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The role of NGOs and civil society engagements in HIV/AIDS initiatives in Africa: The case of Ghana

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Abstract

This paper discusses the multiple dimensions of civil society engagements (both local and international) in HIV/AIDS initiatives in Africa, with Ghana as the case. It particularly considers how the transnational interpretation of non-governmental organisation (NGOs), faith-based organisations (FBOs), and international civil society organisations shapes health and civil spaces in the context of HIV/AIDS in Africa. Drawing on my ethnographic research on HIV/AIDS and medical systems in Ghana since 1999, this paper shows how political agenda and uncertainties of organisations working in affected communities, activism and people's rights are shaped by AIDS and have shaped the global epidemic. It concludes that NGOs and civil society engagements in HIV/AIDS initiatives in Ghana and other African countries are not merely about activism and the disease; they also demonstrate the 'politics' and power relations in the HIV/AIDS field in Africa.

Keywords: HIV/AIDS, NGOs, civil society, activism, power relations, Africa

Introduction

Civil society and non-governmental organisations (NGOs) have become significant actors in local, national and international spheres. The participation of civil society actors such as the UN, World Bank, the EU, and the World Health Organisation (WHO), as bilateral and multilateral systems, has become a key feature in national and local levels development projects (Katsui & Wamai 2006). NGOs¹ and other civil society actors (generally also referred to as the third sector) are seen to fulfil fundamental roles in Africa. Researchers and experts have traditionally emphasized the third sector's role in giving a 'voice' to vulnerable or marginalized groups and ensuring their inclusion and social capital (Olsson, Larsson, Nordfeldt, and Kendall 2005). There is today a strong recognition of the role of NGOs and civil society actors relating to advocacy (promoting a group's interests, lobbying, propaganda making) and, more importantly, its contribution as a service provider.

In HIV prevention and support in Africa, NGOs and other civil society actors, international donors/ agencies as well as state institutions play a crucial role in delivering treatment and care services. Huge sums of aid money donated by international donor agencies are channelled to and through local government institutions, NGOs, activist groups and other civil society organisations for HIV/AIDS initiatives. Civil society² is hugely recognised by

¹ NGOs are generally private, non-profit, organisations with public welfare goals (Clarke 1998: 36). NGOs include philanthropic foundations, church development agencies, academic think-tanks and other organisations focusing on issues such as human rights, gender, health, agricultural development, social welfare, the environment, etc.

² According to Castells (2008: 83-84), civil society is a generic label that lumps together several disparate and often contradictory and competitive forms of organisation and action. Every society has local civil society actors who defend local or sectoral interests, as well as specific values against or beyond the formal political process. Civil society includes grassroots organisations, community groups, labour unions, religious groups, civic associations, the academia, NGOs, and the family, and these are also generally referred to as the "third sector" of society, distinct from government and business.



both international donors and African governments as important actors and partners in the HIV/AIDS responses, including prevention, impact mitigation, treatment and care (Follér & Thörn 2013).

Sub-Saharan Africa remains the worst affected region in the global HIV epidemic. A United Nations Programme on AIDS (UNAIDS) report in 2011 estimated that 23.5 million people living with HIV were resident in sub-Saharan Africa, representing 69% of the global HIV burden (UNAIDS 2012). The rate of HIV in women is reported to be higher than in men of the same age group. Ghana's prevalence rate is about 1.4%, with 260,000 people living with HIV. Since the 1990s, a range of different groups and institutions—activists and local NGOs, central government and grassroots organisations alongside development agencies such as the World Bank, the International Monetary Fund (IMF), the World Health Organisation (WHO), and UNAIDS—have come together for HIV prevention, treatment and care efforts.

The question arises to what extent these interactions affect democratization processes and offer the potential for civil society actors in Africa to increase health, social and political participation and hold the state/public institutions to account. What meanings should be read into 'bad behaviour', acts of propaganda, lobbying and other political machinations by some NGOs? HIV/AIDS is a highly sensitive issue, frequently charged with ideologies and personal convictions and acts shaping gender relations and sexual intimacies within social, economic, religious and political processes. AIDS has emerged alongside globalization, affecting governance, democracy, civil society organisation, human rights and neoliberal values and underlying value systems in AIDS policy.

Recent scholarly attention has focused on financial aid and other resources for AIDS responses through NGO and civil society operations and the relationship between NGOs and the state in health development projects (e.g., Asad & Kay 2004; Follér & Thörn 2013; De Rosis 2013). It is this body of literature that my discussion of NGO and civil society engagements in HIV/AIDS initiatives in Ghana falls into. The level of financial aid or resources to NGOs and other civil society actors and collaboration in HIV/AIDS responses (prevention, education, treatment, care, etc.) has generated debate among scholars (e.g., Seckinelgin 2005; Kelly et al. 2006; Ferrari 2011). Others analyse how government modalities affect the rationalities and everyday practices of civil society organisations, as well as how power is articulated, reproduced, resisted and/ or transcended in the relationship between international donors and local civil society actors involved in HIV/AIDS works in Africa (e.g., Follér & Thörn 2013).

I examine value systems and the social, political and economic factors underlying Ghana's health policies in the context of HIV/AIDS, NGOs and civil society engagements while identifying the power arrangements (both national and global) that are crystallized in everyday practices and articulation. The paper contributes to discourses about third sector issues in Africa and to anthropological understandings of the underlying motives, power relationships and everyday articulation of this sector in the HIV/AIDS field in Ghana.



