

VU Research Portal

Patients, providers, and systems

Angwenyi, V.

2020

document version

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

citation for published version (APA)

Angwenyi, V. (2020). *Patients, providers, and systems: local models for chronic care and self-management support in southern Malawi*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

E-mail address:

vuresearchportal.ub@vu.nl

CHAPTER 1

Introduction

Chronic non-communicable diseases (NCDs), such as cardiovascular diseases, diabetes, cancer and chronic obstructive pulmonary diseases, accounted for 71% (41 million) of all global deaths (57 million) in 2017, with the majority occurring in low- and middle-income countries [1, 2]. In sub-Saharan Africa (sSA), it is estimated that 70% of the deaths were attributable to these conditions, and causing 80% (12 million) of premature deaths [2]. Moreover, sub-Saharan African countries continue to face high morbidity and mortality rates caused by communicable diseases (such as HIV, tuberculosis and malaria), nutritional and maternal health related problems [3]. HIV and AIDS continues to represent a major public health concern in sub-Saharan Africa, and among the countries with the highest number of people living with HIV, and mostly from the southern Africa region include South Africa, Swaziland, Mozambique, Zimbabwe, Zambia, and Malawi, respectively [4].

The changing patterns of mortality across the globe has been attributed to changes in life expectancy and morbidity patterns [2]. This rapid and ongoing shift in the global pattern of diseases and causes of death is referred to as the demographic and epidemiological transition [5]. These transitions are driven by changes in demographic structures of countries fuelled by a growing ageing population – who are more prone to multimorbidities – urbanisation and industrialization, and certain lifestyle changes such as physical inactivity, unhealthy diets, smoking habits and alcohol consumption, which affect people's health and wellbeing [5, 6]. While these processes occur at a global level, there are inter-country differences, which influence (policy) response measures [6]. For instance, the state of healthcare is more advanced in high income countries compared to low income countries, partly due to increased political commitment (which has led to improved investments and resourcing), levels of advancement in medical technology and available resources for health promotion and care [6, 7]. The growing population of patients with chronic conditions who require care on a continued basis puts enormous pressure on government spending on both health and social care [8]. Breaking this epidemic cycle requires multiple initiatives, including those focusing on empowering patients to better self-manage their conditions, provision of services centred around patient's care needs, and preventive measures targeting populations most at risk [3, 9, 10]. Given budget and resource constraints, sub-Saharan African countries continue to draw on experiences from existing health programmes, transferring lessons and practices to shape how newly emerging conditions and epidemics are dealt with. One salient example is the utilisation of the HIV/AIDS response for addressing the continent's growing burden of NCDs, which is elaborated further below.

LEARNING FROM THE HIV/AIDS EXPERIENCE

Sub-Saharan African countries continue to face an overwhelming HIV burden, with 69% (19.6 million) of the estimated 36.9 million (31.1–43.9 million) people living with HIV globally residing in this region [4]. Since the onset of the HIV/AIDS epidemic in the 1980s, significant advancements have helped transform HIV from a life-threatening condition to a lifelong manageable condition [11]. This turning point in the management of HIV can be attributed to multiple factors, including the availability of efficacious antiretroviral therapy, which extended the life expectancy of people living with HIV [11]. Availability and access to lifesaving HIV treatment to a large population across the globe became possible through increased concerted political and advocacy efforts enabled by new global initiatives like the Global Fund to Fight AIDS, Tuberculosis and Malaria and the United States President's Emergency Plan for AIDS Relief (PEPFAR) [12]. On the service delivery front, a key public health strategy in addressing the difficulties for patients in accessing treatment in sSA was to decentralise medical treatment to the primary care level, providing it as close to the patients as possible [13]. A novel approach to treatment delivery has been to engage and train lay community caregivers and peer-patients in the distribution of medicines and provision of care, based on patients' needs, within community and home-settings [14]. The experimentation with this approach was born out of challenges experienced with health workforce shortages in the region, and the absence of adequate medical personnel to provide care to HIV patients within facility settings [13]. At the community level, the existence of community and home-based care (CHBC) programmes, mostly led by faith-based and civil society organisations, were instrumental in supporting and linking HIV patients to a broad range of health and social services [15, 16]. More importantly, funding support for the formation of grassroot patient organisations helped catalyse patient involvement in care, and the establishment of peer-to-peer support services, ranging from provision of health education, distribution of medicines and referring patients for testing and treatment, to tracking patients lost to care [17].

