Introduction

Access to affordable and quality health care is problematic for most citizens in sub-Saharan Africa as health systems in this region face many constraints in the provision of health care services. The population health outcomes are poor and globally agreed targets, such as “Health for All” and the “Millennium Development Goals” remain elusive (Baum, 2007; United Nations, 2014). To make matters worse, health systems are now to respond to an emerging burden of chronic, non-communicable diseases. The projections on the expected size of this burden in sub-Saharan Africa are startling and leave many of us to wonder how health systems will manage these new health care demands. Surprisingly, the hopes are placed on HIV and AIDS. The region’s experience with the management of this disease is considered instrumental in confronting diseases that are chronic and non-communicable. During the last decade, sub-Saharan African countries have made tremendous progress in decentralising complex treatment to lower level health facilities and in establishing care and support networks at community level. All this effort turned HIV from a fatal into a chronic manageable disease. This achievement shows there is health system potential for serving patients with other chronic conditions. The crux of the matter is now whether and how lessons from the vertical HIV programme can be used to prepare health systems for this imminent health challenge. This thesis explores the innovations and service adaptations for patients with HIV and AIDS and their utility for health system re-orientation in four sub-Saharan African countries, notably Ethiopia, Malawi, South Africa and, in particular, Zambia.
Overall aim of the thesis

The overall aim of this thesis is to increase the understanding on how health systems in resource-constrained settings respond and adapt to new health care challenges. It draws on the experiences from thirty-five years of HIV and AIDS in sub-Saharan Africa and, in particular, from the last decade since anti-retroviral treatment became available in this part of the world. The ways and means in which health system capacity was improved and expanded over time for patients with HIV and AIDS present valuable insights. First, they help us understand which adaptations enabled accessibility, affordability and quality of HIV and AIDS services in the context of resource constraints in sub-Saharan Africa. Secondly, they give insight into how national health systems can be strengthened to continue provision of services to millions of HIV-infected patients. Thirdly, they indicate how the accumulated expertise with providing HIV treatment and care can be applied to developing and delivering services for the growing number of patients with chronic, non-communicable conditions.

This thesis focuses on the responses and adaptations which have occurred or are occurring at primary health and community level. I refer here to the longstanding practice of HIV and AIDS community home based care programmes in sub-Saharan Africa. These programmes responded to the fast growing demand for palliative care during the first two decades of the pandemic and, once treatment became available, they were instrumental in the extension of this service to communities. I also refer here to the decentralisation of complex anti-retroviral treatment to primary health care clinics which enabled patients to access clinical services closer to their homes. The collaboration between the two levels facilitated the exceptional treatment programme in sub-Saharan Africa. This development reflects ‘good practice’ in the sense of locating the management of a chronic condition in primary health care facilities and the community (Allotey et al., 2011b; Beaglehole et al., 2008; Kautzky & Tollman, 2008; Maher et al., 2010; Rohde et al., 2008). Experiences with chronic diseases in high-income countries show that this does not require medical doctors and that nurses can deliver many aspects of chronic care at primary health care level, provided protocols and training are available (Bodenheimer et al., 2005; Renders et al., 2001). The largest share of chronic care takes place outside the health facility, whereby the patient is his/her own, principal caregiver (Gately et al., 2007b; Holman & Lorig, 2004). In order to do this effectively, patients need to possess the appropriate skills and knowledge as well as have access to family and community support (Swendeman et al., 2009).

Many factors have been responsible for shaping the provision of HIV treatment, care and support at primary health and community level in sub-Saharan Africa. Changes occurred (and continue to occur) in a highly dynamic context, whereby the availability of anti-retroviral treatment (ART) has been a key development. Another crucial
development was the prioritisation of the disease at global level, which gave rise to changes in, among others, the governance, finance and the delivery of health care in sub-Saharan African countries. I present a short history in order to put these developments in context.

Thirty five years of HIV and AIDS (1980–2015)

There is a world of difference between the world’s first encounter with the disease and current developments in the field of HIV and AIDS: in the 1980s and early 1990s, there was a reactive response to the emergence of the AIDS epidemic, whereas now, there is systemic action, based on the experience and knowledge of how to intervene and manage this disease. This evolution has been well documented, both globally as well as for sub-Saharan Africa, the region most heavily affected by the disease (Barnett & Whiteside, 2002; Colvin, 2011; Deeks et al., 2013; Epstein, 2007; Fee & Krieger, 1993; Kippax & Race, 2003; MSH, 2009; Okie, 2006; Piot et al., 2008; Pisani, 2010; Sawires et al., 2009; Szekeres et al., 2008; Tarantola, 2000; Whiteside & Smith, 2009).

The initial response to AIDS was complicated as the disease was associated with marginalised groups (homosexuals and drug users), sexuality and fatality. These associations, coupled with limited knowledge on the virus, inhibited effective containment and soon the disease took epidemic proportions. In 1996, a special United Nations programme for AIDS, called UNAIDS, became responsible for co-ordinating global action. By then more than 4.6 million people had died of AIDS and over 15 million HIV patients, out of a global total of 20.1 million, lived in sub-Saharan Africa (UNAIDS, 2008). As health facilities were not able to serve these large number of AIDS patients within their institutional settings, home based care became the norm. Community members volunteering in these programmes were confronted with bedridden patients, often living in impoverished conditions, and in need of palliative (end of life) care. Scholars reported the devastating impact of AIDS on socio-economic development and life expectancy and projected a gloomy future for sub-Saharan Africa (Bongaarts, 1996; Garnett & Anderson, 1993; Piot et al., 2001; Poku, 2001; Whiteside, 2001). Between the mid-to-late 1990s, the co-ordination of HIV interventions which, since the start of the epidemic, had largely been driven by Ministries of Health was taken over by multi-sectoral bodies. ‘National AIDS Commissions’ were put in place to facilitate and co-ordinate HIV and AIDS interventions across different sectors and in recognition of the wide ranging economic and social threats of the disease for society (England, 2006). Nonetheless, Ministries of Health remained central in the response and developed more systemic interventions as the epidemic matured and anti-retroviral medicines, which suppressed the HIV infection, came on to the market.
During the late 1990s, pressure mounted to lower the price for these medicines in order to provide access to patients in low- and middle income countries (Ford et al., 2011; Nixon et al., 2011). In 1997, UNAIDS launched the Drug Access Initiative in which pharmaceutical companies were invited to supply subsidized drugs in four pilot countries (UNAIDS, 2010a). The initiative, which demonstrated that treatment provision was feasible in African settings, coupled with global lobbying, paved the way for free anti-retroviral treatment in public health facilities by 2003-2005. It was the start of an unprecedented scale-up of treatment services which reduced the region’s high AIDS mortality (Mwagomba et al., 2010; Reniers et al., 2009). The large scale access to treatment was made possible by an enormous influx of external funding and was guided by a globally agreed target to halt and reverse the spread of HIV and AIDS. In 2001, former UN secretary general Kofi Annan called upon the international community to establish a mechanism to jointly finance this effort, which became known as the Global Fund for Tuberculosis, AIDS and Malaria at its establishment in 2002. Other major contributors were the USA’s President’s Emergency Plan for AIDS Relief and the World Bank Multi-country AIDS programme. The three initiatives provided two-thirds of the total funding for HIV and AIDS in low-income countries during the 2000s (Biesma et al., 2009a). The advances in HIV prevention, care and treatment during this decade led to a reversal of the epidemic by 2010 (UNAIDS, 2010). Advances included prevention of mother to child transmission, male circumcision, rapid diagnostics and simplification of ART regimens. The availability of ART not only helped to avert a significant amount of AIDS deaths but also prevented new infections as people on treatment are less likely to transmit the virus.

However, out of 22.5 million people living with HIV in sub-Saharan Africa in 2009, an average of 37% of adults who were eligible for treatment had access to it. It must be noted that this percentage conceals substantive differences between countries, as Botswana for instance reported an adult coverage of 83% in 2009, whereas countries such as South Africa and the United Republic of Tanzania reported an adult coverage below 40% (UNAIDS, 2010). To further increase the access to ART, UNAIDS proposed the ‘Treatment 2.0 approach’ in 2011, which emphasised the need to engage community-level agencies in distributing treatment and promoting treatment adherence (Schwartländer et al, 2011). The ‘Treatment 2.0’ agenda recognised that severe shortages of professional health staff in many African countries constrained efforts to reach all those in need of treatment (van Damme et al., 2008; Bisschof et al., 2009; Frenk, 2009). That agenda was also informed by growing opposition to the exceptional status of HIV and AIDS in global and national health strategies at the expense of other global health challenges, such as maternal and child mortality (England, 2007a), and from 2009 following the global financial crisis, the stagnation in the amount of external aid for HIV and AIDS interventions (AFGH, 2013).
A source of the contention about the ‘exceptional’ status of HIV and AIDS was the dedication of the bulk of this aid for ‘vertical’ HIV and AIDS programmes. Vertical programmes are characterised by structures that are dedicated to one disease, or in other words, a system within a health system; for example separate treatment clinics, use of separate data information systems, drug supply chains and laboratory services as well as use of specialised health professionals to deliver these services. Critics argued that such programmes are not sustainable, and moreover, that the HIV and AIDS programmes burdened rather than benefitted health systems in sub-Saharan Africa (England, 2007b, 2008; Garrett, 2007; Shiffman et al., 2009). While, scientific studies reported both positive as well as negative effects of vertical programmes and funding on national health systems (Embrey et al., 2009; Levine & Oomman, 2009; MSH, 2009; Ooms et al., 2008; Yu et al., 2008), consensus grew on the need to integrate HIV treatment and care into general health services (Kruk, 2011; WHO, 2010a). The Global Fund started financing interventions which helped strengthen the broader health system and experiments emerged in which ART services were integrated into primary health care clinics (Deo et al, 2012; Pfeiffer et al, 2010; Topp et al, 2010, 2012).

Concerns were meanwhile voiced on the capacity of national health systems to provide ongoing care for the growing caseload of patients on ART (Bischoff et al., 2009; Harries et al., 2009; Kell & Walley, 2009; Schneider et al., 2006) and the risks for treatment failure and disease complications if daily treatment was interrupted (Celentano & Beyrer, 2008). Scholars as well as the World Health Organisation (WHO) also started drawing attention to the emerging burden of non-communicable, chronic conditions in sub-Saharan Africa and the need to invest in health system capacity (Magnusson, 2010; Beaglehole et al., 2011; Mbanya et al., 2010; Samb et al., 2010; Stevens, 2011; WHO, 2010a). These capacity constraints pertained not only to financial capacity, but also to the available human and technical capacity to deliver this care (Magnusson, 2010; Schneider et al, 2006). Innovative ways were needed to strengthen existing health system capacity and to prepare for a double burden of infectious and chronic diseases (Harries et al, 2009; Stevens, 2011). It became increasingly clear that there was synergy between the services for HIV patients and those with chronic, non-communicable diseases (NCDs). The accumulated experience and expertise with ART programmes could be used to strengthen the capacity of health system to address NCDs. Scholars from Malawi, for instance, suggested using their HIV treatment model for other chronic conditions (Harries et al., 2009) and they were followed by UNAIDS and others advocating for application of this principle in low- and middle income countries (Levitt et al., 2011; Mills et al., 2011; Rabkin & El-Sadr, 2011; UNAIDS, 2011; van Olmen et al., 2012a). The calls for a ‘combined agenda’ were also substantiated by studies which showed that ART patients were at risk of developing NCDs such as cardiovascular diseases, diabetes, osteoporosis and cancers, as a result of immunodeficiency complications (these can occur as treatment does not fully restore the immune system) and as a result
of toxic effects arising from long-term exposure to ART regimens (Currier & Havlir, 2009; Deeks et al., 2013; Ellis et al., 2010; Furuya-Kanamori et al., 2013; Haregu et al., 2012). One implication of this combined agenda is that this also supports arguments to integrate HIV services into general health services; the latter becoming the basis for providing long-term treatment, care and support to all patients with chronic conditions, including those with HIV.

Re-orienting health systems for chronic conditions

The problem is that health systems in sub-Saharan Africa are not yet sufficiently equipped to provide services to patients with chronic conditions. Their primary orientation is on the delivery of acute and episodic care for infectious diseases (Beaglehole et al., 2008), which constitute the largest share of the region’s disease burden. However, the WHO projects that NCDs will surpass those diseases and become the most common causes of death in sub-Saharan Africa by the year 2030 (WHO, 2010a). This requires health system capacity to monitor, treat and provide patients with NCDs ongoing care (Beaglehole et al, 2008; Levitt et al., 2011), but the pre-requisites for such a system, for example, presence of multi-disciplinary teams and laboratory equipment, are hardly present (Rabkin & El-Sadr, 2011). As a consequence, patients with NCDs are currently deprived of access to proper diagnostics, medication and care (Samb et al., 2010). Moreover, there is the problem of additional mortality, morbidity and health care costs which could have been prevented if health systems were equipped and oriented towards the early detection, control of risk factors and complications of NCDs in the population (Sacco et al, 2011).

The good news is that health systems planners and strategists in sub-Saharan Africa do not have to return to their drawing boards. Countries have experience with establishing services for and treating large numbers of patients with a chronic condition, and with success. In 2012, almost seven million patients in the region received ART, which represents 68% of those in need (UNAIDS, 2013). This achievement now even sparks hope that the end of AIDS is in sight (UNAIDS, 2014). The majority of HIV-infected patients accesses their treatment and receives care and support at primary health care facilities and in their communities. This is where chronic conditions are ideally prevented and managed and I thus postulate that this is where the re-orientation of national health systems needs to be directed to.
The central research question which guides this thesis is:

*What adaptations have occurred at primary health and community level in sub-Saharan Africa to provide long-term treatment, care and support to patients with HIV and in what way do these adaptations contribute to the realisation of a chronic care subsystem within national health systems?*

In the next two chapters, I present the theoretical concepts used in this thesis and the research design.
Theoretical concepts

This chapter presents the theoretical concepts used in the thesis. The chapter has two parts. The first part defines the health system. This is followed by an exploration on how health systems adapt, using the health system building blocks framework, complex adaptive systems, and system innovation theory. The second part defines chronic care. It describes the relation between primary health, community and chronic care as well as theoretical models on chronic care. This is followed by an elaboration on how actors in and services for chronic care can be connected by applying the concepts of integration, co-ordination and integrated care. The explanation of a number of theoretical concepts in this chapter are accompanied by brief, historical backgrounds to demonstrate the evolution in thinking and practice around these concepts.
Chapter 2

Conceptualising the health system

A commonly accepted definition of a health system is that of the World Health Organisation (WHO):

“a health system consists of all organisations, people and actions whose primary intent is to promote, restore, improve or maintain health” (WHO, 2007, p. 2).