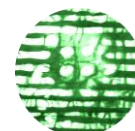
Symbolic fields such as family/kinship obligations, honour and shame systems and gender inequalities denote dominant practices and enduring meaning structures which cannot be ignored by people nor can they be overlooked by stakeholders when interpreting NGO and civil society practices in HIV/AIDS initiatives.

This paper is based on data from ethnographic studies I have conducted in southern Ghana on HIV/AIDS since 2003, through mainly participant observation and interviews with NGO representatives and other civil society actors, AIDS patients, HIV counsellors, and health personnel. This allows me to relate NGO and civil society engagements in HIV/AIDS initiatives to the social, cultural and political system before and after the advent of the epidemic. I begin with a discussion of the theoretical framework within which civil society and NGO operations have been discussed. I then move to HIV/AIDS, NGOs and civil society engagements in changing healthcare policies and the rise of NGOs in Ghana, and to civil society engagements by other actors (the family/kinship, the media, etc.) as well as challenges, ambiguities and paradoxes surrounding NGOs and practices of other civil society actors. The paper concludes by echoing Biehl (2007) that AIDS activism in the face of democracy, governance and civil society demonstrates the reproduction of power arrangements (both symmetries and asymmetries, national and international), and the ideological/political functions of all partners that are crystallized in HIV/AIDS initiatives.

Theorizing civil society and NGOs

In a review of classical theories of civil society, Hyden (1997) outlines two key characteristics—first, how the state and civil society are closely linked and, second, the degree to which civil society involves private economic interests or a space of self-governing associations which protect citizens from an over-bearing state. In another important review, Fisher (1997) has illuminated how NGOs have generally been categorized either as instrumental and apolitical tools for development in an era of neoliberalism or as alternatives to governmental power capable of transforming the state.

These dimensions have been extended into contemporary debates on civil society (Mohan 2002). NGO and other civil society engagements have been framed within the “regime school” (Diamond 1994) and “associational school” (Bratton and Van de Walle 1994) to emphasize the pluralistic space about civil society whereby associations act as transmission belts between the individual and the state. Mohan (2002: 127) emphasizes that the associational school, largely inspired by Tocqueville, “sees associational life keeping the state in check through scrutinising its operations and inculcating in the citizenry a sense of political participation and tolerance”. In contrast, the Lockean-inspired regime school is less pluralist and does not see an active associational life automatically leading to better governance; rather, they are more prescriptive for state reform and the rules by which state-society relations might be altered to foster democracy since civil society does not straightforwardly democratise (ibid). There is a “legitimizing” view too, where NGOs and civil society actors may be used as a tool to play a legitimating role to maintain a perception



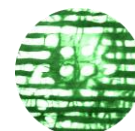
that those processes are participatory and ‘owned’ by a wider section of the population (Lewis & Opoku-Mensah 2006: 667).

Much attention on the role of NGOs and civil society in development in Africa has been on collaboration between state and civil society, or the opposition to state practices, challenges faced. In an article on political themes in NGO operations in developing countries, Clarke (1998: 48) suggests that the most important question raised by the proliferation of NGOs concerns their contribution to political change and to democratization. Burger et al (2011), focusing on NGO regulation in Uganda, identified a number of challenges faced by these organisations. The authors argue that regulatory powers in the hands of politicians and bureaucrats allow them to engage in extortion of bribes and/or political support from NGOs.

Lewis and Opoku-Mensah (2006: 666) have examined the trend of research on NGOs and while noting the positive sides, the authors also stress the ambiguities, paradoxes and disillusionment with NGOs. According to them, the 1990s view of NGOs as new mainstream development actors of largely untapped potential—a ‘magic bullet’ (Vivian 1994) and as having a comparative advantage in organisational terms in view of their flexibility, commitment and community responsiveness has changed. “Talk to a funder such as the UK Department for International Development (DFID) or the World Bank and one finds that NGOs are no longer regarded as positively as they once were.” (p. 666). The authors claim that in donor policy circles, talk of ‘NGOs’ has to some extent given way to an emphasis on ideas about civil society, citizens’ organisation, governance and cross-sectoral partnership (Lewis & Opoku-Mensah 2006: 667).

The Comaroffs (1999: 2) “interrogate the paradoxes, problems, and emancipator possibilities presented by the idea of civil society in various African contexts”. For them, any talk of the ‘underdevelopment’ of the continent in this respect echoes a Eurocentric discourse of older vintage about the “immaturity” of “the African state” (p. 17). Manji and O’Coill (2002:7) have analysed the role of missionary NGOs in development in Africa; they identified racist undertone discourses of the colonial past about Western NGOs in Africa in a vocabulary consistent with the new age of modernity. They state: “It was no longer that Africans were ‘uncivilised’. Instead, they were ‘underdeveloped’, and either way, the ‘civilised’ or ‘developed’ European has a role to play in ‘civilizing’ or ‘developing’ Africa (ibid, original emphasis).

