An Assessment of the Role of Faith-Based Organisations in HIV/AIDS Mitigation, Treatment and Care: The Case of Buddhist Compassion Relief in KwaZulu Natal, South Africa

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Abstract

This study investigates the role of faith based organizations in HIV/AIDS mitigation, treatment and care. Using a qualitative methodology and with specific focus on Buddhist Compassion Relief (Tzu Chi Foundation), this study assesses the efficacy of HIV/AIDS intervention programmes run by the Tzu Chi Foundation (TCF) as well as their impact on the socio-economic and health wellbeing of people living with HIV/AIDS in KwaZulu-Natal, South Africa. It also analyses the challenges of such faith based organisation run public health community intervention programmes. The study finds that such interventions tremendously assist people living with HIV/AIDS (PLWHA) to access home based care in the absence of a well co-ordinated state intervention programme. Through the home based care programmes, PLWHA access more knowledge about how to live positively, safe sex practices to avoid re-infection and strategies of dealing with societal stigmatisation and social exclusion. Furthermore, PLWHA also receive nutritional food, are assisted in adhering to their prescribed ARV therapy and given physiotherapy sessions in an effort to elongate and enhance their quality of life. While there are the foregoing and many other benefits of home based care, the study however finds that such faith based organisation run public health interventions have a number of challenges which include inadequate funding, dubious development paradigm praxis, questionable sustainability thrust as well as organisational structures which do not reflect local population demographics.

Keywords: HIV/AIDS, mitigation, treatment, home-based care, benefits, challenges, South Africa

1. Introduction

The role of religion affiliated non-profit development organisations in community development in Southern Africa remains one of the least researched areas in contemporary sociology. This is despite ample evidence of the positive role of religious affiliated organisations or faith-based organisations (FBOs) in community work especially in the provision of education, water, sanitation, health (e.g., HIV/AIDS, malaria interventions), food, spiritual and other services to poor and vulnerable groups. This dearth of sociological research in this area is surprising because FBOs have a long and rich history of community outreach to help individuals and communities in need (Cnaan 2002 cited in Dubois and Karcher 2005) in Southern Africa. Given this history and scholarly research gap, it is thus imperative for sociological lens to be focused on the community development work of FBOs so as to deeply understand the nature of their work, its ideological and religious underpinnings (and associated ramifications of the same), the positive and negative impacts of this religion driven community intervention work and the programmatic, policy lessons emerging thereof.

Any investigation that attempts to examine the role of FBOs in HIV/AIDS community interventions and development in Southern Africa inevitably has to touch on work done by FBOs affiliated to 'old' mainstream churches such as Catholic Relief Services (Catholic Church), Anglican Relief and Development Fund (Anglican Church), Lutheran World Relief (Lutheran Church), Salvation Army Emergency Disaster Services (Salvation Army Church) and the Adventist Development and Relief Agency (Seventh Day Adventist Church) etc. The reasons for these mainstream churches' FBOs predominance in community development and HIV/AIDS work in Southern Africa are historical for these churches were introduced into this part of the world by missionaries just before colonialism or at its inception. They have

thus been a central element of the religious and social fabric of communities in this sub-region since then to date. Their predominance in this part of the world can also be explained by the fact that donors have generally generously funded their community development interventions. As Clarke (2006:836) explains: "donors have traditionally focused on supporting organisations associated with the mainstream Christian Churches". However, this narrow donor focus has continued to ignore the fact that the spectrum of FBOs "has increased in many faith contexts, including evangelical Christian, Islamic, Hindu" (Clarke 2006:836) and Buddhism. This increase in the gamut of FBOs presents a compelling case for donors (for grant purposes) and researchers (for scholarly and applied research purposes) alike to broaden their focus beyond FBOs affiliated to mainstream churches. It is within that context that this article charts new research territory in the South African context by examining the role of Buddhist Compassion Relief in HIV/AIDS mitigation, treatment and care in KwaZulu-Natal. With specific focus on Buddhist Compassion Relief (Tzu Chi Foundation), this paper assesses the efficacy of HIV/AIDS programmes run by the Tzu Chi Foundation (TCF) as well as their impact on the socio-economic and health wellbeing of people living with HIV/AIDS in KwaZulu-Natal. It also analyses the challenges of such FBO run community intervention programmes.