This definition infers that a health system is larger than, for instance, an institution such as the Ministry of Health or the services provided by health facilities. It is precisely the scale of the system’s constitution which makes health systems complex entities to oversee (Broerse & Bunders, 2010). The oversight over all these actors and actions is considered a government responsibility (WHO, 2007). Governments are expected to steer their health systems to achieve its purpose, and, as the WHO (2007) also emphasizes, to do so in a manner that ensures health equity by being responsive, financially fair and cost efficient.

Adaptations to a health system

Adaptations are necessary to keep a health system aligned with changing health care demands and dynamic national and global contexts (Gruen et al., 2008). Adaptations to improve the efficiency, equity and effectiveness in health systems are referred to as health sector reforms (Berman, 1995). However, such reforms are not easily initiated due to the vested interests of institutions and actors, both in and outside the system, and who may resist change. Roberts et al (2004) explain that it generally requires major political or economic events, such as a change of government or an economic crisis to initiate a reform. Western (or donor) policies and strategies have also heavily influenced health sector reforms in sub-Saharan African countries. Each of these reforms came with a different focus. In the late 1970s and early 1980s, the emphasis was on health equity and access to health care for the poor via delivery of primary health care (PHC) services (Gwatkin, 2001). Between the 1980s and the 1990s, health budgets came under severe foreign scrutiny (Grindle, 1997). This included cuts to human resource budgets and the introduction of payment for services which curtailed health equity. From the late 1990s onwards, the emphasis was on good governance of the health sector (Chhotray & Hulme, 2009) and prioritisation of health services on the basis of cost-effectiveness and impact criteria. The end of the 2000s marked a return to health equity-led reforms via emphasis on the principle of ‘universal health coverage’, meaning provision of accessible, affordable and quality health care for all citizens in a country (WHO, 2010c). The results of the previous reforms were not consistently positive. In 2008, for example, the WHO reported that health systems in the region were increasingly fragmented and “drifted from one short-term priority to another without a clear sense of direction” (WHO, 2008e, p.13). Furthermore, the WHO stated that health
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systems had not improved their responsive capacity in anticipation of new health care challenges. The fragmentation within health systems had to be countered in order to respond effectively to the double burden of infectious and non-communicable diseases. At policy level, the WHO proposed a revitalisation of PHC and the development of integrated health care services (WHO, 2008e).

A review of the literature gave further insight as to what needs to be done to improve the capacity of sub-Saharan African health systems to respond to the demands of patients with chronic conditions. I have clustered these findings according to, what are considered, the building blocks of a health system as defined by the WHO (WHO, 2007). The WHO framework conceptualises a health system according to six interdependent components, notably, service delivery, health workforce, information, medical products, vaccines and technology, finance, and leadership and governance (WHO, 2007). In table 2.1, the first column contains the WHO description for each of those components. The second column summarises the findings from literature on which adaptations are required in each to enable delivery of chronic care (Comino et al., 2012; Maher et al., 2010; Rabkin et al., 2012; Samb et al., 2010).

The inventory gives an indication of the extent of effort that is required across the six building blocks. It is useful in terms of understanding the nature of changes but, while these suggestions were made for health systems in resource-constrained settings, their practical feasibility has not been tested at scale. The literature, at present, refers primarily to chronic care practices in high-income countries and to a very limited extent on practices in sub-Saharan Africa (Rabkin et al, 2011, 2012; Samb et al, 2010). The analysis summarised in table 2.1 also does not provide sufficient understanding of where and how policy makers and health professionals should start making these changes. Processes of system change can, however, be difficult and to obtain further insight into how this process works, we need a more dynamic conceptualisation of the health system.

Complex adaptive system and system innovation theories

Two theories which accommodate this dynamic view on systems are the complex adaptive system theory and the system innovation theory. The complex adaptive systems theory is applied by health scientists to increase their understanding on how health systems respond to new health care problems and how efforts to improve this response penetrate through the subsystems and actors in the system (Gruen et al., 2008; Paina & Peters, 2012; Atun, 2012). This theory borrows from environmental sciences models of ecosystems in which living organisms are seen to continuously interact with other elements in their environment. Ecosystems change their properties in response to external changes (Plsek & Greenhalgh, 2001; Sgro et al., 2011) and the capability of
organisms to survive in changing ecosystems depends on their ability to adapt to new conditions (Fiksel, 2003). The parallel in the health sciences is the emergence of new demands on health systems, such as an HIV epidemic or substantive increase in NCDs which represents a change in the conditions for the organisation and delivery of health services. This, in turn, requires adaptation of the health system if it is to be effective in these conditions (Shigayeva et al., 2010). This understanding of the health system infers that their form and content change over time as a result of the actors in the system who respond to real, perceived and anticipated new conditions for the organisation and delivery

<table>
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<tr>
<th>Health system blocks</th>
<th>Suggested changes</th>
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<tr>
<td><strong>Service delivery:</strong> Good health services are those which deliver effective, safe, quality personal and non-personal health interventions to those that need them, when and where needed, with minimum waste of resources.</td>
<td>Coordinate prevention efforts across sectors for chronic conditions; early detection and monitoring of risk factors; long-term care which combines treatment with psycho-social interventions; integrated care at point of delivery; coordination across continuum of care (referral); empowerment of the patient; decentralization of care (less reliance on highly specialized tertiary care)</td>
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<td><strong>Health workforce:</strong> A well-performing health workforce is one that works in ways that are responsive, fair and efficient to achieve the best health outcomes possible, given available resources and circumstances.</td>
<td>Well trained workforce in chronic disease management, screening, behavioral aspects and long-term care provision; multidisciplinary teams; closer collaboration with the community to enable early detection, home based care and self-management support; public health specialist that can design intersectoral interventions; highly specialized tertiary care professionals; equal workforce distribution; use of evidence-based guidelines and protocols</td>
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<td><strong>Information:</strong> A well-functioning health information system is one that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health system performance and health status.</td>
<td>Include appropriate health indicators for chronic conditions; transfer this data to information products for planning and financial allocation purposes; combination of routine and non-routine data on chronic diseases; where possible electronic data collection to track and monitor patients and burden of disease and use of “health passports” indicating essential clinical information and appointments for review</td>
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<td><strong>Medical products, vaccines and technologies:</strong> A well-functioning health system ensures equitable access to essential medical products, vaccines and technologies of assured quality, safety, efficacy and cost-effectiveness, and their scientifically sound and cost-effective use.</td>
<td>Essential medicine package to include treatment for chronic conditions; ensure reliable supply chain for long-term conditions; avail technology for detection and monitoring of chronic conditions; base forecasting of drug requirements on systematic registration of patients and recording of their outcomes</td>
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<td><strong>Financing:</strong> A good health financing system raises adequate funds for health, in ways that ensure people can use needed services, and are protected from financial catastrophe or impoverishment associated with having to pay for them. It provides incentives for providers and users to be efficient.</td>
<td>Reduce out of pocket expenditure through public subsidy schemes or health insurance to prevent impoverishment of patients with chronic conditions; financial allocation informed by population data; performance based financing</td>
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<td><strong>Leadership and governance:</strong> Good leadership and governance involves ensuring strategic policy frameworks exist and are combined with effective oversight, coalition building, regulation, attention to system-design and accountability.</td>
<td>National health policy to include chronic conditions; decentralization of chronic care to PHC level; linkages to community support for education and extended care</td>
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of health services (Bertalanffy, 1968; Holland, 1995). The complexity of health systems lies in the actions and interactions of many actors within a system, including those who resist change, and in the actions and interactions of actors from other societal systems. From this perspective, health system adaptations are continuous, not always deliberately designed, and they do not always achieve the intended effect(s) on the system. This is not to say that a health system is an unstructured configuration of subsystems and actors that cannot be steered towards the intended changes within a system. There is a collective set of rules which gives guidance and meaning to the operation of the system (Giddens, 1984). The theory of system innovation conceptualises this logic in terms of ‘structures’, ‘culture’ and ‘practices’ (de Haan, 2010; van Raak, 2010). Structures refer to physical, economic, legal, financial, organisational and power mechanisms within a system. Culture refers to the dominant set of values, perceptions and interpretations of health system functions. Practices refer to the actual operations and activities by health system actors. The dominant structures, culture and practices in a health system is called the ‘regime’. It provides the system with stability and guides the decisions and actions of actors in the system (i.e. the collective set of rules).

In system innovation theory, health system reforms are explained as fundamental changes in the regime. This implies that changes are needed in all three properties of a health system. Reforms may fail to reach their intended purpose when the dominant structures, culture and practices do not adapt or only adapt sub-optimally. The theory can also be used as a heuristic method, whereby one diagnoses which phase the health system has reached in terms of regime change (Broerse & Bunders, 2010). Innovation theory calls the process of changing regimes ‘transition’. The transition process is seen to involve three levels: the landscape level, the regime level and the niche level. The levels influence and interact with one another (Broerse & Bunders, 2010; Geels & Kemp, 2000; Loorbach, 2007). The landscape refers to the entire societal context in which transitions, including those in the health system, occur. This includes the macro economy, demography, the natural environment, world views of the populace and their shared values. Examples of landscape level influences on health systems are a global economic crisis, an ageing population and a human rights foundation to health care policies and strategies. The regime is the network of actors who interact via the dominant structures, culture and practices of a system and who, through shared assumptions, contribute to achieving the overall purpose of a health system. In other words, the regime guides the actions and thinking of the actors in the system. At this level, often undertaken by societal frontrunners, novel solutions to health problems are tested, involving new sets of structures, culture and practices (Loorbach, 2007). These can be technological, social or policy innovations and can be the genesis for system transition.
In theory, the transition process goes through different phases which can be represented by an S-shaped curve (see figure 2.1). In the initial or pre-development phase, innovation and experimentation is taking place at niche level. This does necessarily lead to change in the regime. At this point, there can either be a backlash (or lock-in) phase or take off phase. Backlash/lock-in refers to the regime’s rejection of niche initiatives or partial accommodation of them in ways that do not fundamentally alter the dominant structures, culture and practices. Alternatively, there is a take-off phase: the outcomes of these experiments are being recognised and adopted more widely within a health system such that they begin to influence the regime’s structures, culture and practices. The take-off in a transition can be the result of pressure on the regime following developments at landscape level, which provide an opportunity for adopting the niche experiments. This phase marks the beginning of change but the direction of change is still uncertain until there is evidence of fundamental change to structures, culture and practices. When that occurs, it is defined as the acceleration phase. This phase is characterised by collective learning and permeation of adaptations throughout the system. That phase is then followed by a stabilisation phase which refers to the period when new structures, culture and practices are embedded in the health system. During this phase, the system is in a state of relative equilibrium as the health foci, actors and resources are aligned (Gruen et al., 2008).

Scholars theorise that a health system does not exist of only one dominant regime (de Haan, 2010; van Raak, 2010). The demands on health systems are diverse, which systems accommodate in the form of subsystems (or constellations) with different regimes. Van Raak (2010, p. 51) defines subsystems as “structurising elements that together both define and fulfil a function in a larger societal system in a specific way” (van Raak, 2010). Subsystems can be distinguished, for instance, according to the type of health care
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(curative, end of life, chronic) or the care setting (primary care facility, home) and are to a large extent shaped by the actors involved in the particular subsystem (e.g. managers, doctors, patients and their families, implicated government officials). Together they have their own interpretation of the function, position and values of the subsystem. The subsystems within a health system complement each other, but can also compete with each other in such a way that their functions are frequently challenged and altered.

Conceptualising chronic care

Health systems tend to be organised around three levels of care: primary, secondary and tertiary levels (Skolnik, 2012). Primary level care is the first point of contact with a patient and is commonly delivered at a clinic, health post, private practitioner's surgery or in the community. Secondary and tertiary level care refer to hospital-based specialist care. Chronic care takes place at all three levels, depending on the care needs of patients with chronic conditions. As chronic conditions persist over time and require continuous care, primary level care is generally considered to be in the best position to prevent and manage these conditions within a health system (Beaglehole et al, 2008).

However, the current focus in sub-Saharan African countries is on hospital-based specialist care for patients with chronic conditions (Aikins et al, 2010; WHO, 2010a). The development of primary level chronic care is still in a rudimentary stage, except for vertical HIV programmes in which considerable progress has been noted (UNAIDS, 2011). The establishment of chronic care at primary level is the focus in this thesis. Before I draw on theoretical models on chronic care for guidance on how these services can be established, I briefly describe the concept and practice of Primary Health Care (PHC) and Community Home Based Care (CHBC). PHC in sub-Saharan Africa has been developed and refined over a period of nearly forty years. Its development has been aligned to the development of CHBC nearly as long.

Primary Health and Community Home Based Care

The concept of PHC emerged in the 1970s when general thinking on health care started to change, particularly in relation to low-income countries, many of which had recently gained political independence. The change was influenced by general concerns about population growth in these countries and new insights into the relation between health and economic development (Newell, 1975). People started questioning the relevance of importing health care practices from high to low-income countries, and were inspired by the success of community health approaches such as the ‘barefoot doctors’ in China (Schaay & Sanders, 2008). In 1978, the Alma Ata conference produced a formal definition of PHC which reflected these concerns and interests. PHC was defined as:
“essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain… It forms an integral part of the country’s health system of which it is the central function and main focus, and of the social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process” (WHO, 1978, p. 1-2).

This conceptualisation of PHC, at the time, shifted the focus from the construction of large hospitals and the provision of curative care towards preventive care and the closer delivery of health care to communities and families. It was envisioned that ‘comprehensive care’, meaning a combination of preventative, curative, rehabilitative and promotive services, would be delivered at primary level (Rohde et al, 2008). The providers were doctors, nurses, midwives, community health workers and traditional practitioners (Bender & Pitkin, 1987). Community health workers would be the link between the health facility and the community. As noted earlier in this chapter, it was a health system reform process whereby health equity, as well as cross-sectoral collaboration and community participation were key principles in creating better access to health care for the poor and underserved populations in low and middle-income countries. However, as a result of many factors which have been avidly described in the literature, the reform failed to achieve its intended purpose ‘Health for All’ (Baum, 2007; Beaglehole & Bonita, 2009; Bender & Pitkin, 1987; Colvin, 2011; Lawn et al., 2008; London & Schneider, 2012; Poku, 2002; Rohde et al., 2008; Rifkin, 2009; Schaay & Sanders, 2008; Walt, 1988). The comprehensive scope of PHC was rapidly reduced to a ‘selective’ model, in which a few diseases and services were prioritised (Walsh & Warren, 1979; Unger & Killingsworth, 1986). The argumentation was that the delivery of comprehensive care at PHC level was unattainable in countries with restricted health budgets and human resource constraints. Similarly, the vision of embedding a community health worker cadre in national health systems suffered (Berman et al, 1987; Walt, 1990). Thirty years later, African Ministers of Health signed a new declaration, in which they committed to revitalise their PHC services and to deliver comprehensive and integrated care (WHO, 2008d).