Scholarship points to neo-liberalism in Africa that resulted in the surge of NGOs. By late 1970s, events were on the horizon that qualitatively transformed the ‘development’ arena and laid the basis for the proliferation of NGOs in the region, rekindling the missionary zeal (Manji & O’Coill 2002). The authors claim that a so-called ‘oil crisis’ of the mid 1970s resulted in a finance capital surplus although the world economy was already suffering from recession. Developing countries were courted to take loans to finance ‘development’. But the glut of international credit was short-lived and the 1980s saw significant increases in the cost of borrowing.



The US government implemented an avowedly neo-liberal, monetary policy, which drove up interest around the world. Debtor countries became burdened with servicing the interest on loans, which absorbed the proportions of export earnings. Debt had now become the central issue of ‘concern’ in development circles (ibid: 9). A number of other factors have been cited for the proliferation of NGOs in the developing world. For example, Clarke (1998: 38) lists four key factors which include the volumes of aid channelled by development agencies in the industrialized world through local NGOs, the neoliberal climate of disenchantment with the state which saw multilateral donors and their bilateral partners channel increasing amounts of funding from the early 1980s through Southern NGOs. Also, many governments of developing countries that were previously antipathetic to NGOs were forced by economic recession in the 1980s to cede greater recognition and involve NGOs in socio-economic programmes.

Thus far I have argued that despite various theories of civil society and NGOs, the current paradigm is based on a particular vision which sees the role this third sector plays but also acknowledges paradoxes and ambiguities about these social actors. In healthcare or HIV/AIDS initiatives in Africa and the developing world, scholarly discussions focus on relationship between state and civil society and NGOs. In a recent article, Asad & Kay (2014) examined how NGOs work and build relationships with different types of states and what kinds of relationship building lead to more successful health development outcomes on the ground. They found that successful outcomes depended on NGOs’ ability to leverage resources—alliances and networks, political, financial and cultural resources and frames across state and non-state fields.

Others see international NGOs and agencies as playing a key role in helping with efforts in Africa and the developing world. At the same time, these international NGOs and agencies are perceived to have leverage and autonomy, wielding enormous powers and assuming a quasi-government status in poorer countries. In the heat of the HIV/AIDS epidemic in Africa, denial, inaction, and miscalculation on the part of many African governments provided the ammunition for criticism against them by the international institutions. Many African governments were blamed for doing too little in the efforts to address the prevention and spread of AIDS in their societies. South Africa’s HIV/AIDS prevention and treatment policy was heavily criticised both at home and abroad for prevarication and confusion, inadequate analysis, bureaucratic failure and political mismanagement (Butler 2005). Governments try to show their political will to fight the disease in AIDS policies and projects, and state apparatuses have become locally present in AIDS medication dispensation and education. The G8 and international aid agencies have been helping but increasingly demand administrative reforms for effective policy implementation. Many African nations are required to ensure good governance, democratization, and limited corruption before support from Western nations and such international donor agencies as the World Bank and IMF. More proactive responses to HIV/AIDS are added to the demands for good governance, democratization, and limited corruption. The UNAIDS tries to make the international system work more



effectively, pushing and advising governments and health institutions for good practices in HIV/AIDS initiatives in various countries, including Ghana.

HIV/AIDS, NGOs and civil society engagements in Ghana

Ghana recorded the first HIV/AIDS case in 1986, among sex workers who had returned from a sojourn in neighbouring Cote d'Ivoire. The country's current prevalence rate of about 1.4% is not as grave as in other African countries. Sub-Saharan Africa bears the brunt of the epidemic and is home to about 67% of the 33 million people infected with the virus globally. Moreover, in 2008 the region accounted for 68% of the 2.7 million new infections among adults worldwide (UNAIDS 2012). The major mode of HIV transmission in Ghana, as in much of sub-Saharan Africa, is heterosexual contact. The rate of HIV in women aged 20 to 29 is higher than in men of the same age group. Around 260,000 people were living with HIV in Ghana in 2009 with 140,000 being women (ibid).

HIV/AIDS is stretching Ghana's yearly health budget and forcing an over-reliance on foreign financial aid. In 2005 alone, the purchase of anti-retroviral drugs (ARVs) and medications for opportunistic infections cost over 8 million US dollars, which came from foreign donors (Crentsil 2007). Educational campaigns about HIV/AIDS emphasize prevention; those already infected receive counselling and therapy with imported ARVs given at reduced cost to patients. Most HIV prevention programmes have been built on a paradigm of individual behaviour change; people are advised to lead healthy sexual lifestyles by practising 'safe' sex, grounded in the widely-known ABC method— abstain from sex, be mutually faithful to partners or to condomize (using condoms consistently). The most at risk groups are identified to be sex workers and long distance drivers (the Lagos-Abidjan transport corridor, is a project aimed at educating drivers who travel across Cote d'Ivoire, Ghana, Togo, Benin, and Nigeria) and the youth. Hence, much of HIV activities usually are targeted at these groups.

Despite recent declines in incidence, HIV/AIDS remains a serious threat and new infections occur in Ghana. An epidemic of global proportions, HIV is a lived process entangled in a web of existential, individual, social, national and international implications. International and national policies have been in place for prevention. The UNAIDS, the United States Agency for International Development (USAID), WHO, and the POLICY project developed and recommended the AIDS Programme Effort Index (API) as a tool for monitoring the 2001 Declaration of Commitment to HIV/AIDS by measuring high-level programme inputs in the fight against the disease worldwide (Bor 2007: 1587). HIV/AIDS responses everywhere emphasize universal access to treatment and vigorous preventive measures through face-to-face counselling and education. Agencies involved in the HIV prevention strategies on the African continent have made considerable use of the mass media (Benefo 2004). Radio, television/cinema, newspapers, billboards, and posters as forms of mass media exposure and education have been one of the most important predictors of awareness and behaviour change.