Notwithstanding these advancements, there has also been mounting criticism to the manner in which the HIV response has evolved [12, 18]. While advocacy and global solidarity on HIV over the years resulted in the expansion of funding, predominantly from international agencies, the earmarking of funds for HIV has not allowed countries to reallocate some of these funds to other pressing health concerns including health systems strengthening [19, 20]. Furthermore, the exceptional status accorded to HIV has resulted in the creation of parallel structures within some national health systems, using different reporting systems, supply chain systems for HIV commodities, and dedicating a cadre of staff solely for HIV programmes [12, 19]. It is argued that this approach undermines the delivery of general healthcare, and weakens the overall functioning of national health systems [21, 22].

The existing HIV service infrastructure and the experiences in sSA with managing HIV as a long-term condition are very valuable assets, provided they can be utilised more broadly. With the rise of comorbidities among HIV infected patients, such as tuberculosis co-infections and more increasingly NCDs [23], there is demand for a coordinated approach in providing HIV care together with other services, as well as provision of comprehensive services to meet the different needs of patients, especially at the point of primary care [10]. This is arguably a cost-effective approach, given the scarcity of resources in most sSA health systems [10]. Furthermore, with some of the more recent policy changes on HIV care such as universal test and treat, the cohort of patients on long-term treatment is anticipated to rise even further, thereby raising treatment costs for individual countries [24]. There is available evidence of programmatic efforts to integrate services for HIV with other chronic conditions through reorganisation of health system inputs and healthcare delivery processes, although this is limited by weak infrastructure, an overstretched health workforce, and financing heavily dependent on foreign aid directed towards specific diseases, which in the long-run undermines efforts towards integrated initiatives [25, 26]. Responding to these growing challenges into the future calls for breaking away from disease-specific efforts, and strengthening health systems that promote delivery of comprehensive and coordinated care.

HEALTH SYSTEMS RESPONSE TO NON-COMMUNICABLE DISEASES

The growing NCD epidemic bears significant costs for the global economy, with rising health expenditures and loss of human capital due to premature deaths and years lost to disability among adults in their productive years [1]. For patients living with NCDs, the need for continued treatment, multiple health facility visits and hospitalization has a toll on household spending on health, and increases dependency on family caregivers [27]. In response, the World Health Organization launched a Global Action Plan for the prevention and control of NCDs in 2013, which was endorsed by world leaders for implementation [28]. The global plan aims at strengthening national efforts in tackling NCDs, through the provision of a menu of policy options for implementation [28]. Key recommendations include the formation of national NCD coordinating structures at the ministerial level, and the prioritization of preventive measures to control modifiable risk factors at the population level, such as the use of tobacco and alcohol, physical inactivity and unhealthy diets, which are associated with the major NCDs (diabetes, cardiovascular diseases, cancers, chronic obstructive pulmonary diseases [28]), and more recently, fatty liver diseases [29, 30]. Alongside this global action plan, a package was proposed for low-income settings to provide essential non-communicable disease interventions at the primary care level [31]. Implementing these NCD policy prescriptions has been slow in sSA countries and varies greatly among nations. That is, the capacity at the primary

care level remains weak with notable gaps in fulfilling the minimum threshold requirements, for instance, presence of trained healthcare personnel, availability of recommended essential diagnostics and medicines, which hamper prevention, early diagnosis and treatment of NCDs [32-34]. At the governance level, national policy frameworks outlining the NCD response and coordination between health and non-health agencies remain underdeveloped [35, 36]. The United Nations Sustainable Development Goals reiterate the need for prioritisation of NCDs in national health agendas, in order to attain the envisioned one-third reduction in premature mortality from NCDs by the year 2030 [37].