While national community health worker programmes did not take off as planned, the idea to involve community members in the delivery of care was replicated and contextualised in many parts of the world (Schneider et al, 2008). In the introduction, I described one of these ‘offsprings’: the establishment of home based care programmes in sub-Saharan Africa, organised and managed by civil society organisations. These programmes grew exponentially, as part of the response to the HIV and AIDS pandemic in the region (Ogden et al, 2006). The WHO produced a framework in an attempt
to promote a more systematic approach to community care in resource-constrained settings, and importantly, to link these community-based initiatives to PHC services for a continuum of care. It defined CHBC as follows:

“community home based care is any form of care given to sick people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities” (WHO, 1993; 2002a, p. 8).

Families are considered the primary provider of community home based care and form the basis of a so called ‘CHBC team’. This team consists of ill people, family caregivers, health and social welfare personnel, community health workers and community volunteers (WHO, 2002a). At the time this framework was developed, ART was not yet accessible and affordable to the majority of patients and CHBC constituted the delivery of end of life care. With the availability of treatment, the content and form of both community-based and primary health care has shifted towards provision of chronic care. The question is how this change occurred and to what extent models influenced the development of chronic care practices at this level in sub-Saharan African health systems.

**Chronic care models**

The concept of chronic care, to date, has largely been defined and shaped by practices in high-income countries due to their earlier experiences of demographic changes (e.g. ageing populations; urban lifestyles) and epidemiological changes (e.g. rise in NCDs associated with ageing populations and urban lifestyles) in their populations. There are different theoretical models of chronic care, which can help guide countries in building up chronic care services. The differences in these models are largely due to different emphases (some focus more on service delivery, others on prevention), but they all share a common premise on what constitutes ‘good chronic care’. This is the need for patient involvement and the delivery of a continuum of care. The most commonly used models are the chronic care model (Wagner, 1998), the expanded chronic care model (Barr et al., 2003), the innovative care for chronic conditions framework (WHO, 2002b), the public health model (Robles, 2004) and the continuity of care model (Sunol et al., 1998). In this thesis, I draw primarily on the chronic care model (CCM) by Wagner and the innovative care for chronic conditions (ICCC) framework by the WHO. The models are closely related as the ICCC is an adapted version of the CCM, which was developed in the United States of America. The WHO adapted the American model for global use.

The CCM has been widely used by health systems in high-income countries (Ham, 2006; Coleman et al., 2009; Nuño et al., 2012). The model separates the health system from the community, whereby the health system is synonymous for the organisation
of health care. The community is synonymous for community organisations which fill service gaps and mobilise resources for community members’ needs. The emphasis in the CCM is on the provision of chronic care services by professional health teams who actively interact with their patients. It distinguishes four elements in re-orienting health systems towards the delivery of chronic care (see figure 2.2).

Figure 2.2. Chronic Care Model (Wagner, 1998)

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The four elements, notably self-management support, delivery system design, decision support and clinical information systems, are accompanied by clear instructions. In chronic care, health teams are expected to provide self-management support to their patients. This support can come in different forms (e.g. patient education, strategies for living with a chronic condition), but the essence is that they support a patient with the knowledge and skills for managing his/her own condition, once he/she is outside the health facility. The design of the service delivery system needs to be organised in such a way that patients with chronic conditions receive patient-centred care. This care should be guided by individual chronic care plans for patients. These plans contain details on the contents of individual patient care, including monitoring of patients and the roles and tasks of different members of a health care team. Furthermore, health care teams need to make use of evidence-based guidelines for decisions on treatment and when to consult another specialist. These guidelines need to be discussed with patients, so that they are fully informed on care procedures. And lastly, the provision of continuous care for patients with chronic conditions requires a sound clinical information system to
help track and plan care. The information system should serve as a basis for collation and analysis of data from all patients with chronic conditions, to inform chronic care policy and strategies, monitor their performance and improve the quality of care.

The WHO developed the ICCC framework in response to the evidence that chronic conditions were becoming a global health issue (see figure 2.3) (WHO, 2002b). Their aim was to support low- and middle income countries in preparing for this emerging disease burden. The development of the framework was underpinned by the acknowledgement that primary level services in these countries needed to be re-oriented to handle prevention and management of those conditions. It was recognised that this re-orientation would require a shift in the existing clinical practice; from a disease-centred to a patient-centred approach, whereby patients were no longer passive recipients but had a central role and responsibility in their own health care, supported by family members (WHO, 2002b). The WHO acknowledged the ample involvement of communities in the delivery of health care in low and middle-income countries and, therefore, ‘community partners’ were awarded a more prominent place in comparison to the model by Wagner (1998). Scholars have commented that the ICCC is a better reflection than the CCM of the conditions in resource-constrained countries where patients with chronic conditions largely depend on their families and community care providers and have limited access to clinical care (Epping-Jordan et al., 2004; Nuño et al., 2012). WHO also modified the CCM component on evidence-based guidelines in order to emphasise the need for investment in the technology needed to enable health care teams to make informed decisions about the health of their patients. In sub-Saharan Africa, health systems often lack this technology (e.g. laboratory tests, examination supplies) (Epping-Jordan et al., 2004).

The core of the framework is a triad partnership between the health care organisation, the community, and the patient and his/her family. The framework indicates a broader form consisting of the health care organisation, which support the health team, and the community, which support the community partners, and with links between them. As is indicated in figure 2.3., the context for such partnerships is represented in terms of a policy environment which supports the organisation and delivery of chronic care services in this form. For reasons I could not identify, the WHO stopped promoting the framework from 2006 onwards. A review of the ICCC reported that it has served as a reference for designing chronic care interventions around the world but that it has been less influential than the CCM (Nuño et al., 2012).

While the theoretical models provide further guidance for re-orienting health systems in sub-Saharan Africa, the conceptualisation of chronic care is not yet complete. There are additional insights, again from high-income countries, which complement the understanding on chronic care. These insights are derived from the development
Chapter 2

of long-term care services for the elderly. It has been noted that, as part of this development, the quality of care is no longer considered the leading paradigm in health care. Principles of quality of life, self-care and dignity have started to permeate through health care structures, culture and practices in high-income countries (Leichsenring et al, 2013). This paradigm shift is clearly reflected in the WHO and Millbank Memorial Fund definition of long-term care:

“the system of activities undertaken by informal caregivers (families, friends and/or neighbours) and/or professionals (health and social services) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity”. (WHO, 2000, p. 6).

The definition reflects two other important issues, which were less evident in the theoretical models of chronic care. Firstly, the definition of long-term care emphasizes the essential role of informal caregivers and second, it points attention to the engagement of social service providers in chronic care. It reflects the increased understanding that

Figure 2.3. Innovative Care for Chronic Conditions Framework (WHO, 2002b)
chronic care takes place at the junction of health and social care (Leichsenring et al, 2013), whereby patients’ needs are not only medical but include psycho-social needs and, for instance, assistance in acquiring social benefits or housing. Different high-income countries have experimented with the closer collaboration between health and social welfare sectors, which in the literature, is referred to as integrated care systems (Mur-Veeman et al., 2003; Valentijn et al., 2013).

In sum, patient-centeredness, comprehensiveness and a continuum of care are important characteristics in the delivery of chronic care. In order to understand how the primary, secondary and tertiary levels in the health system as well as different disciplines and sectors are connected in the delivery of chronic care, I conclude this chapter with an elaboration on the concepts of integration, co-ordination and integrated care.

Integration, co-ordination and integrated care

Integration, co-ordination and integrated care have been recurrent themes in international health strategies (UNAIDS, 2004, 2005; WHO, 2008c, 2008e, 2009) and in health sector reforms. The 2008 World Health Report and the World Health Assembly resolution 62.12 on ‘PHC and health system strengthening’, for example, called for worldwide health sector reforms to make health systems more people-centred and integrated (WHO, 2008e; WHA, 2009). The ideas around integrated health care were already present in the Alma Ata declaration of 1978; at the time referred to as comprehensive care. From the mid-to-late 2000s onwards, integrated health care regained grounds, following the debates around vertical disease programmes and funding in sub-Saharan Africa, which were briefly discussed in the introduction chapter.

By then, reforms in high-income countries were already trying to address the high degree of fragmented and disjointed care that existed within national health systems (Nolte et al., 2012; Stange, 2009). The presence of a high chronic disease burden in these countries had part in this, as it instigated establishment of all sorts of new specialisations in health care and disciplines who created their own departments and ways of working. The consequences were that patients found it difficult to obtain the health care they needed within health systems (Gröne & Garcia-Barbero, 2001), there was duplication of care interventions and health care costs were becoming difficult to control (Contandriopoulos, 2003; Kodner, 2009). Recognition of these problems inspired (and continues to inspire) high-income countries to promote the co-ordination between actors in the health system (Kodner, 2009; Kodner & Spreeuwenberg, 2002; Shigayeva et al., 2010), and where feasible, to integrate discipline related services (Axelsson & Axelsson, 2006; Gröne & Garcia-Barbero, 2001). A number of countries also pursue the integration of health and social sector services, based on the understanding that
these sectors share common goals (Mur-Veeman et al., 2003; Valentijn et al., 2013). More recently, policies and strategies are being developed to counter the fragmentation of care and rising health care costs in sub-Saharan Africa (Colvin, 2011; Nigatu, 2012; Sweeney et al., 2012; WHO, 2008c, 2009). An example is the integration of interventions to prevent HIV transmission from mother to child into maternal and child health care services (Druce & Nolan, 2007; Ginsburg et al., 2007; Sripipatana et al., 2007) and pilot interventions to shift ART services to outpatient department services at PHC clinics (Pfeiffer et al., 2010; Price et al., 2009; Topp et al., 2012). The above examples show that integration occurs in clinical services, but also between health and social welfare sectors. In order to further conceptualise the term integration, I first refer to the WHO definition of integrated health service delivery:

“the management and delivery of health services so that patients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system” (WHO, 2008c, p. 1).

This definition affirms that integration occurs at different levels of a health system but gives no clarity on the approach itself. Likewise, a recent WHO publication (2015) which proposes five general strategies to achieve people-centred and integrated health services (empower and engage individuals and communities; strengthen governance and accountability; re-orient the model of care; co-ordinate services around people’s needs; and create an enabling environment that brings together different stakeholders in the change process) does not define the process of integration at different levels of a health system. Such clarification is important as the literature describes that integration and integrated care are understood differently by different people (Goodwin, 2013; Kodner, 2009). There are a number of frameworks which conceptualise the terminologies (Atun et al., 2009a; Axelsson & Axelsson, 2006; de Rijk et al., 2007; Fleury, 2006; Valentijn et al., 2013). From these frameworks, I selected the one by Valentijn et al (2013) as their framework combines the concepts of primary and integrated care. Both are reflected in my conceptualisation of chronic care; primary level services and the inclusion of social welfare services and personnel in service delivery. Valentijn et al (2013) from the Netherlands bring these together in comprehensive PHC, integrating bio-medical, psychological and social services, delivered by an integrated care system.

Valentijn et al (2013) first merge the visions on integration of Gomes-Casseres (2003) and Ahgren and Axelsson (2005) in an integration spectrum (Ahgren & Axelsson, 2005; Gomes-Casseres, 2003). Figure 2.4 visualises that at one end of the spectrum, actors work completely autonomous from each other (segregation). At the other end of the spectrum, actors work under the same hierarchical governance structures (integration). In between, there are linkages and co-ordination. This implies that co-ordination is considered a form of integration. It is important to note that linkages and co-ordination
are commonly observed in health systems (Mur-Veeman et al., 2003). For example, in the form of referral linkages between health actors and co-ordination in patient case management between health actors. The actors are typically linked through network arrangements, whereby each actor operates from its own organisational structure. Such arrangements, according to Valentijn et al (2013), require effective mechanisms of governance and accountability in order to co-ordinate the different, but interdependent interventions of actors.

![Image](image_url)

**Figure 2.4.** Inter-organisational integration (Valentijn et al, 2013)

Valentijn et al (2013) combine these insights with a delineation of micro, meso and macro level dimensions in integration, in a more detailed framework, as visualised in figure 2.5. At micro level, there is clinical integration of services when a patient receives patient-centred care which is co-ordinated across professional, institutional and sectoral boundaries in the system. At meso level, professional and organisational integration can be distinguished. Professional integration occurs when the different disciplines in health and social welfare collaborate in the provision of comprehensive and a continuum of care to patients. There are two avenues in which this can take place. One is referred to as horizontal integration in which there is cross-sectoral collaboration between the two sectors. The other is referred to as vertical integration which links the different
system levels, PHC up to tertiary level care, to which the patients is referred and or receiving care from. There is organisational integration when actors also function under a hierarchical structure. I refer back to figure 2.4, which illustrated the different degrees in partnership structures, such as networks or mergers. At macro level, there is systems integration when there are partnerships across traditional, organisational and professional boundaries and in which a common set of rules and policies apply. The objective is to provide a tailor-made combination of structures and processes which match the needs of the population (Valentijn et al., 2013). It is argued that integration at system level counters the fragmentation in health systems and enhances efficiency (Kodner, 2009; Suter et al., 2009).

**Figure 2.5.** Conceptual framework for integrated care (Valentijn et al, 2013)

Functional and normative integration are the ‘pins’ linking the micro, meso and macro level dimensions in the framework. Functional integration refers to the co-ordination and shared policies of key support functions such as financial management, human resources, planning and information management. Normative integration refers to a common frame of reference (e.g. shared mission, values and culture) between actors in the system. And lastly, the framework rests on the principles of person-focused and population-based care. Person-focused (or patient-centred) care in an integrated system centres the delivery of care around the health and social care needs of patients instead of a disease, and facilitates their easy navigation through the health system (Rogers &
Sheaff, 2000). This is important for patients with chronic conditions as they require a combination of services delivered sequentially or simultaneously by different providers and across different subsystems (i.e. primary health and community care; in their home, community and health facility) (Kodner & Spreeuwenberg, 2002). Population-based care pursues the equitable distribution of health and wellbeing in a population, in which service delivery is based on the needs and health characteristics (including political, economic, social and environmental) of a population (Starfield et al., 2005). This ties back to the overall goal of a health system, as discussed in the first part of this chapter.