2. Objectives of the Study

The primary objectives of the study are the following:

- 1. To examine the role of faith based organizations (specifically Tzu Chi Foundation) in HIV/AIDS mitigation, treatment and care in KwaZulu Natal
- 2. To understand the socio-economic and health impacts of HIV/AIDS interventions implemented by faith based organisation (specifically Tzu Chi Foundation) in KwaZulu Natal
- 3. To understand the challenges faith based organisations face in HIV/ AIDS mitigation, treatment and care interventions.

3. Community Health Interventions by FBOs in Sub-Saharan Africa: A Synopsis

Faith-based organisations have a long history in community health interventions and the provision of health services in many countries in sub-Saharan Africa. As the World Health Organisation (2007) observes; faith-based organisations' structures with their associated health service assets have demonstrated longstanding contributions to and hold continued potential for the delivery of primary health care in Africa. Their primary health interventions and services are provided on a foundation of faith basis (Baer 2007) which intertwines religious beliefs, clinical treatment and the need to help the vulnerable and poor in society. Estimates indicate that national FBO health networks often provide 25–50 percent of health services in Sub-Saharan Africa (World Health Organisation 2007, Baer 2007) especially in remote rural areas, low income urban slum neighbourhoods and other marginalised communities. A good example is the Democratic Republic of Congo (DRC) where FBO networks not only provide 50 percent of health services, but also co-manage around 40 percent of DRC's 515 health zones (Baer 2007). In Tanzania and Kenya, "FBOs provide more than 40 percent and 60 percent of health services, respectively. Additionally, faith-based supply chain organizations serve 40 percent of the population in both of these countries" (Blevins et al 2012).

This central role of FBOs in health service provision in Sub-Saharan Africa can not only be explained by their long histories in this continent and the generous funding they continue to receive from western donors. They possess unique features, functions and capabilities that government departments, national and international development agencies do not have. These include well-established health service delivery networks and infrastructure, clear commitments to serve local communities, strong community roots with a deep reservoir of trust on which to draw, and capacity to mobilize an army of volunteers in many local communities (Blevins et al 2012). Using these capabilities and functions, FBOs have been central in HIV/AIDS mitigation, care and treatment in many sub-Saharan African countries. Their HIV/AIDS interventions are aptly described by Blevins et al (2012:6) when he notes that:

Long before the first feature story on AIDS in Africa appeared in USA Today in 1999 and brought the global epidemic to American consciousness, the Salvation Army in South Africa was already caring for dozens of AIDS orphans, a Jesuit priest had established a home for abandoned HIV positive children in Nairobi and mission hospitals were providing palliative care to thousands of AIDS patients often with little or no resources. As the magnitude of the AIDS crisis unfolded, faith-based institutions were firmly planted in communities with existing relationships of trust, resources, and networks that enabled them to mobilize in the face of a disease that sparked fear, denial, stigma, and discrimination, and inspired myth and misinformation.

Today, FBOs continue to run HIV prevention and advocacy programmes (Derose et al. 2010) as well as care and support programmes which provide an atmosphere of acceptance and hope for millions of people living with HIV/AIDS in many African countries. In a continent where many HIV-positive people often find it difficult to speak to their loved ones about their status because of the stigma associated with being HIV-positive, FBOs have joined the conversation (and introduced community interventions) that are slowly lowering the stigma and discrimination barriers in the process (Blevins et al 2012). They are making this progress because FBOs' religious inspired interventions are a powerful social force that advocates the replacement of stigma and discrimination with acceptance, love, and commitment (Blevins et al 2012). This compassionate care which is built on a commitment to emphasise the human dignity and sense of worth of HIV-positive people is a core value of FBOs and is consistent with international best practices of providing decent care (World Health Organisation 2007) to those who are chronically ill.

