasing PLWHAs' access to health and social care through the provision of HBC. TASC also operates a fixed and mobile clinic. Through the installation of water boreholes and teaching clients how to purify water, SHBC are attempting to increase PLWHAs' access to safe water. TASC, however, do not report conducting any activities to increase PLWHAs' access to safe water and sanitation. In relation to the nutritional needs of PLWHA, SHBC attempt to prevent clients becoming vitamin deficient through the distribution of multivitamins. Due to limited resources they are unable to regularly distribute food supplies to clients. TASC on the other hand have established a partnership with the WFP and MOH, enabling them to provide a FBP service. This highlights the benefit of multisectoral collaborations. TASC also encourage home growing, support groups and livelihoods activities, helping increase nutritional intake and revenue streams. TASC and SHBC also promote the psychological health of PLWHA. Through HBC both organisations offer psychosocial support to clients. TASC also offer professional counselling services.

Both organisations also increase the levels of social support available to PLWHA, offering informational, instrumental, emotional, and appraisal support. They also promote PLWHAs' access to SRH services and females' SRH rights. The major difference in the research findings is the way in which the organisations seek to meet the spiritual needs of PLWHA. SHBC caregivers often offer to pray with clients and read passages from the Bible. TASC on the other hand do not report their caregivers

offering prayer or the reading of religious texts to clients. These types of activities are limited to when church ministers are engaged in client retreats. Instead, trained counsellors conduct meditation sessions with TASC clients in private sessions. However, it is not clear from the research whether this meditation is secular in nature, and therefore more similar to Western mindfulness practices, or whether in fact it makes reference to spiritual antecedents; antecedents of spirituality include faith and religious belief (Mahlungulu and Uys 2004). Thus it can be concluded that both FBOs and secular NGOs can promote a holistic approach to the HRQOL of PLWHA. However, it is arguable that FBOs are best placed to provide spiritual care due to their ideology and ethos (Root and van Wyngaard 2011).

6.3   Policy implications

This dissertation has shown that the HIV/AIDS related prevention, care and treatment services delivered by FBOs and secular NGOs can improve the HRQOL of PLWHA. Multisectoral collaborations can increase the effectiveness of national responses to the HIV/AIDS pandemic, and subsequently their ability to meet development goals. As Rau (2006: 292) states,

> Neither civil society groups nor governments alone can adequately or effectively meet the challenges of HIV/AIDS prevention, care and mitigation. Each brings major strengths that can complement the gaps and weaknesses of the other.

The above is of particular relevance in contexts such as Swaziland. Swaziland has faced an economic downturn, reduced foreign direct investment and is classified as a low-middle income country (UNAIDS and WHO 2000; Whiteside and Whalley 2007). Resultant of the latter, Swaziland "is only eligible for lending at non-concessional rates" (Whiteside and Whalley 2007: 11). Thus in the case of Swaziland, CSOs will be central to ensuring the HIV/AIDS pandemic does not continue causing declines in social and economic indicators (UNAIDS and WHO 2000; Whiteside and Whalley 2007). They will also have a vital role to play in continuing to increase the accessibility of ART – both through the delivery of services and by tackling stigma and discrimination – since "only 64 per cent of women and 36 per cent of men who are eligible [were] receiving the treatment" in 2009 (Keregero and Allen 2011: 7). Hence,

they need appropriate financial support in order to increase their capacity to implement effective and sustainable community based programmes, which help ensure service demand is met by sufficient supply (Keregero and Allen 2011). In addition, rigorous M&E systems can help to ensure PLWHA receive the best care possible, regardless of the implementing organisation (Grossman et al 2003).

Despite the literature raising some criticisms of FBOs, this dissertation finds Parry's (2003) argument, which asserts that FBOs should be taken seriously as CSOs, convincing. As organisations such as Progressio (2011) stipulate, due to the presence and powerful influence of faith communities and FBOs in many societies, they are often able to mobilise volunteers and the financial support needed to implement HIV/AIDS prevention and treatment services. Due to their influence they can also advocate for the needs of PLWHA and tackle barriers to PLWHA accessing health care, including stigma and discrimination.

The dissertation has also evidenced the positive impact a holistic approach to the needs of PLWHA can have on HRQOL. It has highlighted that HIV/AIDS related prevention, treatment and care services should not neglect the spiritual domain of QOL. Spiritual care has both physical and psychological health benefits. Hence, services offered to PLWHA need to offer a "fusion of biomedical and socio-religious care" (Root et al 2014: 12). As Lerner stated in 1973 "health is more than just a biomedical phenomenon: it involves a social human being functioning in a social environment with social roles he must fulfil" (cited in Bowling 2001: 9). However, in providing spiritual care to PLWHA, organisations need to ensure they are respectful of the belief systems of those they assist (Ferris 2005).