The framework illustrates that integration is a complex concept and, in practice, requires policy as well as organisational changes at systems level to facilitate the delivery of comprehensive services at primary level. The literature on integration processes in high-income countries testify to this complexity (Bengoa, 2013; Goodwin, 2013; Tsasis et al., 2012). While, the rationale behind integration appears logical, the achievements in relation to its objectives have been mixed. Many high-income countries opted for integrating their health institutions through mergers but the expected benefits in cost-efficiency were often not realised and clashes between organisational cultures have constrained the integration process (Suter et al., 2009). Positive effects of integration included a reduction in hospital utilisation and improvements in patient satisfaction and quality of life (Armitage et al., 2009; Ouwens et al., 2005). The reviews on experiences with integration in low and middle-income countries highlighted the dearth of studies on this topic (Bhutta et al., 2008; Briggs & Garner, 2006; Lewin et al., 2008; Wallace et al., 2009). This implies that there is still little to draw from in terms of a (published) evidence base for policy and strategies on integration in these parts of the world. It means that, for the most part, I have to rely on theoretical concepts that originate from high-income countries, which may be less appropriate for the settings in which my research is situated. It is therefore imperative to build on the existing experiences in sub-Saharan African health systems, and study their adaptations in context and over time. The theories of complex adaptive systems and systems innovation, coupled with theoretical models on chronic care and the concepts of integration, co-ordination and integrated care, form the theoretical framework for understanding the adaptations at primary health and community level. My theoretical framework combines several complex concepts. To help clarify how they are combined, figure 2.6 illustrates schematically how they are linked. The intersection of all three sets of concepts (in the centre) represents the focus of my analysis of developments in the form and content of primary level care in African settings.
Figure 2.6. Schematic presentation of theoretical concepts used in the thesis
Research design

The first two chapters introduced the topic and the theoretical framework for the research. This chapter presents the research design, starting with the central research and sub-research questions, and followed by a description of the research approach and research methods. The chapter ends with a section on the research validity and the thesis outline.
Central research question

The central research question in this thesis is:

What adaptations have occurred at primary health and community level in sub-Saharan Africa to provide long-term treatment, care and support to patients with HIV and in what way do these adaptations contribute to the realisation of a chronic care subsystem within national health systems?

In chapter 1, I referred to how the availability of anti-retroviral treatment profoundly changed the way in which we manage the disease; from a fatal to a chronic disease. In order for these treatment services to be effective in extending the lives of patients, health systems in sub-Saharan Africa were compelled to make the necessary changes. My overview of key developments in thirty-five years of HIV and AIDS showed how these changes occurred largely within the confines of a vertical programme. Now, the demand is for the integration of vertical programmes into general health services, which implies further system changes. System changes are also necessary to respond to the health care demands arising from patients with non-communicable, chronic conditions. At a time where these two processes are seemingly converging, a study on how these changes occur contributes to the, at present, limited knowledge on how chronic care subsystems in this part of the world are being realised. Current theoretical understanding of how health systems should adapt to provide chronic care is informed by the experiences and practices of sophisticated health systems in high-income countries. Therefore, my central research question has been formulated in such a way that it enables the construction of new knowledge on the basis of theory and on actual practices in resource-constrained settings. The purpose is to gain a greater understanding of the possible route(s) for re-orienting health systems in sub-Saharan Africa and informed by the experiences with HIV and AIDS.

It is my assumption that the experimentation within the HIV and AIDS programme, despite its vertical orientation, has permeated into the structures, culture, and practices of national health systems, and has set changes in ‘motion’. While changes are expected at all levels of the health system, I postulate that the development of health system capacity for the provision of chronic care is particularly essential at primary health and community level, hence my formulation of the central research question. This focus is informed by a review of the literature, which emphasizes the involvement of the patient, family, community and primary health care providers in chronic care as well as by the longstanding practice of PHC and community care in sub-Saharan Africa.

In order to guide this study, the central research question has been specified into four sub-research questions.
1. How have HIV and AIDS community home based care programmes in sub-Saharan Africa evolved in response to the implementation of anti-retroviral treatment programmes and subsequent changing needs of their patients?

The purpose of the first sub-research question is to retrace the adaptations made within community home based care programmes in response to changing health care demands of patients with HIV and AIDS. Following system innovation theory which explains that societal actors are often the frontrunners in system innovation, I postulate that these programmes contain valuable lessons on the development and implementation of chronic care at community level. Their experiments are likely to provide tangible information on the feasibility of implementing this care in resource-constrained settings for HIV patients as well as patients with other chronic conditions.

2. What has been the influence of HIV and AIDS community home based care programmes on the delivery of primary health care, and the influence of primary health care policies and strategies on HIV and AIDS community home-based care programmes?

System innovation theory explains how global trends and strategic thinking influence health system change. The policy debates on what is PHC and how this should be delivered have been of considerable influence on the provision of community care in the past. I also postulate that the experimentation in HIV and AIDS community home based care programmes have influenced the delivery of PHC in sub-Saharan Africa. Hence, this sub-research question seeks to explore and understand what the influences between the two subsystems have been. A further interest is to see to what extent community home-based care programmes are being considered in national revitalisation strategies.

3. How are primary health and community level services being connected to enable the delivery of comprehensive services for patients with HIV and other chronic conditions?

The purpose of the third sub-research question is to examine the structures and mechanisms for collaboration between primary health and community care agencies in the delivery of comprehensive services to patients with HIV and other chronic conditions. The application of the concepts of integration, co-ordination and integrated care in chronic care, which were introduced in chapter 2, are further explored in this sub-research question.

4. To what extent are existing models of chronic care being applied in sub-Saharan Africa and are they appropriate in contexts of large-scale HIV pandemics and health system resource constraints?
The purpose of the fourth sub-research question is to critically reflect on the principles and practice of chronic care. At the start, my literature research recognised that existing models of chronic care have been developed mainly in high-income countries whereas my research was to be conducted in the contexts of HIV and AIDS and health system resource constraints and with no published evidence of systemic development of chronic care services in these contexts. Such a critique provides a basis for assessment of the utility of existing models and also on the challenges encountered with the development of chronic care services in sub-Saharan Africa.

**Research approach**

The research used an emergent design in which exploratory studies formed the initial basis of the research framework, whereas insights from the literature review and preliminary analysis of field data guided the operationalisation of the research questions. The research questions were addressed in a systematic review of the literature and in case studies. The research followed an iterative process, using insights from theory (deductive method) and observations from practice (inductive method). This approach was considered necessary to maintain study relevance in the dynamic context of health systems and HIV and AIDS.

**Systematic review of the literature**

The research included a systematic review of studies of self-management interventions for patients with chronic conditions. The aim of the review was to increase the understanding on the form and content of these interventions, gain insight into who was involved and to assess their contribution to health outcomes for HIV-infected patients. Furthermore, the review aimed to contribute to sub-research question 4, whereby findings would be used to reflect on the relevance of the reviewed self-management interventions for chronic care policy and practice in sub-Saharan Africa. The review was conducted according to the review’s protocol. This protocol contained a concise search strategy and detailed the inclusion and exclusion criteria for the studies. The initial sifting of the literature was carried out by one researcher. Two researchers independently assessed the eligible studies and a third reviewer was available if differences of opinion on inclusion arose. A total of fifty-two studies were reviewed and assessed on the basis of four outcome measures (health status, emotional status, health behaviour and health care utilisation) and on their study methodology. The study methodologies were assessed according to SIGN checklists (SIGN, 2011). The review included a heterogenous group of studies such that it was not possible to pool this data for a meta-analysis. The studies were instead grouped into five analytical clusters,
Research design

defined by similarity of interventions, and provided the basis for a comparative analysis. Further details on the study methodology can be found in chapter 4.

Case study approach

The research applied the case study approach to collect data on the adaptations and changes made at primary health and community level to enable provision of chronic care. This approach is used in social science to obtain an in-depth understanding of a complex phenomenon in a real-world context (Yin, 2009). The analysis of this phenomenon, in a single or small number of cases, can be used to explore, validate or illustrate theoretical concepts, such as chronic care models or integrated care. The case study method relies on multiple sources of information to add to a deeper understanding of the research topic. The research included a case study in Zambia, called the chronic care study, which was embedded in a multiple case study covering four countries, and called the multi-country study. Figure 3.1 illustrates the case study approach.

Figure 3.1. Case study approach used in this thesis

The aim of the chronic care study was to examine, in-depth, the theory and practice of chronic disease management in one country, addressing sub-research questions 3 and 4. The multi-country study examined the adaptations at primary health and community level and the connection between CHBC programmes, national primary health care strategies and providers, as formulated in sub-research questions 1, 2 and 3. This study was conducted in Ethiopia, Malawi, South Africa and Zambia. Table 3.1 provides an overview of the studies covered in this thesis.
Chapter 3

Research methods and sampling criteria of the case studies

The four countries in this research were purposively selected on the basis of three, pre-set criteria. Criteria included the presence of a generalised HIV pandemic, presence of firmly established care and support programmes at community level (at least 10-15 years), and evidence of government commitment towards the revitalisation of PHC. An additional, and more pragmatic, criteria in the country selection was that the sample fitted the eligibility list of the agencies that funded the research. The selection of Zambia for further in-depth study was a convenience sample, based on the author’s previous research experience in this country.

In the chronic care study, different research methods were used. Methods included desk reviews, at several intervals in the study, during which national policy and strategy documents, quantitative data (e.g. epidemiological and demographic data) and country specific literature (grey and scientific) were studied. Semi-structured interviews were conducted with key informants at national level (n=18) and at district, primary health and community level (n=17). The research covered visits to eight different health facilities (from a rural health centre to a tertiary facility), during which interviews were held and services were observed. Focus group discussions (n=4) were conducted with community (or secondary) caregivers from two selected CHBC programmes (n=36). The sample covered an urban programme, which was managed by a non-governmental organisation with a specific focus on HIV and Tuberculosis, and a rural programme, run by a faith-based organisation, and with a broader health focus. A research assistant conducted interviews with an additional nineteen key informants to obtain in-depth information on the functioning of the Zambian health management information system. In order to validate the findings of the study, repeat interviews were held with a smaller sample of the national level key informants (n=8). The study was extended with explorative interviews as interim results had revealed substantive changes in policy and governance structures in the country, in relation to integrated care and the goal of equitable health care (n=7). The selection included both local and international informants and was

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Table 3.1. Overview of studies covered in this thesis

<table>
<thead>
<tr>
<th>Study</th>
<th>Method</th>
<th>Sub-research question</th>
<th>Thesis chapter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literature study</td>
<td>Systematic review</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Chronic care study</td>
<td>Desk review, semi-structured interview, focus group discussion, service observation, explorative interview</td>
<td>3, 4</td>
<td>5, 6, 7</td>
</tr>
<tr>
<td>(single case)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multi-country study</td>
<td>Online survey, desk review, semi-structured interview, focus group discussion, structured interview, service observation, community mapping, questionnaire survey</td>
<td>1, 2, 3</td>
<td>5, 6, 8</td>
</tr>
<tr>
<td>(multiple case)</td>
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<td></td>
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</tbody>
</table>

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based on the informants’ experiential knowledge on recent developments and changes to the national health policy and on past periods of health sector reforms. Further details on the research methodology, including sample sizes, is presented in table 3.2 and in chapters 5, 6 and 7. The qualitative data from the chronic care study was coded and analysed using Atlas.ti. The quantitative data, which was derived from secondary sources during the study, was entered into excel software for presentation purposes.

Table 3.2. Informant samples of the two studies

<table>
<thead>
<tr>
<th>Research Method and Sample Categories</th>
<th>Study 1 Multi country</th>
<th>Study 2 Zambia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online survey among international experts</td>
<td>17</td>
<td>n/a</td>
</tr>
<tr>
<td>Key national level informants in government and care organisations</td>
<td>49</td>
<td>18</td>
</tr>
<tr>
<td>Key informants CHBC programmes</td>
<td>71</td>
<td>17</td>
</tr>
<tr>
<td>FGD with CHBC programme staff</td>
<td>17</td>
<td>n/a</td>
</tr>
<tr>
<td>FGD with secondary caregivers in the CHBC programmes</td>
<td>115</td>
<td>36</td>
</tr>
<tr>
<td>FGD with community representatives in the CHBC programmes</td>
<td>65</td>
<td>n/a</td>
</tr>
<tr>
<td>Individual interviews with clients</td>
<td>98</td>
<td>n/a</td>
</tr>
<tr>
<td>Individual interviews with primary caregivers</td>
<td>99</td>
<td>n/a</td>
</tr>
<tr>
<td>Additional round of interviews with key informants on H-MIS</td>
<td>n/a</td>
<td>19</td>
</tr>
<tr>
<td>Validation Interviews: key informants at national level</td>
<td>21</td>
<td>8</td>
</tr>
<tr>
<td>Validation Questionnaire survey: care and support organisations</td>
<td>46</td>
<td>n/a</td>
</tr>
<tr>
<td>Additional round of telephonic interviews on the Zambian national health policy with national and international informants</td>
<td>n/a</td>
<td>7</td>
</tr>
</tbody>
</table>

In the multi-country study, mixed methods were used to obtain information from a range of respondents. The study commenced with an online survey among international experts in HIV and PHC, with experience in Africa, to obtain their views on the research objectives and foci (n=17). This was followed by a desk review and a round of semi-structured interviews with key informants at national level in each country (n=49). Within each of the countries, three CHBC programmes were purposively selected for in-depth study. The four criteria for sampling the programmes were that they had to be managed by different organisations, had been running for at least 10 years\(^1\), were representative of a frequently applied implementation model in the country under study\(^2\), and demonstrated a diversity in the offered care package (not exclusively health), range of patients (HIV as well as other chronic illnesses), and level of integration in the health system.

\(^1\) The rationale behind selecting older programmes is that there is a wealth of information and experience within these programmes. Such programmes would have been able to (firmly) establish themselves, adapt to contextual changes and achieve a level of embedding within the community and linkages with other actors in community care. Importantly, they would have provided services to people living with HIV both when ART was and was not available, offering an important perspective regarding the changes seen over time.

\(^2\) The application of this criteria was informed by national level interviews which had been conducted as one of the first steps in the multi-country study and which preceded the selection of programmes.
The selected in-depth cases were important in understanding the real-world context in which CHBC programmes were operating, how these programmes evolved and experimented with care following the introduction of ART, and how their services were influenced by, or influenced, national level policy changes on HIV and AIDS and PHC. Table 3.3 provides further information on the sampled programmes in each country, whereby the sample in Zambia’s chronic care study is indicated in italics.

In each programme, semi-structured interviews were held with staff members and external stakeholders of the programme, such as local clinic staff (n=71). Different focus group discussions were held with staff members of CHBC programmes which entailed a timeline exercise (n=17), with community caregivers which included a community mapping exercise (n=115) and with community representatives (n=65). Structured interviews were conducted with clients of CHBC programmes (n=98) and with family (or primary) caregivers (n=99). Repeat interviews were then held with national level key informants to discuss interim results (n=21) and a questionnaire survey was conducted among a larger sample of CHBC programmes in each country (n=46).