In addition to providing an atmosphere of compassionate care, FBOs also play a key role in distributing life-saving antiretroviral (ARV) treatment to people living with HIV/AIDS in the most remote rural areas, poor densely populated urban slums and other marginalised areas in Sub-Saharan Africa. This is acknowledged by the 2012 U.S. President's Emergency Plan for AIDS Relief (PEPFAR) report which notes that providing antiretroviral treatment for nearly 4 million people living with HIV in 2011 and other interventions to prevent mother-to-child transmission would not have been possible without the robust participation of community based well-networked FBOs around Sub-Saharan Africa.

Furthermore, relying on scientific evidence which shows that nutritional food intake can improve antiretroviral absorption and tolerance (Raiten 2005), FBOs also recognise that proper nutrition and food security is essential for people living with HIV/ADS (PLWHA). They also recognise that specific and targeted nutrition interventions can be integrated within HIV/AIDS treatment and care programs in an effort to improve outcomes for PLWHA (PEPFAR 2006). In line with this, many FBOs have spearheaded, funded and technically assisted the introduction of food production gardens (nutrition gardens) by families or communities affected (and afflicted) by HIV/AIDS to cater for PLWHA. In Zimbabwe, for example, World Vision International spearheaded and supported the establishment of urban community gardens in low income Bulawayo townships. While food produced in these gardens is also benefiting households not affected or afflicted by HIV/AIDS, research by Moyo (2010) shows that proper nutritional intake and food access by many households with PLWHA has been enhanced by these community gardens. This FBO spearheaded improvement in household food and nutrition access for PLWHA is playing a role in minimising the vicious cycle of poverty, malnutrition and disease progression, all of which adversely affect the health and well-being of PLWHA and their household members (Helen Keller International 2013).

Alongside Christian, Islamic and Hindu affiliated FBOs, Tzu Chi Foundation (which is a Buddhist FBO) is one of the many FBOs which continue to implement some of the above mentioned HIV/AIDS community interventions in developing countries such as South Africa. Tzu Chi Foundation's (TCF) community interventions are founded on a set of principles and a mission which aims to "cultivate sincerity, integrity, faith, and honesty within while exercising kindness, compassion, joy, and selflessness to humanity through concrete actions" (TCF 2009). TCF's international relief and recovery efforts have availed food, clothing, water supply equipment, seedlings and clinical medicine to thousands of poor and vulnerable communities in the Global South. These TCF compassionate care international development efforts are community driven by an 'army' of volunteers who are also active in its community health interventions which "aim to perfect the 'four entireties' of patient care: the entire treatment process, the patient's entire body, the patient's entire family, and the entire medical team" with the ultimate goal being "to ensure proper care of the body, mind, and soul of the patient" (TCF 2009). It is within this praxis that TCF's HIV/AIDS community interventions in KwaZulu Natal should be understood and will be analysed below.

4. Research Methodology and Methods

In order to address the above questions and objectives of the study, a qualitative research methodology was employed. Within the qualitative framework (see Babbie 2013) non-probability sampling was used. This involved use of purposive (or judgemental) sampling (see Babbie and Mouton 2011, Babbie 2013). Using this sampling technique, a total of 20 respondents were identified in KwaZulu Natal. The twenty respondents comprised five Taiwanese senior volunteers and the balance of fifteen were black South African (Zulu speaking) senior volunteers. Both senior Taiwanese and Zulu volunteers are deeply involved in home-based care and support for PLWHA in KwaZulu Natal. These senior volunteers were the ideal choice as respondents since they have a deep understanding of TCF's role, activities and challenges in HIV/AIDS prevention, treatment and care in KwaZulu Natal.