CHRONIC DISEASE MANAGEMENT: MODELS OF CARE WITHIN SUB-SAHARAN AFRICAN CONTEXT

The concomitant burden of chronic communicable diseases and non-communicable diseases pushes sSA governments, and particularly their ministries of health, to rethink ways in which health care is currently organised. A key challenge for most sSA health systems is to reduce the reliance on models which facilitate the provision of acute episodic care [38], and embrace alternative approaches to health care which accommodate active case finding, early detection of diseases in patients, as well as regular monitoring of patients in care at both the facility and community level [10]. Experiences from high-income settings have shown that the effective provision of chronic care requires modifications in practice and organisation of services such as the delegation of tasks previously performed by physicians to non-physician providers, supporting healthcare teams with clinical guidelines and mentorship in chronic care, availability of self-management support resources for patients, and the provision of care centred around patient's needs [39-41]. The chronic care model, originally developed for use in the United States of America in 1996, embodies some of these salient features [42]. Its principles have been widely cited to guide the organisation of chronic care delivery in other country contexts [39]. Important elements of the model include the organisation of coordinated care through a robust referral chain, and the empowerment of and support to patients in managing their own health [42]. However, it has been critiqued for its dominant focus on the clinical aspects of chronic care, with limited attention to the broader social determinants of health including the system-wide factors that enable (or restrict) the optimal delivery of care. In response, WHO developed the Innovative Care for Chronic Conditions (ICCC) framework in 2002 [43], and situated chronic care within a community and policy environment [44], with a view to increase its transferability to other less advanced healthcare settings.

Various chronic care frameworks have since been adapted to suit specific country contexts in the sSA region [42, 43, 45]. For instance, South Africa developed the Adult Chronic Disease Policy framework for implementation at primary care level,

covering prevention and management of a broad range of chronic conditions [46]. Other countries, such as Uganda, Rwanda and Malawi, have rolled out models which combine HIV and NCD community-based screening and referral activities [47], and promote the establishment of chronic care clinics (both as stand-alone and as part of multi-purpose clinics) in remote settings [48, 49]. What is evident from these examples is the move towards combining or merging interventions from one disease programme with another, although the extent of integration will vary from model to model, and is largely determined by the policy environment and resources, including financial, to support such integration efforts. However, there is a dearth of evidence on the operationalisation and effectiveness of approaches within health systems in resource-limited settings for tackling the growing burden of chronic conditions, in order to understand which characteristics or features of these models are of particular relevance and use in such specific contexts. This thesis seeks to investigate this further by presenting a case study from a rural district in Malawi, focusing on patients living with various chronic conditions, and examining how community-based structures and the health system are responding to chronic care.

THESIS OUTLINE

The central research question of this thesis is:

What local innovations and practices exist for the self-management of patients living with chronic conditions and how do they contribute to patient outcomes, and to the delivery of responsive chronic care at the primary care level in Malawi?

Chapter 2 describes the various concepts and theories guiding this thesis. **Chapter 3** describes the research design and research sub-questions. It provides further contextual information on the research setting and the methods. To address the overarching research question, the thesis has been organised into two parts: The *first part* of the thesis (**Chapters 4 to 6**) utilise theories of health behaviour to investigate patients' and care providers' micro-practices, and innovations in self-management support for chronically-ill patients in Malawi, and discusses their impact on various self-management outcomes. The *second part* (**Chapters 7 and 8**) applies a systems approach and examines how the local health system is currently designed in Malawi, and which adaptations and innovations may be required to achieve chronic care at scale in the future. **Chapter 9** discusses the research, policy and practice implications of the findings presented in **Chapters 4 to 8**.