In an article on mass media and HIV prevention in Ghana, Benefo (2004: 2) points out that governments and NGOs have used the mass media as components of information, education and communication (IE&C) and in social networking campaigns to disseminate information about HIV/AIDS, reduce misinformation and induce behavioural changes against risks of HIV infection.

Medical services are severely limited and inaccessible to many people, especially in the rural areas. Ghana and other countries in (West) Africa suffer from a weakened and fragile health system with a shortage of health workers and lack of facilities, especially in rural areas. Hence, NGOs, community-based organisations (CBOs), Faith-based Organisation (FBOs), the churches and other civil society organisations help with community outreach campaigns (Crentsil 2007, 2012). Big-time NGOs long involved in campaigns for good reproductive health, such as the Planned Parenthood Association of Ghana (PPAG) and the Ghana Social Marketing Foundation (GSMF), entered the HIV/AIDS scene and today they give free condoms to revellers during festive occasions. They undertake to support people living with HIV/AIDS (PLWHAs); they counsel them, organise peer education and training workshops, and are engaged in advocacy, radio talk shows, home visits and condom promotion. As Peter Redfield (2006: 3) has pointed out in an article on the Medecins Sans Frontieres (Doctors Without Borders), the activities of such NGOs play a central role in defining secular moral truth through humanitarianism.

Changing health policies and rise of third sector in Ghana

Healthcare in Ghana has always been framed as a ‘right’ of citizenship, whereby all Ghanaians could seek medical care in any public health facility (hospitals, clinics, health posts, etc.) without having to pay out-of-pocket fees (Kpessa et al. 2011: 2125; Agyepong & Adjei 2008). Healthcare emphasised preventative and community care, as opposed to the hospital-centred system that existed during the colonial period from 1844-1957. From the 1960s, health improved and child mortality (for children aged between 1 and 4 years) declined across sub-Saharan Africa, including Ghana. This, Adesina (2009: S44) points out, was the result of the socialisation of consumption, especially at the level of primary healthcare services whereby social spending on health was part of a wider objective of defeating the triad of ignorance, poverty, and diseases.

Ghana experienced an economic crisis from late 1970s into 1980s, and in 1983, the government adopted the IMF and World Bank-supported Economic Recovery Programme (ERP) to stem the decline in the country’s economy (Sowa 2002). Incomes fell and unemployment rose. By mid-1983, the country was a classic example of one faced with stagflation, as inflation was running at 123 percent and output declining at an average of about 1 percent per annum (ibid: 3). These economic disasters attracted more aid money and attention.



Ghana later adopted the Structural Adjustment Programme (SAP) but within 10 years of adjustment, the improvements in health had been reversed. The public healthcare system and sanitation services were left to deteriorate. Adesina (2009: S44) suggests that perhaps it was in the area of healthcare provisioning that the aggressive retrenchment of the state and cuts in social spending produced extreme effects in African countries. The weight of healthcare provisioning shifted from a national fiscal responsibility to the end-users. “User fees” (the cash-and carry system) were introduced in hospitals and pharmacies in the early 1980s. The call for putting a “human face” on adjustment by some United Nations agencies and NGOs was finally heeded to, and towards the close of 1990s consensus was reached between the donor community, the United Nations and developing countries. Ghana was one of the first countries to attempt to put a “human face” to structural adjustment (Sowa 2002: 1).

In Ghana and most part of Africa, many new international solidarity movements or transnational civil society networks and their local counterparts emerged to support “grassroots” activities (Mkandawire 2006: 6). What Fonjong (2001: 227) said about Cameroon in those times was similar in Ghana. The catastrophic effects of the economic crisis in the 1980s and the harsh adjustment measures that later followed, among other factors, encouraged the rise of NGOs and other civil society actors in Ghana. State influence waned, as it were, and the government was unable to meet most of the basic needs of the people, which left the population to take charge of their destiny through self-reliant (or self-help) development activities. The Provisional National Defence Council (PNDC) government of Jerry Rawlings, under which NGOs and other social organisations operated in a generally repressive political climate with little room to organize and act on their own initiative (Darkwa et al. 2006), softened the stance on these civil society actors. As part of a strategy to quell growing opposition, the Rawlings regime encouraged NGOs to fill the service delivery gap as a result of cuts in government expenditure. However, as pointed out by Darkwa et al. (2006), the real impetus behind creating a greater role for NGOs in ‘development’ not from the PNDC government [but rather] from the World Bank UN and bilateral donors [who] contributed over US\$80 million for poverty alleviation programmes, and they requested that NGOs be allowed to assist in service delivery (p. 23).