In-depth semi-structured interviews were the primary data collection instrument. These interviews were the ideal

data collection instrument because they encouraged interviewees to express their views at length, reveal more about their beliefs, attitudes (Denzil and Lincoln 2003) about the specific HIV/AIDS subject under discussion. This flexibility of interviews also allowed the researchers to gain both in-depth and quality data concerning (Shebi 2006) TCF HIV/AIDS community interventions without manipulating the research setting. In addition to in-depth semi-structured interviews, non-participant observations were also a vital research instrument in adding depth and quality to the collected data.

5. Tzu Chi Foundation's HIV/AIDS Mitigation, Treatment and Care Programme in KwaZulu Natal: Analysis and Discussion of Findings

Our findings indicate that one of Tzu Chi Foundation's (TCF) intervention activities in KwaZulu-Natal is community based HIV/AIDS educational (awareness) programmes designed to prevent and/or reduce new infections, as well as reduce (and eventually eradicate) stigma and discrimination against PLWHA. Volunteers from TCF conduct regular presentations focusing on safe sex practices, abstinence and HIV transmission channels in communities that include Umbumbulu, Addington and Isipingo. Organised through their well-established community networks, these presentations are done in the local Zulu language (by Zulu speaking TCF volunteers) thus enabling community members to fully understand subject matter under discussion. These HIV/AIDS prevention and anti-stigma messages are also phrased and delivered in culturally relevant and contextually acceptable language which again makes them easy to understand by community members.

Dispelling community established myths about HIV/AIDS treatment is also central to TCF's community awareness programmes in Umbumbulu, Addington and Isipingo. One such myth in some sections of South African rural society is that having sex with virgin girls cures HIV/AIDS (Slavery 21st Century 2011). Due to this myth, the South African Police Service notes that in 2011 there were in excess of 100 reported cases of young virgin girls being raped by HIV positive males with the perpetrators believing that rape was a means of curing HIV/AIDS (Slavery 21st Century 2011). In an attempt to dispel this myth in rural KwaZulu Natal, TCF has instituted community awareness programmes which educate people about this fallacy. The emphasis has not only been on reminding community members that having non-consensual sex is criminal but also educating people on the availability of life-prolonging ARV treatment. The message being cultivated in the communities is that even though there is currently no absolute clinical cure for HIV/AIDS, recourse to ARVs prolongs one's life subject to leading a physically healthy prescribed nutritional lifestyle supplemented by ARV therapy.

For long, some PLWHA have been stigmatised and discriminated against in many sub-Saharan African countries as observed by Blevins et al (2012) and the World Health Organisation (2007). Using its compassionate care ideology, TCF runs community educational programmes in Umbumbulu, Addington and Isipingo which focus on fighting and reducing stigma and discrimination against PLWHA. One of the simplest interventions by TCF involves educating family (and community) members afflicted by HIV/AIDS and living with PLWHA that there is no risk of HIV infection through sharing basic household paraphernalia with PLWHA. While this might sound mundane and obvious to the informed, the reality is that many people especially in rural communities are still ignorant (and suspicious) about such basics hence the relevance of TCF's educational intervention. Through this basic educational intervention TCF has also made strides in reuniting families that were on the verge of disintegration as HIV negative family members are reviewing their discriminatory behaviour which had pushed them to neglect family members living with HIV/AIDS in fear of infection through close contact and sharing of utensils.

The foregoing TCF HIV/AIDS educational programmes emphasise knowledge sharing in the community for the public good. This sharing occurs through a community knowledge chain and flow that involves senior volunteers, volunteers, community members and PLWHA. While not explicitly stated by TCF, this HIV/AIDS information and knowledge dissemination model appears to be based on the diffusion of innovation theory. This behaviour change theory was developed by Rogers (1985, 1995) and later modified, applied in research thereafter by people such as Surry and Farquhar (1997), Yates (2001), Montano and Kasprzyk (2004) among others. It argues that

over time, an idea or product gains momentum and diffuses (or spreads) through a specific population or social system. The end result of this diffusion is that people, as part of a social system, adopt a new idea or behaviour. Adoption means that a person does something differently than what they had done previously (i.e., acquire and perform a new behaviour, etc). The key to adoption is that the person must perceive the idea or behaviour as new or innovative. It is through this that diffusion is possible (Boston 2013).