REFERENCES

1. World Health Organization. *Noncommunicable diseases country profiles 2018*. 2018. Available from: <https://apps.who.int/iris/handle/10665/274512>. [cited 2019 2 January].
2. GBD 2017 Disease and Injury Incidence and Prevalence Collaborators. *Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017*. *Lancet*, 2018. 392(10159): p. 1789-1858.
3. Maher D, Smeeth L, and Sekajugo J. *Health transition in Africa: practical policy proposals for primary care*. *Bulletin of the World Health Organization*, 2010. 88: p. 943-948.
4. The Joint United Nations Programme on HIV/AIDS. *UNAIDS DATA*. 2018. Available from: http://www.unaids.org/sites/default/files/media_asset/unaids-data-2018_en.pdf. [cited 2019 19 April].
5. Omran AR. *The epidemiologic transition: a theory of the epidemiology of population change*. *The Milbank Quarterly*, 2005. 83(4): p. 731-757.
6. Defo KB. *Demographic, epidemiological, and health transitions: are they relevant to population health patterns in Africa?* *Glob Health Action*, 2014. 7: p. 22443.
7. World Health Organisation. *Everybody business: strengthening health systems to improve health outcomes: WHO's framework for action*. 2007, World Health Organisation.
8. Geldsetzer P, Ortblad K, and Bärnighausen T. *The efficiency of chronic disease care in sub-Saharan Africa*. *BMC medicine*, 2016. 14(1): p. 127-127.
9. Aikins Ad-G, Unwin N, Agyemang C, Allotey P, Campbell C, and Arhinful D. *Tackling Africa's chronic disease burden: from the local to the global*. *Globalization and health*, 2010. 6(1): p. 5.
10. Samb B, Desai N, Nishtar S, Mendis S, Bekedam H, Wright A, Hsu J, Martiniuk A, Celletti F, Patel K, Adshead F, McKee M, Evans T, Alwan A, and Etienne C. *Prevention and management of chronic disease: a litmus test for health-systems strengthening in low-income and middle-income countries*. *Lancet*, 2010. 376(9754): p. 1785-97.
11. Rabkin M and El-Sadr WM. *Why reinvent the wheel? Leveraging the lessons of HIV scale-up to confront non-communicable diseases*. *Global Public Health*, 2011. 6(3): p. 247-256.
12. Bekker L-G, Alleyne G, Baral S, Cepeda J, Daskalakis D, Dowdy D, Dybul M, Eholie S, Esom K, and Garnett G. *Advancing global health and strengthening the HIV response in the era of the Sustainable Development Goals: the International AIDS Society—Lancet Commission*. *The Lancet*, 2018. 392(10144): p. 312-358.
13. Bemelmans M, Baert S, Goemaere E, Wilkinson L, Vandendyck M, van Cutsem G, Silva C, Perry S, Szumilin E, Gerstenhaber R, Kalenga L, Biot M, and Ford N. *Community-supported models of care for people on HIV treatment in sub-Saharan Africa*. *Tropical medicine & international health : TM & IH*, 2014. 19(8): p. 968-77.
14. Decroo T, Van Damme W, Kegels G, Remartinez D, and Rasschaert F. *Are expert patients an untapped resource for ART provision in sub-Saharan Africa?* *AIDS research and treatment*, 2012. 2012.
15. Aantjes C, Quinlan T, and Bunders J. *Integration of community home based care programmes within national primary health care revitalisation strategies in Ethiopia, Malawi, South-Africa and Zambia: a comparative assessment*. *Globalization and health*, 2014. 10(1).