Further details on the research methodology, including sample sizes, is presented in table 3.2 and described in chapters 5, 6 and 8. The quantitative data from the questionnaire was analysed using SPSS software. The qualitative data was coded and analysed with Atlas.ti software. This analysis was standardised for each country, using a structured coding model which was based on themes emerging from a previous exploratory study on home based care, the research objectives, and recurrent themes in the literature. Broad categories and subcategories were used for coding the country data, allowing for local interpretation and application of theoretical concepts and variations between countries.

**Research teams**

The systematic review and the case studies were conducted by a team of researchers. The systematic review was performed by two researchers; the author of this thesis and a junior researcher. The junior researcher performed the database search and the initial exclusion of studies on the basis of title and abstract under the author’s supervision. The assessments of all included studies followed a pre-defined format, which was developed as part of the review’s protocol. These assessments were conducted by both researchers, independently from each other, as is the norm in systematic reviews.

The author was the principal investigator in the chronic care study in Zambia and the overall research co-ordinator of the multi-country study. The author conducted the field research for the chronic care study in Zambia with the support from research assistants. She designed the study tools, collected, coded and analysed the data. A local
### Table 3.3. Sample information

<table>
<thead>
<tr>
<th>Organisational type</th>
<th>Geographical focus</th>
<th>Service provision</th>
<th>Functional model/structure</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ethiopia</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NGO</td>
<td>urban</td>
<td>medical care (incl. ART), HBC, nutritional, educational and material support, IGA, referral</td>
<td>community caregivers are supervised by HBC coordinators and selected by local community structures</td>
</tr>
<tr>
<td>FBO</td>
<td>urban</td>
<td>medical care (incl. ART), HBC, nutritional, educational and material support, IGA, referral</td>
<td>community caregivers are supervised by nurses and selected by local community structures</td>
</tr>
<tr>
<td>CBO</td>
<td>rural</td>
<td>HBC, nutritional and material support, IGA, training, ambulance service</td>
<td>community caregivers are all peer patients, supervised and selected by the CBO</td>
</tr>
<tr>
<td><strong>Malawi</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FBO</td>
<td>urban and rural</td>
<td>medical care (incl. ART), HBC, farm inputs, nutritional support, IGA, housing for OVC</td>
<td>community caregivers are coordinated by Diocesan structure and linked to FBO health facilities</td>
</tr>
<tr>
<td>CBO</td>
<td>rural</td>
<td>network of support groups, promotion of VCT, mentoring CBOs, outreach to high risk groups</td>
<td>co-ordination of CHBC referral network to provide continuum of care (from prevention to treatment)</td>
</tr>
<tr>
<td>FBO</td>
<td>urban and rural</td>
<td>HBC, community based child centres, youth networks, nutritional support, herbal gardening</td>
<td>community caregivers coordinated by Church health programme</td>
</tr>
<tr>
<td><strong>South-Africa</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NGO</td>
<td>urban</td>
<td>HIV counselling and testing services, management of treatment clubs within ART clinics</td>
<td>training of counsellors who are assigned to state health facilities</td>
</tr>
<tr>
<td>NGO</td>
<td>rural/semi-rural</td>
<td>HBC (majority of clients are elderly, frail, minority is HIV positive)</td>
<td>nurse-supervised community caregivers who receive client referrals from state health facilities</td>
</tr>
<tr>
<td>FBO</td>
<td>peri-urban/semi-rural</td>
<td>HIV testing, provision of ART, link to HBC, OVC programme, day care for disabled</td>
<td>co-ordinated by FBO structures, operating from 2 testing and dispensing facilities with consultation days of medical professional staff and community caregivers in the community</td>
</tr>
<tr>
<td><strong>Zambia</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FBO</td>
<td>urban</td>
<td>HBC, OVC support, IGA</td>
<td>FBO structure coordinating community caregivers</td>
</tr>
<tr>
<td>FBO</td>
<td>rural</td>
<td>HBC, general community development, hospital services including ART and VCT, OVC care</td>
<td>several health and community development programmes coordinated from hospital setting, with community caregivers providing a broad set of services to the community (not just health related)</td>
</tr>
<tr>
<td>NGO</td>
<td>peri-urban</td>
<td>medical care (incl. ART) for HIV and TB, HBC, VCT, education for OVCs, nutritional support</td>
<td>community clinic with testing and treatment facilities, co-ordination of community caregivers providing HBC and referring clients to the community clinic or state clinics</td>
</tr>
</tbody>
</table>
research assistant assisted in the translation of focus group discussions and verbatim transcription of interviews and discussions. Another two research assistants in the Netherlands assisted in the verbatim transcription of interviews. Under the author's supervision, a student from the Research Masters on Global Health collected additional data on the Zambian health management information system.

In the multi-country study, the author of the thesis took the lead in conceptualising and designing the research framework, with inputs from a large reference group consisting of representatives from UNAIDS, WHO, international NGOs and lobby groups. The author did not participate in the data collection for this study. This was carried out by country research teams which were selected through a competitive selection process and in which the author had been one of the reviewers. Country research teams collected, transcribed, coded, analysed and reported on the country data, guided by structured formats. Throughout the study, there was an extensive communication between the author, the country researchers and the regional research co-ordinator, Professor Dr. Quinlan. In close collaboration with Professor Dr. Quinlan, the author developed the data collection tools and analysed and compared the country findings. The research findings were presented at the head office of UNAIDS in Geneva, one of the agencies who funded the study, as well as at the XIX International AIDS Conference in Washington D.C. The names of the researchers and research assistants per country are provided in table 3.4.

**Research validity**

The studies were subjected to a number of procedures to minimise possible threats to the internal and external validity of the research outcomes (Denzin & Lincoln, 1998; Roberts et al., 2006; Stake, 1995).

The internal validity of the research was addressed by applying two types of data triangulation. Firstly, there was triangulation of multiple data sources, which were derived from the interviews, focus group discussions, desk studies and others and, in the case of the multi-country study, covered datasets from more than one country. Secondly, multiple researchers were involved, most notably in the multi-country study. In this study, the in-country research teams worked with generic research tools and followed a phased study approach. They closely communicated with the research co-ordination team, which also visited the teams during the execution of the study. In-country researchers triangulated their data throughout the study whereby desk studies preceded two parts of field research and the field researches were followed by a questionnaire and validation interviews. Others methods to minimise researcher bias included the extensive documentation of primary data (interviews and focus group discussions were audio
<table>
<thead>
<tr>
<th>Research study</th>
<th>Researchers</th>
<th>Research assistants</th>
<th>Affiliations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Multi-country study</strong></td>
<td>Carolien Aantjes</td>
<td></td>
<td>VU University, Amsterdam</td>
</tr>
<tr>
<td></td>
<td>Prof. Tim Quinlan</td>
<td></td>
<td>VU University, Amsterdam / University of KwaZulu-Natal, South Africa</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>Ass Prof. Mirkuzie Woklie</td>
<td>Garumma Tolu Feyissa Zewdie Berhanu</td>
<td>Jimma University</td>
</tr>
<tr>
<td></td>
<td>Prof. Sudhakar Morankar</td>
<td>Ameyu Godeso</td>
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<td></td>
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<td>Biritu Admasu</td>
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<tr>
<td></td>
<td></td>
<td>Tsion Asefa</td>
<td></td>
</tr>
<tr>
<td>Malawi</td>
<td>Dr. Winford Masanjala</td>
<td>Irene Kumwenda</td>
<td>Chancellor College (Economics Department), University of Malawi, Zomba</td>
</tr>
<tr>
<td></td>
<td>Murphy Kajami</td>
<td>Monice Kachinjika Martina Chimzimu</td>
<td></td>
</tr>
<tr>
<td>South-Africa</td>
<td>Dr. Ermien van Pletzen</td>
<td>Beth Vale</td>
<td>University of Cape Town</td>
</tr>
<tr>
<td></td>
<td>Dr. Hayley McGregor</td>
<td>4 translators</td>
<td>Institute of Development Studies, United Kingdom</td>
</tr>
<tr>
<td>Zambia</td>
<td>Alice Mwewa</td>
<td>Fred Chisanga</td>
<td>Development Support Services</td>
</tr>
<tr>
<td></td>
<td>Gregory Sali</td>
<td>Beldon Mwanga</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Joseph Simbaya</td>
<td>Clive Mumba</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Thomson Mwewa</td>
<td>University of Zambia, Institute of Economic and Social Research</td>
</tr>
<tr>
<td><strong>Chronic care study</strong></td>
<td>Carolien Aantjes</td>
<td>Lipota Ngobola</td>
<td>VU University, Amsterdam</td>
</tr>
<tr>
<td></td>
<td>Yunuen Fortanell (intern Global Health Research Master)</td>
<td>Lotte Ramerman</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Andrew Gilmoor</td>
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</tr>
</tbody>
</table>
taped and transcribed verbatim) and regular reflection on findings within the research teams. Key informants from interviews and focus group discussions were provided with summaries of the respective transcripts and asked to check the accurateness of the researchers’ interpretations and feed this back to the researchers. Interviews and focus group discussions which were not in English were first transcribed in the native language, after which they were translated into English. Furthermore, both field studies incorporated a round of repeat interviews, with a selection of the key informants who participated in the studies, to check the accurateness of the research findings. Thematic analysis was performed by the in-country research teams and communicated with the overall research co-ordinator in case of doubt on the thematic codes. The teams received technical assistance in using the software for qualitative analysis, and coding was cross-checked by the research co-ordinators. Quantitative data from the questionnaire among CHBC programmes in the four countries was cross-checked by the research co-ordination team. The team entered the data into SPSS software and adjusted for missing data.

The in-country researchers compiled interim research reports which were submitted and discussed with the research co-ordinators as well as with national advisory boards in each of the countries. These national advisory boards comprised of representatives from relevant Ministries, such as the MoH, large care and support organisations and patient and caregiver networks. The study included restitution meetings in each country, in which key informants and other relevant stakeholders were invited to respond to the research findings. These meetings took place prior the publication of the research reports and scientific papers to accommodate for the incorporation of these inputs. A separate research report on the Zambian chronic care study was disseminated to the Ministry of Health, the Ministry of Community Development, Mother and Child Health, the Churches Health Association of Zambia and the bio-medical ethical committee of the University of Zambia prior to scientific publication.

The research co-ordination team was responsible for monitoring the execution of the different phases in the study and for providing assistance to the in-country research teams. In turn, an international reference group monitored the overall progress and quality of the research via reflection on documentation and in skype conferences with the research co-ordination team. At country level, this occurred in a similar fashion via the national advisory boards who monitored the in-country studies for the full length of the study.

Various measures enhanced the internal validity of the chronic care and multi-country studies. The research design of the multi-country study, for example, included the use of expert interviews at the start of the research to inform the research focus. Furthermore, the studies covered the perspectives of a range of informants; from patients, family
members, caregivers, programme staff, health professional staff, and senior programme managers of national CHBC programmes to government officials and representatives of donor and technical agencies. The aim was to obtain a comprehensive overview of the adaptation processes in each country. All researchers, including the author of this thesis, joined in on home visits to CHBC patients in the community to understand the context in which CHBC programmes are operating as well as the demands of patients for care and support. Furthermore, researchers visited health facilities to observe daily operations and interactions between health professional staff and CHBC caregivers. These observations were additional to the interviews conducted with different actors, who provided health care and support to HIV patients at the community- and health facility level.

The multi-country study helped strengthen the external validity of the research as it created the possibility to examine whether similar trends and patterns in sub-Saharan African health systems could be identified. The findings from the chronic care study in Zambia were also compared to the few studies that were published on chronic care and health system re-orientation in sub-Saharan Africa. The systematic review findings were compared to findings from other reviews on self-management. This comparison was confined to the effectiveness of self-management studies in general, as there were no previous reviews on self-management interventions for patients with HIV or for patients with other chronic conditions from low-income countries.

**Ethical considerations**

Ethical review boards in Ethiopia, Malawi, South Africa and Zambia approved of the research protocols. The studies were also approved by the ethical board of the VU University; the VU Medical Centre. During the studies different procedures were followed to adhere to ethical research standards. For example, the study respondents received an information sheet, explaining the purpose of the research and the contact details of the researcher(s). Study respondents were asked to sign a consent form and were informed that their participation in the study was voluntary and could be withdrawn at any time. The respondents were not exposed to harm and not exposed as patients with HIV during a research intervention. Researchers acted upon the advice of staff members from the community programmes, where patient and primary caregiver interviews could best take place to safeguard confidentiality. The processing and reporting of data was done anonymously and did not expose the identity of respondents. Research data were stored in a secured place, either in the offices of the researchers or on password protected computers. In the chronic care study in Zambia, research assistants signed a confidentiality agreement for the processing of data. Financial remuneration for people’s participation in interviews or focus group discussions was provided in some
of the community programmes, following the rules and regulations of the respective organisations. This remuneration was used to compensate for the travel costs, which volunteer caregivers had incurred to participate in a group discussion. Researchers also provided refreshments and a small snack during these discussions. Where needed, researchers were assisted by translators to support respondents who were not well versed with the English language.

Outline of the thesis

The thesis is structured into nine chapters. The first three chapters provide a description of the rationale and aim of the thesis (chapter 1), the theoretical concepts underlying the thesis (chapter 2) and the design of the research (chapter 3).

Chapters 4-8 present the findings of the thesis. Individual chapters have been either published or are currently under review. Chapter 4 presents the findings from the systematic review on self-management interventions and the relevance of these studies for sub-Saharan Africa. Chapter 5, 6 and 7 present the findings of one country, Zambia, in relation to the four sub-research questions. Chapter 5 discusses the evolution and changes in community home based care programmes in the country. Chapter 6 discusses the process of health system re-orientation towards the provision of chronic care services. It analyses the development of policies on chronic care and compares current services for HIV patients with patients who have non-communicable diseases. It discusses current challenges in the provision of chronic care and reflects on the relevance of existing chronic care models in the Zambian context. Chapter 7 continues with a historic reflection, post-independence to date, on equitable health care; a principle in consecutive Zambian health policies and prominently expected in the post 2015 global development agenda. The opportunities and challenges to achieving universal health coverage are analysed and discussed in relation to the growing chronic disease burden and socio-economic inequality in the country. Chapter 8 compares government policies and strategies from Ethiopia, Malawi, South Africa and Zambia to integrate community home based care into primary health care services. It discusses these findings in light of the literature on integration and integrated care and reflects on the capacity within these national health systems to respond to the demands for chronic care.