This theory has been used successfully in many public health interventions in the Global South. It has been applied in HIV/AIDS interventions in Zimbabwe by Montano and Kasprzyk (2004) in a two-arm randomized community-

level HIV behavioural intervention trial utilizing a Community Popular Opinion Leader (C-POL) model. The idea behind Montano and Kasprzyk's (2004) CPOL model – which is also mirrored in TCF's KwaZulu Natal HIV/AIDS intervention – is to use a specific group of people (volunteers in TCF's case) to diffuse HIV/AIDS messages and knowledge in the community so as to encourage behaviour change. These messages and knowledge shared by TCF volunteers diffuse within the community to reach large numbers of people to cultivate behaviour change. This TCF model is thus self-sustaining as it organically permeates the KwaZulu Natal communities of Umbumbulu, Addington and Isipingo through long established networks accessible to TCF volunteers.

Home based care for PLWHA run by trained senior and junior volunteers is also one of the key intervention strategies being implemented by TCF. These volunteers were trained by St John's Aid Services in HIV/AIDS patient care, protection methods for caregivers to avoid new infections through body fluids, caregiver-patient communication and interaction skills. Through their daily visits, caregivers ensure that PLWHA take their ARV medication at prescribed times. This drive to ensure strict adherence to ARV therapy is informed by the well documented benefits of ARVs for PLWHA (for more on this, see Blower and Farmer, 2003; Kalichman et al., 2005, Foster and Lyall 2008 etc). Furthermore, volunteer caregivers assist PLWHA to do daily human basics such as eating, bathing, physiotherapy and outdoors light physical exercise. This physical exercise and physiotherapy provides many benefits to physically inactive PLWHA who spend long periods of time in bed or in hospital due to the multisystem pathology of opportunistic infections. Their inactivity brings up complications such as contractures, muscle wastage, stiff joints, bedsores and respiratory problems (Simfukwe, 2013). Physical exercise and physiotherapy care thus attempt to avert and address these complications through maintaining normal joint ranges and increasing circulation to dependent limbs by doing passive mobilization, stretching exercises as a prevention of painful contractures, active mobilization through to independent walking and provision of assistive devices (e.g., crutches, walking sticks, wheelchairs) (Simfukwe, 2013). Caregivers in KwaZulu Natal thus help PLWHA to improve their levels of physical activity and in the process reduce potentially disabling consequences arising from neurological, musculoskeletal and other associated syndromes. While the benefits of physical exercise and physiotherapy provided by caregivers to PLWHA are clear, it was however not possible to make an informed judgement about their capacity in assisting those patients with an acute AIDS condition. It is uncertain whether they could be able to administer clinically advanced physiotherapy procedures such as maintaining clear the pulmonary system by clearing chest secretions and expanding lung tissue if there is a collapse, postural correction to prevent any deformities, pain management by using electrotherapy and restoration of body image due to weight loss by strengthening wasted muscles (Simfukwe, 2013).

As part of its home based care activities, TCF also runs a food relief programme for PLWHA in KwaZulu Natal. Through this food relief programme, food parcels donated by TCF headquarters in Taiwan and the Rotary Club in Durban are distributed to PLWHA. The main advantage of such food relief is that it increases direct food supply to and access by households affected and afflicted by HIV/AIDS. However, these food parcels are never enough to ensure household food security for PLWHA. They are also not sustainable as a food source for these households simply because they are a short term relief intervention. Furthermore, as evidence from elsewhere in sub-Saharan Africa shows, such direct food relief has potential to discourage household investment in agricultural production, crowd out private transfers and other means of informal responses to shocks (Abdulai, Barrett and Hoddinott, 2005).

