From end of life to chronic care in Zambia: how community-based programmes adapt to new challenges in health and social care.

Abstract

Pragmatism and sense of Christian duty drove Zambian communities in the late 1980s to provide end of life care for the rapidly rising numbers of HIV-infected individuals. The advent of anti-retroviral treatment changed the form and content of home based care in Zambia to chronic condition management. We present this evolution of primary-level HIV and AIDS services and draw attention to the opportunities and threats for the future of Zambia’s nascent chronic care system. Our study took place in 2011 and 2012 and was part of a multi-country study. It used a mixed method approach involving semi-structured interviews, focus group discussions, structured interviews, service observations and a questionnaire survey. Our research revealed a history of extensive mutual support amongst residents in many settlements, the invocation of cultural values that emphasised social relationships, and organisation of people by civil society organisations in care and support programmes. This laid the foundation for a locally conceived model of chronic care capable of addressing the country’s changing burden of disease. However, this capacity has come under threat since the reduction in donor funding to community and home based care programmes alongside government interventions which have changed the nature of these programmes in the country. We argue that Zambia’s health system risks losing capacity to fulfil its vision “to bring health care as close to the family as possible” if government strategies do not acknowledge the need for empowerment approaches and continuation of the brokering role by civil society organisations in health and social care.
Introduction

This chapter is about the evolution of HIV/AIDS-oriented community and home based care (CHBC) practices in Zambia. It discusses the origin of these practices in the mid-1980s when the AIDS epidemic inspired local responses to care for the sick and dying. It covers the processes which created, by 2011, a national HIV programme capable of providing hundreds of thousands patients with anti-retroviral treatment (ART). This programme is now a platform for further development of chronic care services, using the experience with addressing the long-term care needs of ART patients; the advent of ART having enabled HIV/AIDS to become a manageable chronic illness (Deeks et al, 2013; Volberding & Deeks, 2010). We discuss the opportunities of this nascent chronic care system for confronting an emerging burden of chronic, non-communicable diseases (NCDs) as well as the erosion of this system, following a reduction in funding to CHBC and government interventions which have changed the nature of CHBC in the country.

CHBC in Zambia articulates local and international concepts of care. There is Zambian research which intimates this articulation (Blinkhoff et al, 1999; Bond et al, 2005; Chela & Siankanga, 1991; Nsutebu et al, 2001). It builds on the principles of community participation in Primary Health Care (PHC), social relationships, and values of mutual support in Zambian society. Community participation in health is a much debated topic (Bender & Pitkin, 1987; Morgan, 2001; Zakus & Lysack, 1998). The gist of the debate has been about whether community participation is a means to save health care costs or a tool to empower people to take responsibility of their own health. Boyce & Lysack (2000), for example, distinguish between top-down initiatives in which community participation amounts to the voluntary contribution of people’s time and resources towards a common goal, and transformational participation in which people’s capacities are developed to organise themselves and make decisions on issues that affect their lives (Boyce & Lysack, 2000). This distinction is explained by others as the difference between ‘community-oriented’ and ‘community-based’ health care approaches. The former refers to the use of health management structures to determine community-level initiatives and to define the terms for community participation (Rifkin, 1981). The latter refers to programmes which are aligned to local needs and which have adjustable structures to respond to changes in local conditions (Kark, 1981; Rifkin, 1981; Tollman, 1991).

The Alma Ata declaration on PHC in 1978 invoked the transformational approach in its conception of community participation (WHO, 1978). At country-level, community health worker programmes would be the main vehicle to foster community involvement in health care (Walt, 1988). While African governments struggled to implement these programmes in the context of a global economic crisis (Lawn et al, 2008; Walt, 1988),
Civil society organisations (CSO) started mobilising settlement residents to respond to another crisis: the HIV and AIDS pandemic. These initiatives actively engaged patients, families and settlement residents to provide home based care to HIV-infected patients (Ncama, 2005). Thirty years later, CHBC programmes continue to be appropriate in the context of changing health care needs in the population. They reflect the theory and practice for the delivery of health care to patients with chronic conditions (Barr et al, 2003; Wagner, 1998; WHO, 2002b). For example, the emphasis on patient involvement in chronic care is based on the understanding that the largest share of chronic care takes place outside the health facility, for the patient primarily ‘self-manages’ his/her condition (Gately et al, 2007b; Holman & Lorig, 2004). ‘Self-management’ refers to patients managing the bio-physical, psychological, social and economic aspects of their conditions (Swendeman et al, 2009). It depends on family and community support (Swendeman et al, 2009), patients acquiring appropriate skills and knowledge to adopt new lifestyles and behaviors (Aujolet et al, 2007) and to seek medical assistance when necessary (Lorig, 1993).