6.4 Recommendations for further research

Further qualitative research could be conducted into the ways in which both FBOs and secular organisations meet the holistic needs of PLWHA. In particular, research could further explore the impact secular meditation has on HRQOL, compared to meditation which refers to spiritual antecedents. This could involve obtaining subjective perceptions, which may be beneficial for monitoring the relevance,

effectiveness and quality of care (Root 2011; Root and Whiteside 2013). However, the potential biases of subjective perceptions need to be borne in mind. Research could also be conducted with a larger sample size, in different contexts and with FBOs from different faith traditions. Further research could also explore the factors which influence the comprehensiveness of organisations' activities and the extent to which they take a holistic approach, for example, their ethos, support systems or financial and human resources (Smith et al [n.d]).

6.5 Conclusion

This research has explored the role of both FBOs and secular NGOs in the provision of HIV/AIDS related prevention, care and treatment services in Swaziland. It has demonstrated the impact these services can have on the HRQOL of PLWHA, exploring whether claims of FBOs' distinctiveness are supported by research findings. This research has demonstrated that the HIV/AIDS related services both FBOs and secular NGOs provide for PLWHA can be holistic in nature, meeting PLWHAs' physical, psychological, social and spiritual needs. However, FBOs may be better able to provide spiritual care to PLWHA due to their ideology and ethos.

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Appendices

Appendix 1: Sample Questionnaire

Section A

1. Please state the name of your organisation below.
2. Would you classify your organisation as a faith-based or secular organisation?
3. Who are your target beneficiaries?

Section B

1. What impact do your activities have on the accessibility of antiretroviral therapy (ART) for people living with HIV/AIDS (PLWHA)?
2. What services, if any, does your organisation provide for PLWHA to help them control their pain levels and any other symptoms being experienced?
3. Please describe any services your organisation offers PLWHA for the prevention and treatment of opportunistic infections.
4. In what ways, if at all, does your organisation ensure PLWHA are able to meet their nutritional needs?
5. Does your organisation offer sexual and reproductive health services to PLWHA? If so, (a) what types of services do you offer? (b) what forms of contraception do you make available to PLWHA?
6. Could you describe any ways your organisation helps to promote women's sexual and reproductive health rights?
7. Do the PLWHA you are seeking to help have access to safe water and sanitation facilities? If yes, who provides this service? If no, please detail some of the common challenges they face in accessing safe water and sanitation facilities and tell us of any ways in which your organisation is helping them to overcome these.
8. Do members of your staff or volunteers refer to any religious texts or spiritual principles in counselling and support sessions with beneficiaries? If so what are these and how would they be used?

9. In what circumstances, if any, would members of your staff or volunteers offer a) prayer b) meditation for PLWHA?

10. Could you describe any counselling and support services that you offer for PLWHA suffering from any of the following: substance abuse, anxiety, stress, depression, low self-esteem?

11. Please describe any ways in which your organisation tries to prevent and/or tackle HIV/AIDS related stigma and discrimination.

12. (a) What does your organisation perceive to be the key reasons for the low social support experienced by some PLWHA? (b) Are there any ways in which your organisation tries to overcome these and increase the levels of social support received by PLWHA?

13. What influence, if any, do your activities have on the ability of PLWHA to secure a stable source of income?

14. Please describe any financial costs that PLWHA incur when accessing the programmes or treatment your organisation offers.

15. What barriers are you aware of which prevent some PLWHA from accessing quality health and social care? Please describe any ways in which you try and overcome these.

16. Please detail below any activities your organisation carries out which aim to increase knowledge and awareness amongst PLWHA of how HIV/AIDS is spread and the treatment that is available.

17. Please describe any ways in which your organisation tries to prevent ART suboptimal adherence.

18. What do you perceive the impact of your activities to be on the quality of life of PLWHA?

Appendix 2: SHBC Consent Form

University of Manchester
School of Environment, Education and Development

Research Title: The role of faith-based organisations (FBOs) in the care of people living with HIV/AIDS (PLWHA) in Swaziland

Consent Form

If you are happy to participate please read the consent form and initial it: **Please Initial Box**

1. I confirm that I have read the attached information sheet on the above project and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.

2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to any treatment/service.

3. I agree to the use of anonymous quotes.

Appendix 3: TASC Consent Form

University of Manchester
School of Environment, Education and Development

Research Title: The role of faith-based organisations (FBOs) in the care of people living with HIV/AIDS (PLWHA) in Swaziland

Consent Form √

If you are happy to participate please read the consent form and initial it: **Please Initial Box**

1. I confirm that I have read the attached information sheet on the above project and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.

√

2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to any treatment/service.

√

3. I agree to the use of anonymous quotes.

√

Signed on behalf of participating organisation:
Thandi Nhlengethwa (Ms), Executive Director
Date: 05 August 5, 2014