It was in this period of economic failure that the first HIV case was recorded in 1986. Although a non-prioritization of the HIV/AIDS occurred and it was not until 1998 that questions of people’s perception about risk of infection were seriously explored, Ghana had taken the responses against the disease at the highest governmental level and in 1988 a medium-term plan was developed with the WHO’s Global Programme on AIDS saw the setting up of the National AIDS/STI Control Programme (NACP) in the Disease Control Unit of Ghana’s Ministry of Health (MOH). NGOs increased and engaged in the campaign against HIV/AIDS. The presence of NGOs was felt everywhere—seen on billboards, in newspaper advertisements, in the television, etc. A few years later, a progressive multisectoral mobilization of political parties, universities, labour unions, and NGOs united around democracy in Ghana, culminating in the drafting of a new constitution in 1992.



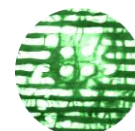
Health personnel in the HIV/AIDS sector acknowledge the work of representatives of NGOs as support services in HIV prevention/education, treatment and care efforts. As an HIV counsellor put it in 2003: “Without their help, we couldn’t cope with the number of patients we must attend to and counsel”.

Ambiguities and paradoxes: NGOs and civil society in Ghana’s HIV/AIDS initiatives

NGOs and civil society are today ever present in HIV/AIDS initiatives (prevention, care and treatment) in Africa and other developing countries. Many such organisations engaged in campaigns face key problems like lack of logistics and difficulty in reaching most of the rural areas. Inputs have been sub-optimal for strengthening local NGOs and CBOs as the bulk of resources are channelled through international or large NGOs (Pothapregada & Arun 2009: 71). In many instances, NGOs become dormant or their operations fall below expectation.

There is heterogeneity of NGOs and other civil society actors, and cooperation between the Ghana government (through state agencies) and the sector has been a distinctive feature in Ghana. However, there is an implicit or explicit anti-state bias, and when NGOs collaborate with states they cease to be seen as a progressive force (Asad & Kay 2014). The 31 December Women’s Movement, formed by the wife of Rawlings, is seen in Ghana as an informal organisation but with political links. There is also a perception of the hegemonic stance NGOs take over state performance (Adesina 2009). Ghana’s civil society organisations have not been very active in non-partisan political action, since civil society organisations in Ghana are mainly based in urban areas, and the organisations that possess the highest level of technological and financial resources operate in the main cities (Darkwa et al. 2006).

Many of these NGOs that were supposed to complement health delivery are seen to have lost their idealist tendencies and passion. It is obvious they use AIDS as a tool for their own political, economic, and moral gains. A perception exists that with large sums of money made available there has been an unprecedented surge in the number of NGOs, and identifying credible ones has become a challenge. In 2003, a popular opinion was that establishing an NGO to combat HIV/AIDS was one of the easiest and quickest ways to enrich oneself in Ghana. While this perception may be unjustified, it is still strongly believed that some NGOs capitalise on the dire AIDS situation to make money for themselves by embezzling funds from the Ghana AIDS Commission and other international donors. In mid-2003, it was reported that 114 CBOs embezzled 1.4 billion cedis (about US 160 million dollars at that time) belonging to the Commission. Such negative attitudes have attracted concern and condemnation in the media. Other bogus organisations even give unreliable addresses as points of contact (GAC 2003). These obviously are the bad nuts whose unsavoury activities paint a generalised negative picture of NGOs in Ghana today despite the fact that the bulk of them are genuinely involved in community development to the benefit of rural dwellers and sincerely campaign actively for HIV prevention and behaviour change.



Ghanaian civil society has been particularly active and successful in providing a range of services to marginalised groups such as AIDS patients, but not as successful in lobbying activities and influencing policies in general (Darkwa et al. 2006: 11). The increased interest in NGOs as participants in ‘development’, with its attendant increase in available international aid, affected the nature of NGO and state relations. For example, the PNDC government and the United Nations Development Programme decided to use the umbrella NGO, the Ghana Association of Private Voluntary Organisations in Development (GAPVOD) as the vehicle for enlisting NGOs in PAMSCAD (the Programme of Action to Mitigate the Social Costs of Adjustment). GAPVOD had only seventeen members in 1987, but through PAMSCAD it received over US\$600,000 from 1990-92 and membership in GAPVOD became a de facto criterion for local NGOs to receive external funding. As a result, GAPVOD no longer existed as a collective voice for NGO members; instead, it was used as a tool of control by government and donors (Gary 1996: 160).

FBOs offer material and moral support to patients and communities (Liebowitz 2002). They have been important partners with the public health system for health care delivery and HIV/AIDS initiatives, although in the early years of the epidemic in Ghana representatives of FBOs contributed to the stigmatization and shame about the disease by referring to it as a punishment from God. AIDS patients were sometimes seen as being punished for their sexual ‘sins’. These days, the increased ownership and access to mobile phones is encouraging some NGOs to establish HIV helplines for AIDS patients even though a recent study on mobile phones and healthcare communication in the HIV/AIDS sector in southern Ghana (Crentsil 2014) revealed many patients’ lack of ownership and access to a phone (Table 1). Of the 584 patients on anti-retroviral drugs, only 150 (25.8 per cent) used mobile telephones. At a rural hospital, of the 170 female HIV/AIDS patients, 45 (26.5 per cent) had mobile phones, 123 (72.4 per cent) did not, and two (1.1 per cent) did not provide this information.³

Table 1: Mobile phone users among HIV patients on antiretroviral therapy (N= 584).

Males	148
Females	436
Employed	525
Unemployed	63
Have mobile phones	150
No mobile phones	434
Over 40 years	254
Under 40 years	330

³ The hospital’s list of male patients was not yet fully compiled at the time of my fieldwork.