The earlier practices of home based care for HIV-infected patients have been documented (Campbell & Foulis, 2004; Ogden, 2006; Uys, 2002). However, there has been little research on current practices involving chronic care in Africa. Studies that describe chronic care practices in this region tend to focus on facility-based services (Aantjes et al, 2014a; Levitt et al, 2011; Rabkin et al, 2011, 2012; Samb et al, 2010). Our study explored how community-based programmes mobilised people to help care for HIV-infected patients and, as ART became available, adjusted their services towards providing chronic care, including patient self-management support, in four sub-Saharan African countries. This chapter discusses the findings from the Zambian component of the study in light of changes in government policy and strategies to facilitate integration of health and social welfare interventions, as well as other developments which influence the nature of community participation.

**Methods**

The Zambian research was part of a multi-country study of CHBC programmes, conducted in 2011 and 2012, in Ethiopia, Malawi, South Africa and Zambia. The study used a historical, comparative approach to distinguish commonalities and differences between the four countries; an approach that is commonly used in the discipline of social anthropology (Pocock, 1961). The study had four research objectives. This chapter draws primarily on the results from the first research objective.
1) Explore the adaptations and changes in caregiving at the community level since the rapid scale up of anti-retroviral therapy while focusing on the tasks of caregivers and the needs of their clients;

2) Assess how and to what extent caregiving by informal caregivers at community level has been integrated in the health system and is being recognised as part of primary health care structures and policies;

3) Investigate the contributions, potential role of and benefits for caregivers in the expansion of HIV prevention, treatment and primary health care programmes;

4) Assess the potential means for formal and informal community health worker programmes to complement each other in the context of decentralisation of HIV treatment programmes, taking into account current initiatives and arrangements.

Criteria for country selection included the presence of a generalised HIV epidemic, well-established CHBC programmes (10+ years old) and national government commitment to the African PHC revitalisation agenda. The research was conducted in several parts by in-country research teams, supported by two project co-ordinators. The study design began with an online survey among international HIV and health experts to help define the foci and objectives of the proposed research and, thereafter, to inform the development of the research tools. The first part of the in-country studies included literature reviews and semi-structured interviews with key informants at national level. Informants included officials from health, social welfare and community development ministries, the national AIDS council, large care and support organisations, HIV patient networks and CHBC programme funders. The second part included in-depth study of selected CHBC programmes in each country. Selection criteria for the programmes were: 1) they had been operational for more than 10 years, 2) their care models were generally representative of CHBC in each country, 3) were managed by different types of organisations, 4) offered diversity in care and range of patients, and 5) inclusion of rural and urban programmes.

Programme selection was guided by national advisory boards set up in each country, consisting of representatives of CHBC programmes, staff from national HIV programmes and community caregivers. Primary research methods included semi-structured interviews with programme and clinic staff, service observations, focus group discussions (FGDs), community mapping with caregivers, and structured interviews with patients and their relatives. Internal validation of the research included the use of standardised interview schedules and field work procedures in each country and verbatim transcription of the data from interviews and FGDs. Data analysis was standardised using structured coding and findings were validated via another round of
key informant interviews and a questionnaire survey. The qualitative data was analysed with the software programme Atlas.ti. The quantitative data was processed with SPSS software. National advisory boards monitored the quality and progress of the in-country studies. An international reference group monitored the study as a whole. Further details on the methodology can be found in another publication which presents findings on objectives 2 and 3 (Aantjes et al, 2014c).

All study informants provided written informed consent prior to study participation. The study was approved by the ERES Converge Ethics Review Board in Zambia and the medical ethics review committee of the VU University in Amsterdam (reference 2011/180). Table 5.1 presents the sample sizes from the Zambian research and from the overall study.