16. Wringe A, Cataldo F, Stevenson N, and Fakoya A. *Delivering comprehensive home-based care programmes for HIV: a review of lessons learned and challenges ahead in the era of antiretroviral therapy*. Health policy and planning, 2010: p. czq005.
17. UNAIDS. *Chronic care for HIV and noncommunicable diseases. How to leverage the HIV experience*. 2011, Joint United Nations Programme on HIV/AIDS: Geneva, Switzerland.
18. Resch S, Ryckman T, and Hecht R. *Funding AIDS programmes in the era of shared responsibility: an analysis of domestic spending in 12 low-income and middle-income countries*. The Lancet Global Health, 2015. 3(1): p. e52-e61.
19. England R. *Are we spending too much on HIV?* BMJ, 2007. 334(7589): p. 344-344.
20. Dieleman JL, Haakenstad A, Micah A, Moses M, Abbafati C, Acharya P, Adhikari TB, Adou AK, Kiadaliri AA, and Alam K. *Spending on health and HIV/AIDS: domestic health spending and development assistance in 188 countries, 1995–2015*. The Lancet, 2018. 391(10132): p. 1799-1829.
21. Stange KC. *The problem of fragmentation and the need for integrative solutions*. The Annals of Family Medicine, 2009. 7(2): p. 100-103.
22. Mills A, Rasheed F, and Tollman S. *Strengthening health systems, in Disease control priorities in developing countries*. 2006. p. 87-102.
23. Narayan KV, Miotti PG, Anand NP, Kline LM, Harmston C, Gulakowski III R, and Vermund SH. *HIV and noncommunicable disease comorbidities in the era of antiretroviral therapy: a vital agenda for research in low-and middle-income country settings*. 2014, LWW.
24. Hayes R, Sabapathy K, and Fidler S. *Universal testing and treatment as an HIV prevention strategy: research questions and methods*. Current HIV research, 2011. 9(6): p. 429-445.
25. Haregu TN, Setswe G, Elliott J, and Oldenburg B. *Integration of HIV/AIDS and noncommunicable diseases in developing countries: rationale, policies and models*. International Journal of Healthcare, 2015. 1(1): p. 21.
26. Njuguna B, Vorkoper S, Patel P, Reid MJ, Vedanthan R, Pfaff C, Park PH, Fischer L, Laktabai J, and Pastakia SD. *Models of integration of HIV and noncommunicable disease care in sub-Saharan Africa: lessons learned and evidence gaps*. Aids, 2018. 32: p. S33-S42.
27. Kankeu HT, Saksena P, Xu K, and Evans DB. *The financial burden from non-communicable diseases in low- and middle-income countries: a literature review*. Health Research Policy and Systems, 2013. 11(1): p. 31.
28. World Health Organization. *Global action plan for the prevention and control of noncommunicable diseases 2013-2020*. 2013. Available from: http://apps.who.int/iris/bitstream/10665/94384/1/9789241506236_eng.pdf?ua=1. [cited 2014 18 Dec].
29. Paruk IM, Pirie FJ, and Motala AA. *Non-alcoholic fatty liver disease in Africa: a hidden danger*. Global health, epidemiology and genomics, 2019. 4.
30. Younossi ZM. *Non-alcoholic fatty liver disease—A global public health perspective*. Journal of hepatology, 2019. 70(3): p. 531-544.
31. World Health Organization. *Package of essential noncommunicable (PEN) disease interventions for primary health care in low-resource settings*. 2010.
32. Fairall L, Bateman E, Cornick R, Faris G, Timmerman V, Folb N, Bachmann M, Zwarenstein M, and Smith R. *Innovating to improve primary care in less developed countries: towards a global model*. BMJ Innov, 2015. 1(4): p. 196-203.