In an effort to supplement the inadequate food parcels supplied to households with PLWHA, TCF volunteers have also ventured into agricultural production. They produce a variety of food crops and vegetables in community gardens. As one of the volunteers noted; "we plant vegetables in our gardens in the community and use these vegetables to feed patients. Surplus vegetables are sold in the market and we use the money to buy rice or maize meal". This food production thus ensures that households affected and afflicted by HIV/AIDS have access to fresh organic produce. Household food and nutritional gaps are covered in the process. Such access to food is vital for PLWHA who must be on a balanced nutritious diet in order to improve ARV effectiveness in their immune system. As the World Health Organisation and Food and Agriculture Organisation (2002) observe; for PLWHA, good nutrition also helps to reduce the impact of future infections and extends an individuals' physical working life. Access to food for PLWHA is therefore not only important for improving their nutritional status but their health as well. However, one of the major challenges with reliance on such social capital driven community gardens is their sustainability. For how long will these volunteer run community gardens continue to produce food for PLWHA? What if these gardens collapse and cease to produce food due to operational deficiencies or community conflict and tension? What will happen to households that rely on them for food if these community gardens collapse?

Lastly, it is however important not to romanticise TCF's HIV/AIDS intervention in KwaZulu-Natal. There are a

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number of challenges which directly affect the operations of the organisation thus partly compromising the quality and effectiveness of care for PLWHA. For example, while the KwaZulu Natal programme does receive substantial material support from the Tzu Chi Foundation headquarters in Taiwan, it however does not receive direct hard cash funding from the headquarters. The emphasis from Taiwan has been on building local self-sufficiency and sustainability. Theoretically, this is a sound local development paradigm since it encourages a 'bottom up approach' with local people at the centre and in charge of a public health intervention. Practically (in terms of implementation) this has however created a number of challenges. For example, at times there are shortages of cash to buy more food parcels, gloves, soap and disinfectants used when bathing HIV/AIDS patients. Volunteers – most of who are unemployed – do not have the financial wherewithal to cover such resource gaps.

Secondly, in order for the Tzu Chi Foundation to fully claim that the KwaZulu Natal intervention is locally owned, run and self-sufficient, there is a need to transform the organisational structure of the programme. Presently, its administrative echelons are dominated by Taiwanese volunteers while the majority of local Zulu speaking volunteers operate at the community (grassroots) level. Organisational transformation is thus needed so as to have a substantial number of locals involved in the administrative decision making processes. Such a transformation will further inculcate a strong sense of ownership of the intervention by locals while at the same time empowering them through direct active involvement in decision making processes.

6. Conclusion

This study has shown that faith-based organisations such as Tzu Chi Foundation tremendously assist people living with HIV/AIDS (PLWHA) to access home based care in the absence of a well co-ordinated state intervention programme. Through their home based care programmes, PLWHA access more knowledge about how to live positively, safe sex practices to avoid re-infection and strategies of dealing with societal stigmatisation and social exclusion. Furthermore, PLWHA also receive nutritional food, are assisted in adhering to their prescribed ARV therapy and given physiotherapy sessions in an effort to elongate and enhance their quality of life. While there are the foregoing and many other benefits of home based care, the study however finds that such faith based organisation run public health interventions have a number of challenges which include inadequate funding, dubious development paradigm praxis, guestionable sustainability thrust as well as organisational structures which do not reflect local population demographics. In an effort to address some of the challenges, the study recommends that TCF in KwaZulu secures a more sustainable funding source so as to avoid operational deficiencies that arise due to resource constraints. Such funding can be sourced from international development partners and other South African institutions that award grants to organisations involved in community HIV/AIDS interventions. There is also need to train volunteers in more advanced clinical physiotherapy procedures so as to enhance the quality of care and physical exercise they render to PLWHA. Lastly, there is need to transform the organisational structure of TCF in KwaZulu Natal so as to include more local people in the decision making processes of the intervention programme. Such transformation is vital if this intervention programme is to remain selfsufficient, community rooted and sustainable.

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