Table 5.1. Informant samples.

<table>
<thead>
<tr>
<th>Method and Sample Categories</th>
<th>Zambia (total sample size of 4 countries)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online survey: international experts</td>
<td>n/a (17)</td>
</tr>
<tr>
<td>Key national level informants: government and care organisations</td>
<td>13 (49)</td>
</tr>
<tr>
<td>Key informants: CHBC programmes</td>
<td>8 (71)</td>
</tr>
<tr>
<td>FGD: CHBC programme staff</td>
<td>9 (17)</td>
</tr>
<tr>
<td>FGD: volunteer caregivers in CHBC programmes</td>
<td>29 (115)</td>
</tr>
<tr>
<td>FGD: community representatives in CHBC programmes</td>
<td>20 (65)</td>
</tr>
<tr>
<td>Individual interviews: clients</td>
<td>30 (98)</td>
</tr>
<tr>
<td>Individual interviews: family caregivers</td>
<td>30 (99)</td>
</tr>
<tr>
<td>Validation Interviews: key informants national level</td>
<td>5 (21)</td>
</tr>
<tr>
<td>Validation questionnaire survey: CHBC programmes</td>
<td>9 (46)</td>
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</tbody>
</table>

Findings

This section presents the research findings historically to show how community-based end of life care evolved to chronic care and how approaches to community participation changed over time in the context of global and national level influences.


The first Zambian AIDS case was reported in 1984 (WHO, 2005). Study informants reported that Zambian civil society responded to the increasing number of deaths by providing end of life care to afflicted individuals in their homes in 1985/86. Christian
churches were at the forefront of this initiative. They incorporated the concept of home based care (HBC) into their health facility outreach programmes whereby medical teams visited patients and provided basic medical care. For example, the Salvation Army which had a hospital and clinics in the south of the country, had teams who visited patients with tuberculosis (TB) and leprosy and who then began to visit HIV and AIDS patients. The medical teams started to draw on the assistance of trained lay-volunteers who, on occasion, replaced these teams to reduce costs and increase contact time with patients and families. The development of these HBC programmes coincided with national health reforms in Zambia; notably, decentralisation of health services in line with the PHC agenda set at Alma Ata and following the WHO’s decentralisation model (Bosman, 2000; Bossert et al, 2003; Lawn et al., 2008; WHO, 1978). The reforms involved establishing health posts and clinics and mobilising settlement residents, via neighbourhood health committees, in health care. The government’s health decentralisation policy created favourable conditions for further development of the HBC concept and more use of lay-volunteers. In 1986, the Churches Health Association of Zambia (CHAZ) officially adopted the HBC model. In 1991, the Catholic Diocese of Ndola established a large HBC programme in the north of the country. By 1992, 47 HBC programmes were registered in the country (MoH, 1994).

HBC programmes were also established by CSOs independently of church-based initiatives. For example, in 1996, Bwafwano established a programme in Lusaka, using volunteers to care for TB and AIDS patients who had little or no family support. These volunteers were generally elderly women motivated by their religious beliefs and sense of duty; as one study informant stated:

‘There was a problem and it needed to be fixed.’ Community caregiver, FGD.

By 1996, there were over 100 HBC programmes (Illife, 2006). Two factors shaped HBC in the 1990s: the relative lack of government involvement in HBC and the provision of care largely by familiar lay-persons responsive to patient needs. The Zambian government acknowledged the importance of HBC but viewed it as a form of pastoral care by churches. Linkages between volunteer caregivers and medical staff were merely to facilitate home nursing. A few ‘AIDS care handbooks’ were in circulation (WHO, 1993) but the basis for HBC was charity. A study informant, who had been a doctor in the Salvation Army’s HBC programme, reported there was limited external funding. Christian organisations provided care and support mostly with their own resources and via congregation members.