33. Mutale W, Bosomprah S, Shankalala P, Mweemba O, Chilengi R, Kapambwe S, Chishimba C, Mukanu M, Chibutu D, and Heimbürger D. *Assessing capacity and readiness to manage NCDs in primary care setting: Gaps and opportunities based on adapted WHO PEN tool in Zambia*. PLoS One, 2018. 13(8): p. e0200994.
34. Nyarko KM, Ameme DK, Ocansey D, Commeh E, Markwei MT, and Ohene S-A. *Capacity assessment of selected health care facilities for the pilot implementation of package for essential non-communicable diseases (PEN) intervention in Ghana*. The Pan African medical journal, 2016. 25(Suppl 1).
35. Atun R, Jaffar S, Nishtar S, Knaul FM, Barreto ML, Nyirenda M, Banatvala N, and Piot P. *Improving responsiveness of health systems to non-communicable diseases*. The Lancet, 2013. 381(9867): p. 690-697.
36. Nyaaba GN, Stronks K, de-Graft Aikins A, Kengne AP, and Agyemang C. *Tracing Africa's progress towards implementing the Non-Communicable Diseases Global action plan 2013–2020: a synthesis of WHO country profile reports*. BMC Public Health, 2017. 17(1): p. 297.
37. The United Nations. *Sustainable Development Goal 3; Ensure healthy lives and promote well-being for all at all ages*. 2015. Available from: <https://sustainabledevelopment.un.org/sdg3>. <https://sustainabledevelopment.un.org/sdg3>.
38. Allotey P, Reidpath DD, Yasin S, Chan CK, and de-Graft Aikins A. *Rethinking health-care systems: a focus on chronicity*. Lancet, 2011. 377(9764): p. 450-1.
39. Davy C, Bleasel J, Liu H, Tchan M, Ponniah S, and Brown A. *Factors influencing the implementation of chronic care models: A systematic literature review*. BMC family practice, 2015. 16(1): p. 102.
40. Elissen A, Nolte E, Knai C, Brunn M, Chevreul K, Conklin A, Durand-Zaleski I, Eler A, Flamm M, Frolich A, Fullerton B, Jacobsen R, Saz-Parkinson Z, Sarria-Santamera A, Sonnichsen A, and Vrijhoef H. *Is Europe putting theory into practice? A qualitative study of the level of self-management support in chronic care management approaches*. BMC Health Serv Res, 2013. 13: p. 117.
41. Holman H and Lorig K. *Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care*. Bmj, 2000. 320(7234): p. 526-7.
42. Wagner EH, Austin BT, and Von Korff M. *Organizing care for patients with chronic illness*. The Milbank Quarterly, 1996: p. 511-544.
43. World Health Organization. *Innovative care for chronic conditions: building blocks for actions: global report*. 2002. Available from: <http://www.who.int/chp/knowledge/publications/icccglobalreport.pdf>. [cited 2014 18 Dec].
44. Epping-Jordan JE, Pruitt SD, Bengoa R, and Wagner EH. *Improving the quality of health care for chronic conditions*. Quality and Safety in Health Care, 2004. 13(4): p. 299-305.
45. Barr V, Robinson S, Marin-Link B, Underhill L, Dotts A, Ravensdale D, and Salivaras S. *The expanded chronic care model*. Hosp Q, 2003. 7(1): p. 73-82.
46. Draper CA, Draper CE, and Bresick GF. *Alignment between chronic disease policy and practice: Case study at a primary care facility*. PLoS ONE, 2014. 9(8).
47. Chamie G, Kwarisiima D, Clark TD, Kabami J, Jain V, Geng E, Petersen ML, Thirumurthy H, Kamya MR, and Havlir DV. *Leveraging rapid community-based HIV testing campaigns for non-communicable diseases in rural Uganda*. PloS one, 2012. 7(8): p. e43400.

48. Bukhman G and Kidder A. *The PIH guide to chronic care integration for endemic non-communicable diseases*. Rwanda Edition ed., 2011, Havard Medical School: Partners in Health.
49. Wroe EB, Kalanga N, Mailosi B, Mwalwanda S, Kachimanga C, Nyangulu K, Dunbar E, Kerr L, Nazimera L, and Dullie L. *Leveraging HIV platforms to work toward comprehensive primary care in rural Malawi: the Integrated Chronic Care Clinic*. *Healthcare* (Amsterdam, Netherlands), 2015. 3(4): p. 270-6.