Chapter 9 will reflect on the central research question of this thesis, bringing together and discussing the findings per sub-research question and as presented in the chapters 4-8. This chapter also contains a reflection on the validity of the research findings and suggestions for further research.
Conclusions and discussion

This chapter presents the conclusions of my research on health system adaptations to enable the provision of chronic care for patients with HIV in sub-Saharan Africa. Chapters 4 to 8 addressed the central research question, which guided the research:

*What adaptations have occurred at primary health and community level in sub-Saharan Africa to provide long-term treatment, care and support to patients with HIV and in what way do these adaptations contribute to the realisation of a chronic care subsystem within national health systems?*

The central research question was specified into four sub-research questions, which are answered and discussed in the first part of the chapter. This is followed by a reflection on the central research question and the validity of the research findings. The chapter closes with suggestions for future research.
Conclusions on the sub-research questions

1. How have HIV and AIDS community home based care programmes in sub-Saharan Africa evolved in response to the implementation of anti-retroviral treatment programmes and subsequent changing needs of their patients?

The thesis looked at the evolution of CHBC programmes in four countries, of which one country was studied in-depth. In order to understand this evolution in response to the implementation of ART programmes, the form and content of these programmes prior to ART were also studied. Complex adaptive system and system innovation theories were used to understand this change process.

Zambia began to experiment with providing palliative care in the homes of people in the late 1980s (Nsutebu et al, 2001). Chapter 5 described how local models of home care emerged in response to the rapidly growing number of AIDS patients which could no longer be accommodated by Zambia’s hospitals. Faith-based organisations, which managed their own health facilities, were at the forefront of this initiative. The initial form was an outreach programme in which medical teams visited patients and provided basic medical care. Over time, this changed to a model that concentrated care within settlements and in the hands of volunteer caregivers who received limited training. The model borrowed from the existing practice in congregations whereby church members received home visits in times of sickness or spiritual need. The development of these home based care programmes coincided with national reforms of the health sector, which were inspired by the Alma Ata declaration on PHC (WHO, 1978). The Zambian government actively promoted community participation in health care and decentralisation of the health sector with a two-fold purpose in mind: mitigating the impact of human resource shortages and bringing primary health care services as close to the people as possible. In this supportive policy environment, HBC programmes further developed and became the primary providers of care for HIV and AIDS patients from the mid-1980s and throughout the 1990s. By 1996, there were over 100 HBC programmes in the country (Illife, 2006). While, the government acknowledged the importance of the programmes, it did not provide a regulatory framework. FBO-led HBC programmes operated independently from government and government health facilities, using their own management structures and financial resources. More formal collaborations between the providers of HBC and the government occurred towards the end of the 1990s. The Ministry of Health approved the contents of the training courses for volunteer caregivers and set the medical standards for basic nursing care in people’s homes. International agencies, such as the WHO, recognised the need for further guidance on the concept and practice of HBC and developed an international framework (WHO, 2002a). From the early 2000s onwards, HBC programmes increasingly received financial support from international non-governmental organisations. These
developments marked the beginning of a period of professionalization and substantial expansion of HBC programmes in the country.

This brief history shows how the novel development of home care expanded in the country, pioneered by faith-based organisations and with a relative lack of government involvement. Towards the end of the 1990s, early 2000s, these programmes started gaining momentum as the government (regime) responded with the first regulatory steps and developments at global (landscape) level promoted wider support to these community-based initiatives. This is the point of departure (2004/2005) for the implementation of large-scale, national treatment programmes in all four countries and for further changes to the form and content of CHBC programmes.

The findings infer that the practices of HBC programmes permeated further into national health systems, as treatment is being rolled-out and their structures are used to reach hundreds of thousands of eligible patients. Chapter 8 described how governments of South Africa, Malawi and Zambia put legislation in place to confirm their position in national systems at approximately the same time as the treatment programmes transpired. The HBC programmes initially took up the role of promoting treatment uptake among their patients and voluntary counselling and testing in the wider community. As treatment services were being decentralised, they also started supporting PHC facilities in the adherence and retention of patients on ART at community level. It is important to see their changing role in the context of a vertical HIV programme, which pioneered a series of service innovations to enable the provision of complex treatment at the level of PHC facilities. Examples of such innovations, like the introduction of new technology to enable diagnostics at this level, the shifting of certain tasks from high to lower cadre staff and the establishment of an electronic patient filing system, were discussed in chapter 6 and are also described in the literature (Callaghan et al, 2010; Ford et al, 2011; Harries et al, 2006). As patients on treatment recovered their health, the form and content of the HBC programmes started to change. The findings of the research refer to notable changes in location, approach and service package. As the mobility of their patients increased, the programmes started providing care at community points, in addition to home care. This care was provided via group-based approaches with a two-fold purpose: they could reach more patients and cultivate peer to peer support. Programmes expanded their services from basic nursing care, psycho-social and spiritual care to support patients in treatment adherence and in rebuilding their livelihoods. Thereafter, HBC was commonly referred to as community and home-based care (CHBC) programmes. The thesis described this as the process of diversification in these programmes; a phenomenon also referred to in the literature (Bond et al., 2005; Cataldo et al., 2009; Ncama, 2005; Wringe et al, 2010). This marks a period in which CHBC programmes make the shift from the provision of end of life care to chronic care and when further innovations in the vertical HIV programme prepare PHC
facilities for the delivery of ongoing treatment and monitoring of patients on ART. By 2011-2012, this results in the implementation of the first, large-scale chronic care programme in each of the four countries. This is an impressive achievement, given the size of the programme and the multitude of actors that jointly provide these services. The majority of suggested adaptations from literature (Comino et al., 2012; Maher et al., 2010; Rabkin et al., 2012; Samb et al., 2010), as I compiled them per health system building block in table 2.1, had been implemented in Zambia by the time of this study and indicated the presence of a nascent chronic care subsystem.

The findings of the research indicate that the experimentation has not stopped there. In the case of the CHBC programmes, experiments were looking to refine community approaches in chronic care. Examples included nurse-supervised treatment clubs in South Africa and the use of multi-disciplinary community teams in Zambia. In the case of the vertical treatment programme, the experiments were aiming at a reconfiguration of ART services at PHC level, that is, the integration of ART into the clinical services of out-patients departments. This confirms that countries are working towards the ‘dismantling’ of the vertical HIV programme and subsuming the delivery of chronic care for HIV patients in primary health level services. It occurs at a time in which there is a growing demand for CHBC organisations to accommodate a broader range of health conditions, and at a time in which countries revitalise their PHC services. I discuss these developments in the next section.

2. What has been the influence of HIV and AIDS community home based care programmes on the delivery of PHC and the influence of PHC policies and strategies on HIV and AIDS community home based care programmes?

The complex adaptive system and system innovation theories were used to understand the influences on and interactions between primary health and community care services and actors. A specific interest was to explore to what extent national revitalisation strategies considered CHBC programmes.

Since their inception, CHBC programmes have made an important contribution to how PHC delivery in sub-Saharan Africa is conceived and implemented. While international and national efforts faltered (Lawn et al, 2008), these programmes demonstrated that it is possible to deliver comprehensive services as close to the people as possible in resource-constrained settings. The findings of this research show the continuity of this approach. Prior to ART, there was comprehensive delivery of HBC which included basic nursing and palliative care in the homes of patients, HIV preventive and promotive activities in families and communities as well as patient referrals to health facilities for the treatment of opportunistic infections. CHBC now constitutes the comprehensive delivery of chronic care, covering a range of health and ‘non-health’ services to support patients
Conclusions and discussion

and their families in self-management of a lifelong condition. It includes preventive and promotive activities as well as referrals to health facilities for treatment. In both instances, CHBC programmes provided these services with the full participation of patients and families and of which many became volunteer caregivers themselves. The findings of the research also show that these community care initiatives did not remain isolated niche experiments. As discussed in the previous section, they became part and parcel of national HIV treatment programmes and, more recently, are being included in national PHC revitalisation strategies. Interestingly, the CHBC programmes emerged and professionalised at a time in which the selective PHC model dominated policy and practices in sub-Saharan African health systems (Walsh & Warren, 1979). One can argue that the focus in the majority of CHBC programmes was on one disease, and hence selective, but their approaches were comprehensive, as described above. Moreover, recipients of their services have always extended beyond HIV-infected patients. This included the patient’s family, also after his/her death, and now, as the findings of this research reveal, programmes have started to provide services to patients with other chronic conditions. The point is that CHBC programmes base their services on the needs of their patients and the communities they serve. By doing so, their services are congruent with the health system objectives of responsiveness, health equity and financial fairness. The access to large-scale funding enabled them to respond to the high demand for CHBC in a context of widespread poverty and restricted governmental provision of social welfare services. However, as was noted in chapter 5, the conditions attached to this funding negatively started to influence the comprehensiveness of CHBC. The heavy focus on treatment compliance came at the detriment of psychosocial and spiritual support and the interest of donors to finance home care and food support waned, from an understanding that patients on ART were no longer bedridden and were (economically) productive.

The findings of the research show that PHC policies and strategies have similarly been of influence on the concept and practice of CHBC in sub-Saharan Africa. At first, the conceptualisation and understanding of PHC supported the independent development and growth of HBC programmes during the 1980-1990s. Thereafter, a period of professionalization and expansion followed as donors, and later governments, began to see the value of these programmes in creating access to primary-level health services. All sorts of ‘community health workers’ appeared in vertical disease programmes, whereas, in contrast, government-paid CHWs were downsized or subsided all together in national PHC strategies (van Ginneken et al, 2010; Walt, 1988). The huge diversity in community workers was symptomatic for the fragmentation that occurred in health systems. HIV was considered the biggest culprit in this development (England, 2007a, 2007b). While there is truth in the matter, I would counter argue that despite the verticality of this programme down to PHC level, the programme realised this on the basis of a proper conceptualisation of PHC. It realised delivery of comprehensive
care via equitable access (decentralisation), community participation and inter-sectoral collaboration. These three principles were also reflected in my typologies of ‘health system responsiveness’ to the needs of HIV-infected patients, which were formulated and tested during an exploratory phase of this research.\(^1\) (see box 9.1).

In congruence, Rohde et al (2008) stated that the HIV pandemic forced a revitalisation of PHC and community-based services (Rohde et al, 2008). The research showed how countries such as Ethiopia, Malawi, South Africa and Zambia have returned to the premises of PHC, and as part of their revitalisation agenda, also began to define the future course of CHBC programmes. Three out of four governments (with the exception of Ethiopia) have included CHBC programmes into their national strategies.

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**Box 9.1 ‘Ideal types’ of responsive health systems.**

*Decentralisation.* This refers to the provision of HIV (treatment) services at lower levels in the health system in order to bring services closer to where the patient lives.

*Co-creation.* This refers to the partnerships amongst the public sector, private non-profit and for profit institutions in the delivery of health-related HIV services and non-health related support to patients.

*Self-mobilisation.* This refers to the initiatives by and for patients with HIV in establishing support groups and services for patients as well as to the deployment of specific patient expertise within services provided by public and private institutions.

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\(^1\) This phase consisted of explorative interviews with health and HIV experts with experience in sub-Saharan Africa (n=16) on the basis of which twenty-one examples emerged of services, practices or programmes which were responsive to the needs of HIV-infected patients. A thematic analysis of these examples informed the construction of three ‘ideal types’, using the Weberian method (1978). The ideal types were presented to another set of health and HIV experts based in Uganda, Swaziland and South Africa to verify whether the ideal types resembled in-country responses to HIV and AIDS and to explore possible implementation gaps (n=12).
Their aim is to integrate CHBC programmes, by making PHC facilities the focal point for management and state-paid community health workers responsible for the supervision of community-based activities. The current situation represents a major departure from the initial niche position of CHBC programmes in national health systems. Over time, they have become central components of the health systems, that is, they became part of the regime. The findings of the research show that PHC policies and strategies, both at landscape and regime levels, have been of major influence on this process. The imminent question now is how do governments envisage the further incorporation of non-governmental community care services in support of comprehensive PHC service delivery for patients with HIV and other chronic conditions.

3. How are primary health and community level services being connected to enable the delivery of comprehensive care for patients with HIV and other chronic conditions?

The WHO promotes the development of integrated health care services at PHC level (WHO, 2008e, 2015). However, as chapter 2 indicated, sub-Saharan African governments have little to draw from in terms of a published evidence base which contextualises and gives guidance to the concept of integration in resource-constrained settings. In the same vain, I have to draw from ‘Western-based’ theories to discuss research results and to specify integration for the sub-Saharan African setting. In order to do so, I use and discuss the integration spectrum and the integrated framework for primary care.

The integration spectrum, as developed by Ahgren & Axelsson (2005), provided a useful perspective on the different gradations in integration. From left to right in this spectrum, there is segregation, linkages, co-ordination and integration. The findings of the research illustrate the movements along this spectrum in terms of how services and actors in PHC and CHBC have been connected. That is to say, for the connection between governmental and non-governmental actors as the mission hospital-led CHBC programmes as well as those non-governmental organisations which operated CHBC from their own medical facilities have, from inception, provided integrated health services to HIV and AIDS patients. The dynamism was found in the connection between these independent CHBC programmes and governmental health facilities. Between the mid-1980s and early 1990s, this connection consisted of linkages in support of patient referrals. Between the mid-to-late 1990s, mechanisms were put in place at all levels, as part of national AIDS programmes, to co-ordinate all the different actors in HIV and AIDS interventions. These structures were weak (Dickinson, 2005; Putzel, 2004) but improved as Ministries of Health reclaimed this co-ordination from the early-to-mid-2000s onwards. The Ministries’ agenda was in pursuit of a stronger co-ordination amongst health facilities and between them and CHBC programmes with the purpose of facilitating patient recruitment, adherence to, and retention in ART
programmes. The PHC revitalisation agenda, as adopted by those countries in 2008, instigated movements towards integration.

The findings of the research reveal different interpretations and contextualisation of integration within the revitalisation agendas of Ethiopia, Malawi, South Africa and Zambia. This in itself is not an overt surprise as the polymorphous nature of the concept, the different levels of integration and the implication of numerous actors inevitably evoke this. Of interest is how this has resulted into different, systemic ‘pathways’ of integration which all pursue the goal of delivering comprehensive PHC as close to the people as possible. Three pathways could be distinguished for connecting PHC and CHBC: by supervision (Malawi and Zambia), contracting (South Africa) and referral (Ethiopia). Further analysis on the development of these pathways, as described in chapter 8, showed how current applications of the Alma Ata principle ‘community participation’ were shaped by partnership perspectives from the past. In Ethiopia, for example, there has been a historic demarcation between the services of governmental and non-governmental providers. Current PHC policy and strategy continue to reflect this, whereby the government primarily depends on its own workforce and structures to implement a comprehensive PHC programme. In contrast, Malawi has long incorporated non-governmental community partners in the delivery of health care. These partners are accountable to community leadership and expected to support state-paid employees working in health facilities and at community level. The connection between primary health and community care actors is guided by fourteen national policies, including one on CHBC.