Patients’ needs informed the practices of family and volunteer caregivers. The roles of medical staff were largely to monitor patients’ health, treat opportunistic infections, and encourage family members to give care. In contrast, the caregivers provided basic
nursing care, bathed patients, washed clothes, did household chores, ensured patients ate their food, encouraged family members to care for their afflicted kin, mobilised broader support (e.g. food donations), and reminded those on TB treatment to take medicines. In other words, the practice of care drew upon and cultivated social relationships amongst kin, neighbours, and acquaintances within settlements.


Elaboration of HBC through collaboration between CSOs and government agencies occurred from the late 1990s. A foundation was the introduction of formal training for caregivers. CSOs developed Ministry of Health (MoH)-approved training and care manuals and, increasingly, international NGOs began to provide financial support. CHBC informants reported an increase in donor funding from early 2000s onwards. This was also the period when the content of HBC was formally defined. Training courses set out medical standards for basic nursing care in people’s homes, protection of caregivers, detection and treatment (under supervision) of opportunistic infections, pain management, diagnosis and care of TB (co-infected) patients. Caregivers were supplied with ‘HBC kits’ which included surgical gloves, bandages, pain killers, oral rehydration salts and other non-prescription medicines. ART became available in Zambia but few patients could afford the cost of approximately U$8 per month.

The government acknowledged HBC programmes as a component of the health system yet separate to government health services. It did not create regulatory frameworks; instead, international NGO stipulations set the benchmarks for standards of care and voluntary work. One prerequisite for funding was that CSOs employed nurses to supervise the caregivers. Some programmes began to provide non-financial incentives to retain caregivers (e.g. t-shirts, bags, food). HBC programmes also started to create broader support mechanisms; for example, farmer support groups to help provide food for very poor HIV-afflicted individuals and households. The model changed from hospital-based HBC, using mobile medical teams, to a model that concentrated care within settlements and in the hands of volunteer caregivers. Some CSOs had offices on government or mission hospital premises as a result of collaborative arrangements but, generally, HBC programmes became distinct adjunct entities involved in the organisation and management of caregivers in settlements:

“you may realise that the issue of HBC was not born in a government agency, it was born by civil society organisations and more specifically by the faith-based organisations…the government came on board very late, we were actually almost in the second or third stage of HIV and AIDS [that is] when they recognised that we needed to have this type of workforce”. Senior manager CHAZ, semi-structured interview.
From end of life to chronic care: diversification of HBC (2005-2011)

In August 2004, ART became freely available in public hospitals (Schumaker & Bond, 2008). Later, as ART patients recovered their health, HBC programmes found they needed to provide support as much as care for these patients. This is not to say that end of life care was no longer necessary; only that the demand for various support services increased whilst demand for end of life care decreased.

Study informants reported rapid diversification of HBC services during this period and programmes evolved into what are now commonly known as CHBC programmes. Figure 5.1 illustrates the changes in relation to the rapid increase in the number of ART patients (UNAIDS, 2013). Foreign funding facilitated this expansion (Ainsworth & Over, 1997; Ndubani, 2009; Oomman et al, 2007).

Volunteer caregivers became involved in promoting the national ART programme by motivating patients to register for treatment, encouraging people to go for voluntary counselling and testing and, in time, monitoring patients.

“HBC has evolved over the years from mediators to the provision and advice on HIV and AIDS, including the administration of ART”. Community representative, FGD.

CSOs introduced support services in response to the changing needs of their patients. Patients and caregivers were unequivocal about the reasons: patients on ART need psycho-social and economic support to re-establish their lives and, notably, nutritional support. CSOs relied on patient support groups, farmer and business groups to assist ART patients. The programmes addressed issues such as nutrition, infection prevention,
management of side-effects, establishment of vegetable gardens, formation of cash savings groups, and ways to start small businesses. Local gatherings were a means for broad dissemination of information on ART, on patient needs and for mobilising local assistance. CHBC programmes also began to assist people suffering from NCDs and also the elderly, though volunteer caregivers did not have formal training in this area. In sum, CSOs fostered ‘community’ in the sense of diverse forms of assistance to patients and their households by fellow settlement residents. This amounted to mutual support in a context where virtually all Zambians had been affected in some way by the HIV pandemic.