The mechanism of phone sharing where patients can use the phones of family members and friends increases the number of people with access to phones but could compromise confidentiality and privacy of patients who might want to keep their statuses private.

Family/kinship involvement

In an era of HIV/AIDS in Africa, the known relationships of family relatives and care providers have been made prominent. The care of AIDS patients has its own dynamics and inadequacies in day-to-day interactions. Hospital care is not always available or accessible, especially in rural areas. HIV-positive persons are not hospitalised in Ghana. Hence, AIDS patients are usually cared for by family members, throwing a huge burden on family members who care for ailing relatives. This and factors such as shame and stigma result in abandonment and neglect of patients in households (Crentsil 2007; Radstake 2000).

The social relationships between AIDS patients and their caregivers are capable of restoring the former's self-images since care occurs within a changing health politics of encouraging home-based care. The policy of the WHO, national governments and NGOs is to organize care for AIDS patients in developing nations according to the principles of home-based care, which constitutes the provision of basic medical, nursing and psychological care by health workers at home (Radstake 1997). Officials of NGOs and religious persons offer home-based care for AIDS patients. They assume a quasi-kin status and offer a good service complementing care at home but through AIDS they conceptually 'invade' the domain of the family/kinship group.

Moreover, families and households are left out in NGO operations. Since most HIV prevention programmes have been built on a paradigm of individual behaviour change, NGOs involved in HIV prevention/education efforts target individual patients rather than households and families. Hence, involving so-called traditional civil society groups such as the family and chieftaincy to work alongside NGOs and other mainstream civil society actors for development (e.g., Kessey 2006) will be necessary. Mkandawire's (2006) has a good point in his criticism of NGOs for fixing their attention on the livelihood strategies of individual households or communities, without considering the larger developmental context of their activities.

HIV/AIDS and the gender of NGO and civil society engagements

HIV/AIDS has occasioned a vast and rapidly expanding field of research on women's experiences with, and responses to the epidemic (Adomako et al. 2004). Many NGOs have helped vulnerable women outside their homes to cater for themselves and their families, especially in HIV/AIDS-affected communities. In 1990, the WHO's Global Program on AIDS (WHO/GPA) acknowledged that to stop AIDS it was essential to empower women politically, economically, and culturally.



As one writer put it in a feminist magazine, it was apparent that after years of obvious silence on the needs of HIV-positive women and women at risk, women's health was being defined as "a political issue, intertwined with relations of sexual and economic inequality" (Booth 1998: 115). Prior to that time, the WHO framed the problem of heterosexual HIV transmission not as a problem for women but rather for women as either mothers or prostitutes (ibid). In virtually all the nations of sub-Saharan Africa, prostitutes (or sex workers, to be politically correct) were among the first social group to be blamed by governments, the media, and scientists for the heterosexual spread of HIV infections.

Although such representations have eased in recent years, women still the most vulnerable group patients continue to face stigmatisation and shame. Lack of formal education and what many view as inadequate skills restrict women's effective participation in development activities. Although many NGOs in Ghana focus on empowering women and making them more productive and competitive in the job market, they are still left in the background. Training sessions may be targeted at women in workshops, seminars, demonstrations, and training centres and often emphasizes the acquisition of knowledge, skills and information as basics for their self-reliance. Yet, women and the rural population are under-represented in the membership of most civil society organisations and almost completely excluded from leadership roles (Darkwa et al. 2006).

HIV/AIDS, the media, the academia, and 'experts'

A massive amount of media attention has been devoted to the subject of HIV and AIDS in Africa. The presence of AIDS discourses in the media and in massive prevention campaigns has created a new anxiety and 'politics' for avoiding infection. However, the 'politics' of the media in AIDS campaign looks less 'political' since more time is allotted to mainstream political debates and electioneering campaigns than to HIV/AIDS. When AIDS surfaced in sub-Saharan Africa in the mid-1980s, there was the apocalyptic imagery of AIDS in the media. In Ghana, many media houses established AIDS Watch columns in their newspapers and television or radio programmes.

Today, there seems to be a diminishing intensity of press interest in AIDS itself as news worthy item (Lupton 1994). It is inevitable that media attention to heterosexual risk would diminish given the lack of new issues or events to keep the story alive. Attention on HIV/AIDS is enhanced only if the issue involves a high-profile (or government) figure such as when late South African President Nelson Mandela announced that he lost a brother and a son to AIDS. I argue that as the focus moves to governance, activism, democracy, and neoliberal values, policy posturing will continue to get more of the headlines than the plight of poor AIDS patients. HIV/AIDS has also brought into question notions of 'responsible journalism' and 'sensationalism' in the media, which produces uncertainty on the part of journalists. For instance, during the AIDS conference of 2006 in Toronto, Canada, South Africa's Treatment Action Campaign (TAC) activists stormed the South African exhibition (see Wells 2006: 12). They protested against the display of garlic, beetroot, and lemon (a



mixture often promoted by the health minister) alongside ARVs. For the South African journalists on the panel the question was how to cover the incident without making things worse. But one journalist said although not everything is covered by the press “when such activists are given an audience by your health minister, your readers need to know that” (ibid).