The framework of Valentijn et al (2013), which was presented in chapter 2, was used to specify the research findings according to different levels of integration within these country pathways. The ‘highest’ form of integration in this framework is system integration (macro level). It refers to the integration of the health and social welfare system, also called the integrated care system. The pathways of Ethiopia and South Africa did not pursue this level, whereas Malawi and Zambia did. Chapter 8 described how the Zambian pathway was re-routed from an initial set of bio-medically oriented PHC revitalisation interventions to a substantial Ministerial restructuring which accommodated an agenda for addressing the underlying causes for ill-health, i.e. the social determinants of health. This entailed a merger between PHC, social welfare and community development departments under the roof of one Ministry. Chapter 6 and 8 discussed the potential of this pathway to facilitate and further shape the provision of chronic care, as current system modifications better matched the needs of patients with chronic conditions (falling within and outside the health domain, Ouwens et al., 2005) as well as the range of services provided by CHBC programmes. The literature on integrated care systems, again predominantly from high-income countries, describes the many complexities in joining, what are considered, the ‘cure’ and ‘care’ sectors (Davey et
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al., 2005; Friedman & Goes, 2000; Heenan & Birrell, 2006; Hultberg et al., 2005; Leutz, 2005; Meijboom et al., 2004; Mur-Veeman et al., 2003; Suter et al., 2009; Weatherly et al., 2010). This does not mean that system integration will be equally difficult in African settings. In contexts of widespread poverty, the interdependency of the two sectors seems self-evident. Nonetheless, the integration of two systems (or three in the case of Zambia) may give rise to different kinds of obstacles which can prematurely stall or lead to the development of a suboptimal integrated care system. I discuss two potential obstacles for the case of Zambia. The first pertains to accountability in the system. The diagrams 9.1 and 9.2 illustrate the hierarchical structure before and after the transfer of PHC to the Ministry of Community Development, Mother and Child Health (MCDMCH)\(^2\).

The grey lines in diagram 9.2 indicate the new connection between the district health office and the provincial community development office of the MCDMCH, to which it is now accountable. The implication is that the district health team, who has disposal over its own district health budget, now has to report to government officials who a) do not necessarily have the competence to supervise the output of health officials and b) who are not used to a situation whereby lower level authorities are in charge of their own budget. In other words, the provincial community development office cannot exert full authority over the district health office. This new situation may cause conflict between the two offices, and obstruct the integration process. A second obstacle refers to the Ministerial division that was made, whereby the Ministry of Health is in charge of hospital care and the MCDMCH in charge of primary health and community care. At systems level, the division creates a new kind of fragmentation, which, at patient level, may cause problems in referral. Kenya, where there was a similar experimental division upon change of government, chose to abandon this approach after five years (Wamai, 2009; McCollum et al, 2015). The Kenyan strategy was similar to Zambia in terms of its emphasis on primary health care but different in that it did not pursue systems integration.

At meso level, two types of integration can occur: professional and organisational integration (Valentijn et al, 2013). The findings of the research show that all country pathways included approaches of professional integration, connecting CHBC programmes and government PHC facilities in the provision of comprehensive services and a continuum of care for patients with HIV. In Ethiopia, this was practiced in the absence of a regulatory framework, whereas Malawi, South Africa and Zambia legislated this connection. Valentijn et al (2013) do not incorporate this in their framework, but the findings of the research infer that this had been an important step

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\(^2\) In 2011, the Ministry of Community Development and Social Services became the Ministry of Community Development, Mother and Child Health. The PHC department of the MoH was transferred to this Ministry at a later stage.
Diagram 9.1 Before transfer of PHC (adapted from Mwewa et al, 2013)

- Ministry of Health
- Cabinet Committee on HIV and AIDS
- National AIDS Council
- Provincial AIDS Taskforce
- Provincial Development Coordinating Committee
- Provincial Social Welfare Office
- District Social Welfare Assistance Committees
- Community Based Organisations/Groups
- Community Volunteers
- Community level voluntary positions

- Provincial Health Office
- Provincial Hospitals Level 3
- District Health Office
- Provincial Hospitals Level 2
- District Hospitals Level 1
- Health Posts/CHAs
- Community structures e.g. NHCs
- Community Health Volunteers e.g. TB supports, Treatment Adherence supporters
Diagram 9.2 After transfer of PHC (adapted from Mwewa et al, 2013)
in ‘formalising’ the position of community partners in health care. The three countries were now moving towards organisational integration, by subsuming all community-based activities under the management and supervision of PHC facilities and state-paid community health workers. This would require PHC teams that are adequately staffed and equipped, which is not a current reality in any of these countries. In fact, supervision by facility-based staff proved to be a strong bottleneck in the history of PHC (Walt & Gilson, 1990). It raises questions over the feasibility as well as the necessity of this particular approach in these countries’ pathways. Furthermore, the findings of the research suggest that CHBC programmes have well-established management and supervisory structures and have developed their own ways and means to mobilise and retain community members in the provision of care and support. Chapter 5 described the possible consequences of integration for the value-base of community care as the Zambian government works with a different notion on community participation in health care. The findings of the research also draw attention to the possibility that integration will thwart CHBC programmes from providing the non-health aspects of chronic care; a process which appeared to unfold in South Africa. Valentijn et al (2013) underline that professional integration does not necessarily require actors to function under one hierarchical structure; it can also be pursued in network type arrangements which combine flexibility and commitment.

Micro level integration refers to the clinical integration of services in support of individual-level care (Valentijn et al, 2013). The findings of the Zambian research show presence of service structures at all levels in the health system and horizontal (cross-sectoral) and vertical (primary to tertiary) integration between them for patients with HIV. Patients with chronic NCDs did not have this level of access to integrated health services. I discuss this further in the next section. The integration of ART services at PHC level has been in pilot phase since 2007 (Topp et al, 2011). In view of the scientific evidence on NCD co-morbidities in HIV patients on ART (Colvin, 2011; Deeks et al., 2013; Haregu et al., 2012), and the current fragmentation between HIV and NCD services, it would be desirable to scale-up these experiments to more health facilities in the country. However, various difficulties, such as merging the culture and practices of ART clinic staff with those of PHC staff, seem to hamper progress (Topp et al, 2012).

While the benefits of integration may be understood and are supported by literature (Kodner & Spreeuwenberg, 2002; Rogers & Sheaff, 2000; WHO, 2008c), it is also by virtue a complex process as it requires regime change and regular reflection on whether intended effects are being achieved. In chapter 7, I reflected on the difficulties of health system reforms in a context of changing political and economic conditions. The growing income inequality in Zambia, for instance, can undermine current efforts and reverse health outcomes (Wilkinson & Pickett, 2006). I concluded that the integration of health and social welfare systems was a commendable, but not sufficient, leap forward in the
country’s aspiration for universal health coverage. From an understanding that health systems require support to address ill-health in poor people (de Janvry & Sadoulet, 2009; Marmot et al., 2008), I argue that system-level integration in resource-constrained settings also needs to include ministries that are responsible for economic development. This does not imply further Ministerial mergers, but shared policies and responsibility for reducing countries’ high disease burdens.

4. To what extent are existing models of chronic care being applied in sub-Saharan Africa and are they appropriate in contexts of large-scale HIV pandemics and health system resource constraints?

As discussed in the previous sections, the findings of my research reveal extensive experimentation with as well as the systematic development of chronic care approaches for HIV-infected patients in the four countries. In this section, I show that this has led to the emergence of an ‘African chronic care model’.

The theoretical framework in the thesis relied on chronic care models and practices which were largely shaped and referred to conditions in high-income countries. The WHO re-developed one of these models for global use in 2002 (WHO, 2002b). The findings of the research indicate that the development of a chronic care subsystem in Zambia had been guided by necessity and pragmatism and that the WHO framework had not been used to inform health policy discussions or strategies. This finding concurred with the little evidence I had found in both the scientific and grey literature on the implementation of chronic care models in low and lower-middle income countries (Isenhower, 2011; Nuño et al., 2012). The systematic review on self-management interventions produced a similar result (chapter 4). Only two out of a total of fifty-two reviewed studies had been conducted in low and lower-middle income countries. The review’s search strategy had been guided by the WHO framework and included the different actors in chronic care: health professionals, community partners, patients and families. Yet, the majority of studies discussed interventions which depended on health professionals to lead and guide patients in self-management. Chapter 4 pointed at the relevance and need for studies on patient, family and community-led interventions and suggested that CHBC programmes could serve as testing grounds for developing and studying the effectiveness of self-management interventions in sub-Saharan Africa. This suggestion followed from the findings of the case studies, which demonstrate the presence of chronic care practices in four sub-Saharan African countries. These practices all emphasised the role of ‘community partners’, ‘patients and families’ in chronic care and in ways different to the theoretical models of Wagner (1998) and the WHO (2002b). In the elaboration of Wagner’s model, for instance, partnerships between health care teams and community organisations are suggested to help fill any gaps in service delivery. However, the main emphasis is on the role of ‘health
care teams’ in chronic care, which presumably function within well-developed health systems, with adequate numbers of skilled professional staff and the presence of medical technologies, evidence based guidelines and clinical information systems to support them. The model also omits families and peer patients as providers of chronic care, hence its appropriateness for the sub-Saharan African context was limited. As also discussed in chapter 2, the WHO framework was more appropriate in the sense that it emphasises the critical importance of working relationships between community partners, patients and families and health care teams in the delivery of chronic care. A limitation of the framework is its implicitness, as it relies on rather general descriptions of roles in, and conditions for, chronic care. In other words, the contours are provided but further specification is necessary to contextualise practices of chronic care. I use three subsets of evidence to locate the WHO framework in the context of an African setting and to discuss the differences observed between this framework and chronic care practices in Africa. These subsets are the positions of actors within the triad partnership; the connections between them; and the sectoral engagement in chronic care.

**Triad positions.** The findings of the research reveal a range of actors within the triad partnership. Actors included community volunteers, family members, peer patients, support groups, NGO professional health staff, facility-based health staff, community health workers, social welfare personnel, but also, as I discuss shortly, community development assistants and farmers. Within the triad the positions, and hence roles, of these actors were more fluid compared to the division made in the WHO framework. First, ‘health care teams’ in the four countries did not refer only to health professional staff as employed by Ministries of Health. These teams could also be ‘community partners’ in the form of medical personnel who worked for NGOs and FBOs in their own medical facilities and who supervised CHBC programmes. It could also be trained volunteers who fulfilled various roles, ranging from administrative work to psycho-social counselling, within government, and NGO/FBO health facilities. These volunteers could be community residents, peer patients or family caregivers. In the context of the large-scale HIV pandemics in the region, HIV-infected patients were not only managers of their own condition, supported by ‘caregivers’, as is inferred in the WHO framework and the Wagner model. Patients participated in a system of collective management of their own and others’ conditions because the vast majority of caregivers have been affected by the disease and many, if not a majority, are likely to be ART patients themselves. Therefore, patients could also occupy any position in the triad and were not just ‘recipients’ of chronic care. An important conclusion of this thesis is, therefore, that the people who are involved in chronic care in sub-Saharan Africa cannot be ‘boxed’ into one of WHO’s actor-categories; neither in position, nor in the role they have. This is not only the result of the critical shortages of health professionals, it is also an outcome of the local cultural values in this region. These are values that emphasise
social relationships and extensive mutual support, which have become less apparent in Western societies (Nolte et al, 2008).

**Connections.** The findings of the research reveal the presence of substantive networks in all four countries for the provision of chronic care and patient self-management. The discussion in relation to sub-research question three of this chapter illustrated the connections within these networks, using the framework of Valentijn to describe how the concepts of integration and integrated care were applied in each country. A key point is that my research clarifies the nature and operation of what the WHO framework refers to as the ‘links’ between the health care organisation and the community. First, three of the four countries have formalised the link between national governments and CHBC programmes during the last ten years. This is significant in view of the WHO noting in 2002, in its publication of its chronic care model, that legislative frameworks of this kind were a rare occurrence in low-income countries (WHO, 2002b). Furthermore, the findings of the research point to the significant influence of the African PHC revitalisation agenda in furthering these linkages but to different countries adopting different strategies. Ethiopia continued to rely on CHBC programmes referring patients to the health services. South Africa used the approach of contracting ‘community partners’ to work with primary health care medical teams. Malawi and Zambia adopted an integrated model whereby CHBC programmes, PHC medical teams, local officials of ‘non-health’ ministries and local government, community authority and social structures worked together. The different country strategies reveal the complex nature of integrated care in practice, the inevitable variation in practical interpretations of the concept and, particularly in Malawi and Zambia, specification of what chronic care in resource poor settings means and entails. As these are relatively recent change processes, it is still too early to assess their contributions to the broader agenda for integrated health services, and how the provision of integrated health services in this part of the world may differ from that in high-income countries.

**Sectoral engagement.** The findings of the research show the convergence of health structures and mechanisms with structures and mechanisms of social welfare within the context of sub-Saharan African countries. This was particularly the case in the CHBC programmes of FBOs and NGOs and, more recently, in government policies and strategies in Malawi and Zambia. Notably, CHBC programmes were first and foremost the means to organise and use local social welfare mechanisms: the social networks of family, neighbourhoods and religion. As ART patients recovered their health and needed economic support, these networks formed the basis for the inclusion of local economic agencies. CHBC programmes in Ethiopia and South Africa, for example, liaised with micro-finance groups and idirs and local businesses with this purpose in mind. In chapter 7, Malawi was exemplified as a country which, despite many resource-constraints, had been able to entrench structures and mechanisms for delivering a
combination of health, social and economic welfare programmes to the population, via various cadres of local government employees and non-governmental community partners. This accentuation of sectoral engagement in chronic care in Africa draws attention to a limitation in both the Wagner and the WHO model. These models do not define the place and role of a country’s social welfare system in facilitation of the ‘non-health’ needs of patients with chronic conditions.

The above contextualisation of the WHO framework has implications for the broader policy environment in Africa, or what the WHO framework refers to as the ‘positive policy environment’. In the previous section, I discussed the need to solidify partnerships and policies (i.e. the inter-sectoral collaboration) with ministries that are responsible for economic development. The findings from the research show that, at community level, the livelihood aspect forms part of chronic care and hence has a place in the conceptualisation of chronic care in the region.