In 2007, the MoH began to regulate CHBC programmes, beginning with “National Minimum Standards for CHBC Organisations” (NAC, 2007). The document updated standards for caregiver training courses and set standards for the new activities that caregivers were doing (e.g. treatment literacy, ART adherence). The MoH also started its own CHBC programmes in selected health facilities. These programmes recruited and trained volunteers who were supervised by medical staff. The overt difference to the CSO-led programmes was that volunteers focused primarily on treatment adherence, counselling, and tracing patients who defaulted on their medicinal regimens. In 2008, the government adopted a WHO-driven strategy to “revitalise” PHC services (WHO, 2008d). It led to plans to increase the number of nurses employed by the MoH and deployed to PHC facilities, and to recruit ‘community health assistants’ (CHAs) as state-paid community health workers.

By 2011, the key actors as described in chronic care service models (Barr et al., 2003; Wagner, 1998; WHO, 2002b) were in place (‘community partners’; patients; families) or were anticipated (health care teams at PHC facilities). CSOs provided health and social care for the prevention and management of chronic conditions. Their programmes applied the principle of patient ‘self-management’ through multiple, overlapping social relationships between patients, their families and volunteer caregivers. In summary, two important processes occurred from 2005-2011. One, was the diversification of CHBC programme services which, together with the collaboration between government and CSOs in the delivery of ART, created the country’s first large-scale chronic care programme. The other, was the PHC revitalisation agenda which directed the government’s attention to strengthening primary level services. As we discuss in the next section, these processes laid the foundation for the integration of CHBC programmes into government PHC services.
Medicalization of community and home based care programmes (post-2011)

By 2012, the government had revised health and economic development strategies via the Sixth National Development Plan (GRZ, 2011), the National Health Strategic Plan 2011-2015 (MoH, 2011) and a National Health Policy (GRZ, 2012b). The common ethos within these initiatives was commitment to addressing the social and bio-medical determinants of health by aligning health with national economic policies. PHC services were the focus of attention and this was expressed in the new health policy’s commitment “to bringing health care as close to the family as possible”, plans to build an additional 650 PHC facilities according to health officials, and plans to merge the portfolios of PHC, social welfare and community development under a single new Ministry of Community Development, Mother and Child Health (MCDMCH, 2013). In addition, according to MoH officials, the government began in 2012 to recruit 3,000 nurses and to train the first cadre of a projected 5,000 CHAs. It should be noted that these plans were put into effect after the end of this study. Follow up interviews in 2013 and 2014 with health officials revealed that the nurses had been recruited, construction of PHC facilities was ongoing and that the first cadre of CHAs had been deployed. Furthermore, the thrust of the initiatives was to integrate CHBC programmes into PHC services by making PHC facilities the focal point for management and for CHAs to be responsible for the supervision of community-based activities.

However, in 2012, contradictions were already surfacing in these efforts to integrate CHBC programmes with PHC services. Notably, the orientation of these programmes to address the social and bio-medical determinants of health was constrained by what can be described as ‘medicalization’ of health care; meaning that volunteer caregivers were increasingly directed to enabling PHC professionals to implement international medical guidelines for treating ART patients (Schwartländer et al., 2011; WHO, 2010). Two quotes below illustrate health officials’ understanding of the role of CHBC programmes:

“... they (community caregivers) play a critical role.... volunteers help with triaging, keeping records, tracking patients out in the community, linking patients to different services, offering peer support or possibly participating in health education talks, emotional support and all that, so without that cadre there, the programme starts to fall into pieces. In government clinics, .... they are doing the same things as in partner supported facility like patient registration, patient flow in the clinic, helping patients get to the right provider at the right time, weighing patients, help the patients count through their pills, offer adherence counselling, and if patients are missing clinic visits, they go out into the community and track the patients and bring them back into care.” MoH official, semi-structured interview.
“They have a critical role to play to support the whole process. They will need to talk about health education of the client, touching on critical issues like adherence, following up patients in the communities, those who don’t come for follow-ups.” WHO country office official, semi-structured interview.