In the academic world, AIDS has been a phenomenon to study in all its possible aspects. Through the AIDS phenomenon, anthropologists of all theoretical persuasions have studied and still study the subject on a multitude of themes. Some are theoretically oriented and many others have practical implications aimed at influencing policy making societies. Most research on the disease in Africa has centred on the ‘hot spots’ with intensity and funding in southern and eastern Africa, and less so in other parts (Webb 1997). HIV/AIDS is one of the most sensitive areas of research and a reason to tow a particular line of inquiry. Early social research on AIDS in Africa considered the context in bio-anthropological terms, examining the cultural variables and ‘deviance’ within ‘African sexuality’ to provide explanations for the heterosexual spread in the continent. For instance, epidemiological reports of initial AIDS cases in the Democratic Republic of Congo (formerly Zaire) were worded in a way that reinforced cultural and gender stereotypes of black sexual and female immorality in Western terms (ibid: 29).

The power of the Western press and to some extent the Western scientific establishment have been glare as attempts to create the origins of the HIV-1 virus, the biologically causative agent for AIDS in Africa, was widespread. This attempt has been seen as based on a ‘victim blaming’ mentality and fundamentally racist (e.g., Hunt 1989: 367-8). Commentators used AIDS to universalize ‘African sexuality’ and a generalization with gross simplifications without spatial or socio-cultural reference pervaded the literature (Sacks 1996). Many people from research institutions and other organisations have become ‘the new professionals of AIDS’ and ‘experts’, taking up the epidemic as their subject. They speak in the name of AIDS or its patients; but it is also obvious that they use it as a tool to engage in their own political game.

AIDS activism and reconstructions: AIDS patients, Inclusion and medical right as human/political right

HIV/AIDS activism has been prominent with NGOs, CBOs and other AIDS support groups playing a key role in many African countries, especially in South Africa (Schneider 2002). Many people living with AIDS have constructed their identities around disability and, for some it is a way to go into marginality. But others, such as in South Africa and TAC, with support from international NGOs and other advocates, have been very vocal and have ‘fought’ actively for the provision of AIDS drugs and treatment roll-outs from their government. In an article on AIDS, marginalisation, and citizenship in South Africa, Robins and von Lieres (2004) point out that the recent forms of participation are created through the intervention of external forces such as international donors or the state, but others are spaces that the local people create themselves.



HIV/AIDS has become an open and contested area where relations of human suffering, power, and knowledge clash. In Ghana, some patients actively involve themselves in peer advocacy by talking about their statuses in order to create awareness. AIDS has provided patients with a new kind of citizenship and the tool to engage in the struggle for access to treatment. In the past, to say that someone has AIDS was to imply that he or she is a certain type of person, socially and morally defined and labelled usually as of no moral worth. Through NGO activities many patients feel a sense of belonging and empowered.

These days, AIDS has created the phenomenon of ‘patient citizenship’ (as Biehl (2007) has noted in Brazil) in many parts of Africa, notably South Africa where AIDS patients and other activists fight the denial of rights, when they feel they are disenfranchised, and made invisible. Patients in Ghana have not been as ‘vocal’ as those in South Africa, but everywhere AIDS patients’ needs for physical and economic survival dynamically inform private and public involvements, and in turn, redefine the local terms of politics and ethics. AIDS has become a means of advancing civil rights causes of patients and other activists by turning their medical rights into a political and human rights. AIDS activists demand that people living with AIDS are not to be referred to as ‘victims’, when such individuals are still active and vital participants in society rather than passive, disempowered patients living out a death sentence. AIDS activism creates space, a civil space for people to occupy and from where to engage in politics. It has empowered previously marginalized patients to articulate and demand their rights (Biehl 2007). In Ghana, AIDS patients who go ‘public’ give talks, lectures, and advice on the disease, usually based on their own stories and experiences. Some hospitals have formed AIDS associations to give patients a sense of belonging. In other parts, patients create a big ‘politics’ out of the AIDS situation, as is the case of the TAC in South Africa.

NGOs have become active in a complex range of broader development activities that include democracy building, human rights work, and policy analysis (Lewis & Opoku-Mensah 2006: 666), and also empowering AIDS patients to fight for their rights. The particular flexibility of NGOs as an institutional form within neoliberal policy agenda has ensured that non-governmental actors have maintained prominence within international development and humanitarian policy in both the developed and developing worlds (Fisher 1997). As a result, NGOs have ever stronger global and national public profiles. Images and representations of NGOs and their worldview have become main stream. NGOs and the third sector more widely are increasingly ubiquitous (ibid).

The Implications: Democracy and Empowerment

HIV/AIDS today reflects the scope of governance and has brought to the forefront an era of what Biehl (2007) refers to as ‘global governance’. The fusion of AIDS mobilisation with governmental, private, and international initiatives into a new public health policy has often redefined the form and scope of governance in Ghana and elsewhere. At the same time, an underlying politics of these NGOs is always grounded in the notion of the ‘virtuous’ forces



confronting the ‘vicious’ state forces and their inadequacies in the precarious public health care infrastructure.

The response to HIV/AIDS in Africa has largely been led by the NGO sector, which has also created a ‘regime’ of NGOs and donor agencies.