The findings of the research suggest the emergence of an ‘African chronic care model’ which differs from existing theoretical models on chronic care. Box 9.2 summarises the main features of this model. The model can give countries further guidance in the re-orientation of their health systems. The findings of the research already point at the potential as well as unfolding practice in CHBC programmes to serve patients with other chronic conditions. The existing co-ordination mechanisms between these programmes and PHC facilities, and via state-paid community health workers, notably, the health surveillance assistants in Malawi, the health extension workers in Ethiopia, the community care workers in South Africa and the community health assistants in Zambia, could be leveraged to support the early detection, screening and appropriate

**Box 9.2.** Ten features of the ‘African chronic care model’

1. Social relationships and extensive mutual support are the value-base
2. The triad partnership includes a broad range of actors
3. Actor positions in the triad partnership are fluid
4. Patients are not just recipients; they also provide chronic care
5. Chronic care services extend far beyond the health domain
6. Health and social welfare systems converge
7. Inter-sectoral collaboration supports patient’s livelihoods
8. Actors are connected via mechanisms of linkages, co-ordination and integration
9. Application of these mechanisms is country dependent
10. With different degrees in the formalisation of community services
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Referral of those patients. The findings from the in-depth research in Zambia, however, reveal that this potential was not yet put to good use. One of the main obstacles in effectively using these mechanisms was the general lack of access to comprehensive services for patients with NCDs at PHC level. Challenges to provide these services at PHC facilities included drug procurement problems, the limited availability of diagnostic equipment and a lack of different medicinal options to treat the range of NCDs. As a result, patients had to be referred to specialists in secondary or tertiary level hospitals. Chapter 6 discussed how the Zambian government is drawing from the vertical HIV programme to build up NCD services. The findings of the research reveal how efforts, up to date, have tended to focus on curative care, via purchase of technological equipment for hospitals and establishment of provincial, specialist clinics. The pattern is similar to how health care services for HIV patients were initially established. A crucial difference is that the large influx of external funding for HIV accelerated the decentralisation of these services to PHC level. For NCDs, there is little indication of this level investment from external donors in Zambia, or for that matter, in the region (Samb et al, 2010). Another major challenge was the lack of reliable data on the prevalence and incidence of NCDs to inform strategic decision-making in the re-orientation process.

The findings of the research also note a number of ongoing challenges in the provision of chronic care to patients with HIV. These included problems to provide ART to patients living in remote settlements and to children, problems to create sufficient time for medical consultations as a result of congestion at ART clinics and technological difficulties to use the electronic patient record system country-wide. There was limited assimilation of the practice of patient self-management among health professional staff in public health services. This could be explained as a remnant of the traditional disease-focus of health professionals and of the ‘emergency response’ approach to the HIV epidemic. One informant made the point so succinctly that she is quoted in this section:

“we were very much clinicians working on a medical problem and I think there is good things about that. It was just happening fast and it happened quickly and from a public health point of view [...] most decisions were right but I think from an individual patient managed participatory point of view, we failed in many ways”. HIV/AIDS technical advisor to the MoH.

The findings of the research also reveal that the presence of strong community networks was no longer self-evident. In all four countries, CHBC programmes had experienced shortfalls in funding. Chapter 5 discussed additional factors which contributed to the erosion of these networks in Zambia, such as the bio-medical emphasis in HIV care, frustration over salaried community health workers and limited
government acknowledgement of the brokering role of civil society organisations. These developments were discussed as a source for concern with regards to the country’s HIV treatment programme and further development of primary level chronic care services. Chapter 7 discussed two opportunities which could help tackle these concerns. One pertained to the explicit commitment to the social determinants of health in the current government’s agenda, and the other to the country’s substantive economic growth rates during the last 15 years which give an economic foundation to this commitment.

**Overall conclusions**

This thesis examined the process of health system adaptation, following the provision of lifelong, anti-retroviral treatment for HIV patients in four sub-Saharan African countries: Ethiopia, Malawi, South Africa and, in particular, Zambia. This analysis was pertinent in view of the emerging burden of chronic, non-communicable diseases in the region and the concerns about health system capacity to address this new health care challenge. The research was based on an assumption that the vertical HIV programme contained valuable lessons on how chronic care can be delivered in resource-constrained settings. However, it was unclear to what extent these lessons could be transferred and used to re-orient general health services, as they occurred under the ‘exceptional’ conditions of the vertical HIV programme. The research explored this question with a focus on adaptations at primary health and community level from the understanding that this is where chronic care needs to happen.

The thesis showed how local initiatives of home care developed into distinct community home-based care programmes. Global level influences, such as the Alma Ata declaration on PHC and the priority funding for HIV and AIDS, and country level recognition supported the development and expansion of these programmes. Initially, CHBC programmes occupied a niche position and, over time, they became part of the regime of structures, culture and practices which accelerated the access to ART and established the capacity to provide chronic care for HIV patients. This thesis draws attention to the many innovations and valuable lessons from CHBC programmes and the vertical HIV programme, which permeated through the health systems of four countries. In the case of Zambia, these lessons underpinned the country’s health system re-orientation process; a process which was in full swing.

This process was converging with another important agenda; the agenda to revitalise PHC in Africa. The thesis showed how these two agendas were mutually enforcing each other, notably, via the strategies to re-position PHC as the first point of contact for comprehensive service delivery and the integration of CHBC programmes in PHC. The thesis identified interesting country pathways for connecting primary and community
providers in health care. While, all four countries aimed at bringing health care as close to the people as possible, they designed and interpreted the connections differently. The pathways of Malawi and Zambia were highlighted for their potential to further shape the nascent chronic care subsystems in these countries, from the understanding that integrated care systems better match the health and non-health needs of patients with chronic conditions as well as the range of services provided by CHBC programmes in those countries. This was not to say that the pathways of Ethiopia and South Africa were not seen to contribute to the realisation of chronic care subsystems. Their pathways contained other virtues for this purpose, such as a ‘health development army’ in Ethiopia and PHC teams in South Africa. The thesis discussed pathway-dependent challenges for each of the four countries in connection to the literature on integration. It pointed at the current contradictions in national strategies which, on paper, aspire comprehensive PHC services (and in due time universal health coverage) as close to the people as possible. At policy level, integration constitutes a significant development as it underscores the crucial role of community partners in national health systems and a clear attempt to leverage the in-country HIV capacity for a broader purpose. However, in practice, integration can lead to a redefinition and reorganisation of CHBC programmes in ways that could prove detrimental to using them as a platform for addressing the growing burden of NCDs and co-morbidities.

The thesis presented an ‘African chronic care model’. The findings from the research, among which included the country pathways, were used to further contextualise the WHO framework on chronic care. The ‘African chronic care model’ is characterised by the fluid positions of actors within the model, the ways and means in which actors are connected and by the implication of other sectors, such as social welfare. These specifications show, that regardless of the dearth in literature to draw from, local forms emerged and, more importantly, reveal substantive network capacity for the delivery of chronic care in sub-Saharan Africa. This is an important finding and an encouragement to current health reforms and the aspiration for universal health coverage in the region.

And lastly, a key feature of transition theory is recognition that the actions and interactions of different agencies pull health systems in different directions. It is therefore possible that the re-orientation process, as it now unfolds, will not necessarily lead to effective adaptations of health systems and responsiveness to changing conditions and demands. My analysis and reflection on the experiences with HIV and AIDS has shown the tremendous capability of sub-Saharan African health systems to adapt and respond to one, if not the biggest, health care challenge in their history and time. This was equally a complex process and involved many different actors and interests. My thesis expressed a range of concerns but also pointed readers to the presence of community networks which played a vital role in creating the access to treatment, care and support services for patients with HIV. Countries can now draw from experience, and more
importantly, on these networks to offer patients with other chronic conditions equitable access. It is my hope that this research will contribute to guiding those involved in health system development by offering a further conceptualisation of chronic care as well as insight into the policy and practice of integrated health services in sub-Saharan African settings.

**Validity of findings**

Chapter 3 described which measures were incorporated in the design of the research to enhance the validity of findings. In this section, I reflect on the implementation of these measures.

**Internal validity**

The cycle of desk studies, field research, desk studies and validation interviews in each of the countries as well as the data triangulation during and after this cycle proceeded as planned. The in-country research teams followed the study’s phased approach, used the generic tools and implemented all research activities envisaged for each phase. Some country teams faced difficulties in concluding the research activities within time, but this did not compromise the quality and reliability of data. The different feedback loops, which had been incorporated from the start of the study (e.g. research co-ordination teams between in-country research teams, in-country research teams between national advisory boards) functioned well and helped to enhance the validity of the data.

A limitation to the validity of the findings from the systematic review was that the initial sifting of literature was carried out by only one researcher. This limitation was reduced through the screening of abstracts which were considered doubtful for inclusion in the review by the second researcher.

In the chronic care study, one of the last research activities included explorative interviews. These had been added to the original study and the choice was made to conduct the interviews by telephone. A well-known limitation of telephone interviews is that it relies on verbal communication and could miss conversational cues which supplement the researchers’ interpretation. This decision may have affected the quality of data as presented in chapter 7. A review on the use of this method in qualitative studies, however, also pointed at the advantages of telephonic interviewing, such as informants talking more freely (Novick, 2008). The quantitative data in the chronic care study on HIV (e.g. ART coverage) and NCD (e.g. mortality data) was provided by the Ministry of Health. This data could not be cross-checked as this would have entailed
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extensive work and visits to all Provinces. In chapter 6, where this data was presented, the limitations of using this data were discussed.

In the multi-country study, difficulties were encountered with the intended provision of transcript summaries to key informants. This did not occur in all instances as a result of time constraints. Another limitation, again due to time, was that the research had to commence without the planned activity to pre-test the data collection tools in a non-sampled CHBC programme. In the same vain, there was no time to pre-test the questionnaire. However, prior to its dissemination, the contents of the questionnaire was reviewed and commented on by the international reference group. The questionnaire survey was faced with non-responses but came close (78%) to the set target of 80%.

The sampling criteria which had been compiled to guide the country and in-depth CHBC case selection had been rather broad. However, it served its purpose well in achieving maximum variation, both in terms of country policies and strategies and in the foci of CHBC programmes.

External validity

The research findings are based on country case-studies which were sampled purposively, hence there are limitations in generalising the findings of this study for the wider sub-Saharan African region. However, the comparative element in the study enabled the extraction of common trends and patterns in the four countries, which were described in chapter 8. These common trends and patterns can support learning in similar processes taking place in other contexts (Stake, 1995; Stake & Trumbull, 1982), for instance, with regards to the African PHC revitalisation agenda. The strong commitment to this agenda is not only present in the four researched countries, but also elsewhere in the region. A recent study showed how countries pursued similar directions, either opting to reinvigorate their national CHW programmes (e.g. Niger) or to create new cadres of CHWs (e.g. Mozambique and Mali) (Bennett et al, 2014). The study also revealed individual country struggles to incorporate community caregivers from non-governmental projects into national CHW programmes (e.g. Kenya and Burkina Faso). The findings from Bennett et al (2014) suggest that the strategies and experiences of Ethiopia, Malawi, South Africa and Zambia are comparable with other countries in the region.

The findings from the chronic care study in Zambia expressing that PHC facilities had little to offer to patients with NCDs were confirmed by a number of (recent) studies from the region (Draper et al, 2014; Peck et al, 2014; Maimela et al, 2015; Sips et al, 2014; Settumba et al, 2015). Study sites included Kenya, South Africa, Tanzania and Uganda. However, the findings on integrated care in Zambia and Malawi could not be
compared to studies in other countries. While publications on the clinical integration of HIV services are on the increase (Crowley & Stellenberg, 2014; Mutemwa et al, 2013; Oleribe et al, 2014), there continues to be a dearth in the literature on system level integration in the region. This shows that the contribution of this study is timely, both in terms of informing ongoing re-orientation processes for NCDs as well as on the development process of integrated health services at higher levels in sub-Saharan African health systems. In the introduction of this thesis, I hypothesised that the lessons from the vertical HIV programmes could be transferred to general health services and serve patients with other chronic conditions. While the study findings suggest that this is possible, the extent to which they can be extrapolated for diseases such as cancer and cardio-vascular conditions, does require further investigation.

Suggestions for future research

This thesis describes health systems in transition with a specific focus on the organisations, structures and mechanisms that have evolved for primary health and community level chronic care of HIV patients and, as importantly, for other patients with chronic conditions. In the process, it provided an empirical basis and argument for further consideration of an ‘African chronic care model’, the principles and practice of integration in relation to the development of chronic care services and the concept and practice of patient self-management. I outline below the areas for further research, which I believe are of interest to science and society, and can contribute in more detail to our understanding of chronic care and how this is best designed and delivered.

Local models for chronic care in Africa

The thesis suggests there are nascent local models of chronic care in Africa which appear to be evolving with little direct influence of international agencies such as the WHO. Further assessments would be necessary to support the validity of this finding. In addition, the outline of the ‘African chronic care model’, as described in this thesis, could be further enriched by the conceptualisations and practices of chronic care in other countries in the region.

Integrated care studies in Malawi or Zambia

This thesis considered integration in relation to chronic care and showed how Malawi and Zambia are pursuing integrated care systems. These countries provide interesting cases for studying integrated care systems, in general, in Africa. The current dearth of literature on integrated care in low and lower-middle income countries provides little opportunity for policy-makers and practitioners based in these settings to inform policy and practice. There is benefit in conducting further studies which make these processes
more insightful, investigate how obstacles in the process could be addressed as well as assess the outcomes of integrated care systems.

**Self-management intervention studies in Africa**

The concept of self-management requires further study in this part of the world. This could include a variety of studies on the practices and principles of self-management in Africa as well intervention studies to test the appropriate form and content of self-management interventions in different African settings. In the thesis, I suggested the use of CHBC programmes as one of the settings.

**Disease-specific and epidemiological studies in Africa**

The research’ focus was on CHBC programmes and HIV and AIDS. Another interesting angle for studying health system re-orientation in sub-Saharan African could have been a research on non-communicable diseases, such as diabetes or cardio-vascular diseases, and the current gaps in health services for them. While this would have been a useful study, my estimation was that the returns and insights from such a study would be limited for informing the overall purpose of my research. However, as countries are building up NCD services I anticipate there will be a need for subsets of studies that focus on specific NCDs and as they occur in sub-Saharan Africa.

This should be complemented by epidemiological studies. During my research, I was faced with the limitation of insufficient in-country epidemiological data on the burden of non-communicable diseases and on the prevalence of HIV co-morbidities. The insight in epidemiological patterns of the different emerging diseases in sub-Saharan African countries is essential for policy development and proper planning of directed interventions, more accurate financial projections and for monitoring of incidence and prevalence rates. There is a need for rigorous academic research in this area, such as surveys and possibly cohorts, but also for general improvements to health management information systems to allow for regular extraction and review of disease specific data.
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