The redefinition of roles was succinctly illustrated in a report from an informant in one large CHBC programme which had retrained its caregivers, at the instigation of their funders, to be ‘adherence support’ workers and to work in teams under the guidance of health facility staff. A MoH official stated that “the MoH is not up to destroying the volunteer spirit in the community” but volunteer caregivers voiced their discontent in interviews about being unpaid health workers under the supervision of (paid) CHAs. From their perspective, CHAs were different to them only in that they met the MoH’ recruitment standards such as standard of education. Furthermore, CHAs would not necessarily be deployed in their home settlements and, therefore, some would lack familiarity with the social relations and networks which facilitate community participation in health care. In other words, as one CHBC programme manager indicated, the government’s initiatives were ignoring fundamental reasons for the utility of volunteer caregivers:

“These people are found within these localities, so they operate within their locality because they understand the community, they understand the culture, they understand the people, they understand the problems, they experience the problems together with everyone so that gives them a passion to do the work”. CHBC programme manager, semi-structured interview.

It should be noted that CHBC programmes were also under threat as a result of large-scale losses of funding from donors, as one informant highlighted:

“In terms of HBC and OVC [orphans and vulnerable children] care I think international funds have dried up for that. That is my view and I think they are at a point where they are saying communities can do it on their own. We have had eight years to build their capacity and set up systems”. Manager of a large care organisation, semi-structured interview.

Furthermore, the new MCDMCH which was created in late 2012 was given the responsibility of engaging with CSOs and with traditional and local government authorities but did not have detailed plans. The responsibilities included registering CSOs, promoting co-ordination of their activities and collaboration with CHAs and similar level state workers in other sections of the new ministry. However, the MCDMCH’s strategy for 2013-2016 did not contain procedures on how it would fulfil its responsibilities (MCDMCH, 2013).

In summary, post 2011, CHBC was changing from a conglomeration of services that were evolving parallel to government’s PHC services, towards integration of the former into the latter. The different agencies had a common purpose: to expand the content, and improve the delivery of PHC. However, CSOs, government ministries
and international agencies had different perspectives on the structure, organisation, and meaning of community-level health care.

Discussion

We have demarcated qualitative shifts in the form of HIV and AIDS community-based care over time in the following terms:

- Mid-1980s-circa 1995/6: ‘Local innovation’ according to local cultural values and norms and capabilities of existing health service infrastructure, the latter leading to hospital-based organisation of HBC and community care;

- Mid-1990s-2004: ‘Professionalization’ of HBC programmes via introduction of training for volunteer caregivers and establishment of HBC standards;

- 2004/5-2011: ‘Diversification’ of HBC leading to CHBC programmes providing support as much as care in the context of advent and expansion of ART programme and nascence of a chronic care sub-system;

- Post-2011: ‘Medicalization’ of CHBC programmes in the sense of a re-emphasis of the bio-medical components of PHC service delivery and ART treatment (albeit alongside government initiatives to address the social determinants of health).

Figure 5.2 represents these models schematically. It illustrates why ‘community-based’ care figures so prominently as ethos and practice in the country. It also illustrates the foundations for notable achievements within the last 8-9 years: achieving universal access to ART, implementation of key principles and practices of chronic care services, establishment of PHC services oriented towards providing comprehensive care and a continuum of care, and explicit government commitment to incorporating social determinants of health in its intervention agenda.

For thirty years, there has been extensive mutual support amongst residents in many settlements to ease the suffering wrought by HIV and AIDS, facilitated by CSOs. This entailed continuous interventions to replace volunteers and to sustain involvement of different residents and social groups as a result of generational change within families and households. In other words, Zambia has shown what ‘community mobilisation’ and ‘community participation’ means: pragmatism, invocation of cultural values that emphasise social relationships between settlement residents, creation and use of social networks, and organisation of people on the basis of these linkages by CSOs who provide direction guided by the expressed needs of patients. This is in contrast
Local Models

- Rural settlements (shared confidentiality, Christian duty ethos) ➔ Community support ➔ Support groups (interaction of kin, affines, settlement residents)

- Salvation army ➔ Hospital-based Home Care ➔ HBC ➔ CHBC ➔ CHBC, PHC, ART (by volunteer teams with development focus)

Local / Donor

- Bwafwano, CHAZ missions etc. (combine local & donor precepts) ➔ Hospital-based Home Care ➔ HBC ➔ CHBC ➔ CHBC, PHC, ART (volunteer caregivers)