Although NGOs in the health sector are mainly voluntary, non-profit making and outside of state control in Ghana and places like South Africa, most of them have become progressive forces ‘governing’ AIDS activism. As de Waal (2003) has asserted, this means that principles of voluntarism combine with such neoliberal values as gender equality and human rights to guide AIDS projects. These private sector bodies are mobilised and supported by government institutions for AIDS campaigns. They may lack the coercive or regulatory power of the state and the economic power of the market, but they have the social power to influence ordinary people (ibid). Consequently, the partnership between governments and civil society is always praised by politicians and donors alike. Thus, conceptually the state puts pressure on NGOs, which in turn pressures the state—a cycle.

Today, in donor policy circles, talk of ‘NGOs’ has to some extent given way to an emphasis on ideas about civil society, citizen’s organisations, governance and cross-sectoral partnership (Lewis & Opoku-Mensah 2006). This change is partly the result of continuously evolving search for ever new terms and approaches always needed in the development efforts. The new aid design which has been erected to promote new appropriate policy frameworks has led to a mode that engages more directly with governments and with a reduced involvement of NGOs. Fiscal austerity, low economic growth, socio-demographic trends, technological change, and climate change have made it prudent to undertake horizontal policy initiatives not only between different parts of government, but also between governments and international organisations. It has been suggested that coordinated inter-or multi-sectoral actions are required if innovative processes of social transformations needed to promote, secure or achieve effective equitable and durable solutions to some of today’s most urgent local and global health challenges and sustainability are to be met.⁴ Consistent with the goal for improved health, many African governments and NGOs have instituted various policies and programmes aimed at improving health outcomes (e.g., national health insurance schemes, the Global Fund) (Gyimah et al. 2006).

Increased decision-making at the level of globally functioning international financial institutions, transnational companies and NGOs does not mean that African states like Ghana have lost their importance altogether. Monies from the UN’s Global Fund still go to the country’s HIV/AIDS programme division which manages most of the funds. NGOs have been important in revamping the often resource-challenged health sector in in Ghana and other African countries and the ‘right’ of NGOs and other humanitarian agencies to help with

⁴ See, The Second International Conference on Nutrition (ICN2), 12 June 2014. Retrieved from <http://www.fao.org/ICN2> (Accessed 13 June 2014).



campaigns and other activities is repeatedly asserted by the UN, the WHO, and the UNAIDS. Thousands of people have been employed by AIDS NGOs and also work as consultants for governments. Most NGOs receive their funding from international donors to whom they are accountable, and not to the governments in the places where they operate. An underlying politics of these NGOs is always grounded in the notion of the ‘virtuous’ forces confronting the ‘vicious’ state forces and the inadequacies in the precarious public health care infrastructure (Adesina 2009).

The policy environment in Ghana is not found to have a direct impact on the level of collaboration among NGOs, as in South Africa too (Gittelsohn 2011). In Ghana, AIDS therapies and care are the means through which civil society organisations take on and improvise the work of medical and political institutions—they assume the role in defining the field and scope of policy implementation (Biehl 2007). With their participatory and ethical underpinnings, their legitimate presence ensures administrative reforms in public health policy in Africa. The role of NGOs and donor agencies as institutions seeking to effect change, both behavioural and structural, is crucial to the response to HIV/AIDS; yet it is controlling. The efforts of international donor agencies are seen as strategic moves of successfully marketing themselves as donors and to control policy making in poorer nations (Manji & O’Coill 2002).

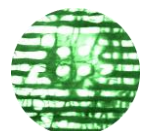
Conclusion

In Ghana, as in other parts of Africa, HIV/AIDS as an epidemic with a hidden mode of infection has become an open and contested area. HIV/AIDS amply displays that responses are now in the hands of not only doctors but many others, including the afflicted persons themselves through activism. The politics of state, formal institutions and informal organisations brings to the forefront the crucial need to examine the deeper meaning attached to the epidemic in Africa. The ‘politics’ underlying responses to HIV/AIDS in Africa assumes a hierarchical character and has also given poorer nations a small window of opportunity to intervene in global governance and to try to recast an uneven correlation of forces (Biehl 2007). The ‘traditional’ groups such as the family and chieftaincy in a more concrete way or getting NGOs to bring them on board in HIV/AIDS initiatives. The potency of such ‘traditional’ civil society groups playing a more meaningful role in local development is noted by Kessey (2006) that their capacity should be expanded to take a more assertive role in community or local level development. As I have also suggested elsewhere (Crentsil 2007, 2008), it is rather the family/kinship group which needs to reform itself (or reformed) as a socializing institution and a vigilante for the moral uprightness of its members and the youth in their communities.

Questions still surround the scope of AIDS awareness and treatment and the ethical grounds for prioritizing the disease over other afflictions of poverty such as malaria, tuberculosis, and diarrhoea. Altman’s (1999) observation many years ago in an article on globalisation, political, economy, and HIV/AIDS, is still relevant today—the state is



increasingly squeezed between international capital and local holders of power. In this sense, I am in agreement with Biehl (2007) that AIDS activism in the face of democracy, governance and civil society demonstrates the reproduction of power arrangements (both symmetries and asymmetries, national and international), and the ideological and political functions of all partners that are crystallized in HIV/AIDS initiatives. In sum, NGOs and civil society engagements in HIV/AIDS initiatives in Ghana and other African countries are not merely about activism and HIV/AIDS responses; they are also about the ‘politics’ and power relations in the HIV/AIDS field in Africa.



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