Donor Models

- Donor (via international agency concepts e.g. WHO; UNAIDS) ➔ HBC ➔ CHBC ➔ ART (sustaining high levels of ART coverage; volunteer caregivers support medical teams)

Government Models

- MoH ➔ Regulate HBC & CHBC ➔ CHBC ➔ CHBC supervision by PHC, ART delivery (bio-medical approach to management of services; community health workers)

- MCDMCH ➔ Integrated community services (social and bio-medical focus)

Figure 5.2. Schematic representation of the evolution of Zambian models of care

to developed countries, where community care tends to be formalised via contracted agencies and their employed carers (Nolte et al, 2008).

However, government interventions since circa 2010/11 are changing the nature of the relationship between ‘communities’ and PHC medical staff. First, the ethic of care and support provided by familiar peers according to the needs of the patients is contradicted by volunteer caregivers becoming quasi-authorities (e.g. ‘adherence support’ workers) who are answerable to PHC clinics; a trend which has occurred elsewhere (Schneider
et al, 2008). Secondly, the introduction of CHAs signal movement away from a PHC system reliant on community caregivers, towards one that is run by medical personnel via state-employed community health workers.

The methodological limitation within the Zambian government’s efforts to improve PHC services, lies in the tacit premise of community-oriented interventions; meaning government engagement with ‘communities’ to extend government services to citizens who do not receive these services. The limitations of this premise, notably the impediments to community participation and emphasis on bio-medical perspectives on health care, have been voiced in the past (Morgan, 2001; Rifkin, 1981). In contrast, CSOs, during the course of their evolution, worked from a different premise of community-based interventions. This is expressed in the extensive involvement of ‘communities’ in the care and support of HIV and TB patients as well as in their flexibility to adapt as the needs of HIV-infected patients changed and to support people with other chronic diseases and the elderly in the community.

Stated differently, the methodological critique here is that ‘community-oriented’ care reflects a narrow conception of integration of health and social care (Kodner, 2006; Leichsenring et al, 2013; Valentijn et al., 2013). Integration, in this instance, means subsuming CHBC programmes within professional medical structures at the cost of discounting the mechanisms within those programmes which empowered people to take responsibility, collectively, for their health (Aujoulat et al, 2007; Fumagalli et al, 2015). One methodological consequence is negation of a fundamental principle of chronic care: patient self-management (Greenhalgh, 2009).

At root, our argument in support of the ‘community-based’ methodology of CHBC programmes is that Zambian CSOs have mediated the interests of patients and medical personnel by building social networks and structures to facilitate the delivery of, and people’s access to, diverse forms of treatment, care and support. In this instance, the argument refers to the large body of literature on the theory and practice of appropriate mechanisms that enjoin diverse agencies to create and apply knowledge for practical purposes and for mutual benefit (Cash, 2001; Drimie & Quinlan, 2011; Guston, 2001; Jones et al, 2009; Kay & Bawden, 1996; Regeer & Bunders, 2009). In sum, Zambian CSOs have played a critical brokering role between ‘communities’ and government agencies to facilitate ‘care (not just health care) as close to the family as possible’.

Conclusion

This history of CHBC programmes in Zambia has focused on the meaning and practice of community participation, the development of PHC services, and how the programmes represent a local model of chronic care. Our research shows that
the Zambian authorities work with the concept of community-oriented participation. We refer here to the equation of community with settlements and their residents who need to be reached by the government’s health services and to the lack of evidence in policy, strategy, and planning documents, which indicates appreciation of community as a qualitative construct. Equally, our research shows that CHBC programmes have demonstrated how to construct ‘community’ and, thereby, to sustain community participation in the development and delivery of PHC services.

Our contention is that the Zambian government is facing a specific challenge now. It risks losing the ground gained in turning HIV into a manageable disease and in establishing chronic care services if it does not recognise the limitations in its ‘community-oriented’ approach to improving PHC services. Simply put, allow CHBC programmes to run down, which is happening due to loss of funding, and Zambia will lose its capacity to promote and sustain community participation in the delivery of health and social care. The solution is to invest in them and enhance their brokering role.