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SUMMARY

Chronic conditions are one of the largest contributors to global mortality and the provision of long-term care places its toll on government health spending. Health systems in sub-Saharan Africa experience a host of challenges, including infrastructural and health workforce capacity constraints, to adequately respond to this growing health problem. African governments are under pressure to reconfigure health services structures and develop tailored interventions to meet the changing healthcare needs of this patient population. Available evidence recommends the application of patient-centred care approaches and integration strategies. Lessons from the HIV/AIDS response serve as a resource in the decentralisation of care and utilisation of community-based programmes to bring chronic care services closer to patients. Wagner's chronic care model and the Innovative Care for Chronic Conditions (ICCC) framework developed by the World Health Organisation are applied in this thesis to understand their relevance and utility in organising chronic care in resource-limited sub-Saharan African settings.

The central research question addressed by 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?

The thesis applies a case study approach, and uses concurrent mixed-methods data collection to answer three interrelated sub-questions. The research setting is a rural Malawian district within which five community home-based care programmes serve as study units. Data is drawn from surveys, structured observations, focus group discussions, and in-depth interviews involving different categories of participants. That is, patients with different chronic conditions, family caregivers, community health volunteers, health care providers, and managers. The evidence from this research is presented in two sections.

Part 1 — Self-management practices, support initiatives, and outcomes for chronically ill-patients

Chapter 4, a qualitative study, explores the self-management practices of patients with different chronic conditions and their strategies to overcome care challenges in rural Malawi. The analysis shows that while patients demonstrate the ability to self-manage conditions, their practices differ and are influenced by individual and external factors such as: the patient's ability to acquire appropriate disease knowledge; socio-economic status; the presence of support from family caregivers and community-based support initiatives; the nature of a patient's social relations; and the ability

to deal with stressors and stigma. Differences were observed among HIV and NCD (including HIV comorbid) patients, in terms of their access to care and support. NCD patients experience notable challenges in meeting their healthcare needs at the primary care level. These challenges are attributed to frequent drug stock-outs and out of pocket expenses, when referred, resulting in delayed care, poorer treatment adherence, and an increased likelihood of poorer treatment outcomes in patients with NCDs and HIV comorbidities. Bandura's Social Cognitive theory helps us understand the underlying mechanisms of a patient's adaptiveness, whereby patients create internal models based on their successful management of past experiences/events to deal with current challenges (symbolising); or avoid situations causing distress (self-regulation); or observe and learn complex skills from others such as peers in support groups (vicarious learning). The study concludes with recommendations to expand peer-patient and support group initiatives for patients with NCDs, and to invest in the decentralisation of integrated health services especially at the primary care level.

The study in **Chapter 5** utilises a mixed-methods design and draws from perspectives of chronically-ill patients and healthcare professionals to characterise the nature and forms of self-management support available in rural Malawi. The chapter further deconstructs the concept of patient empowerment in chronic care and how it is being practiced. Providing appropriate education and productive patient-provider interactions are critical in the facilitation of patient empowerment. The analysis shows mixed practices in the information exchange during clinic consultations. Healthcare providers' focus mainly on the medical aspects and behaviour modification, and pay less attention to activating a patient's own role in care. Health education tends to be unstructured and delegated to non-physician providers, who are mostly untrained in chronic care. At community level, volunteer-led community home-based care programmes offer patients and family caregivers' psychosocial support and emotional encouragement, but programmes are confined in their scope of activities due to limited programmatic resources and volunteers' competence. Patient support groups are valued for offering an enabling environment to deal with stress, positively reinforce health advice, and promote collective problem-solving approaches. The study recommends the establishment of more inclusive support groups, enhancement of family caregivers' agency in care, and the improvement of care providers' technical competence in chronic care so as to promote the practice of patient-centred care within this setting.

Chapter 6 utilises a pre-and post-evaluation survey to investigate the impact of community-home based care (CHBC) programmes on self-management outcomes of chronically-ill patients in rural Malawi. The analysis shows during the 12-months period of CHBC visits, there is a reduction in patient-reported pain, fatigue, and illness intrusiveness. The propensity for improvement in patient's self-efficacy is associated with socio-demographic characteristics (i.e. literacy, employment, and marital status) and condition-related factors that is, better for HIV patients, and patients who have

no comorbidities. Furthermore, prolonged exposure to CHBC interventions positively impacts on self-management outcomes. Programmes that regularly conduct home visits are associated with higher self-efficacy scores and report higher levels of patient satisfaction with CHBC support. The sustainability of CHBC programmes and their effectiveness emerged as key priority areas. The need for sustainable financing of volunteer-led programmes and their entrenchment in government-led health strategies is critical, as they play an important role in delivering home-based interventions and provide essential services in the continuum of care for chronically-ill patients.

Part II — Organisation of chronic care – current practices, innovations, adaptations, and policy directions

Integrated care is recognised as an approach that is central to the management of chronic conditions. Using Valentijn's integrated care framework, Chapter 7 explores this concept within the context of a rural Malawian district experiencing a double burden of HIV and NCDs. The study investigates the extent to which national and district health policies and strategies articulate the concept of integrated care, and how this is translated in the organisation of chronic care services, particularly at the primary care level. Healthcare providers and managers shed light on their experiences of integrating care, and the complexities they encounter while attempting to integrate different disease-specific programmes at the point of care. The analysis shows that integration efforts are severely hampered by human and health resource challenges, for instance inadequate consultation rooms and an overstretched health workforce. As a way forward, the study recommends expanding community-based outreach services to offer multi-disease screening and care; strengthening general primary care services and referral linkages; applying a pragmatic approach in addressing the health workforce crisis through careful task delegation that is supported by proper training and incentive mechanisms; and pursuing collaborative partnerships between public and private sector actors with a view to expand the resource-base and promote cross-programme initiatives.

Chapter 8 reviews the introduction and implementation of Malawi's national community health strategy and the implications of this strategy on existing community health volunteer (CHV) structures. The various functions of the proposed community health team are critically examined and the position of CHVs critiqued. While there is merit in the strategy's important attempt to harmonise the multiple health service structures at the community level, the anticipated challenges which may impede its implementation include: a minimally defined community-level health package for patients with NCDs; ambiguity over CHVs job description; potential overlaps in the proposed coordination structures; and financial challenges to implement the strategy at the district level. To further strengthen Malawi's community health system, the chapter concludes with recommendations to explore

the possibility of co-opting trained CHVs from existing volunteer-programmes into the government-led community health teams (supported by a policy addendum which clearly outlines the task-shifting strategies); to strengthen the coordination mechanism and communication across all community actors; and to actively search for innovative and sustainable financing in order to implement the strategy at scale.

CONCLUSION

The research presented in this thesis contributes to a better understanding and conceptualisation of chronic disease management in resource-limited sub-Saharan African settings, with a focus on the community and primary care level. The findings highlight that, despite the structural and health system level challenges present in rural Malawi, chronically-ill patients develop mechanisms to adapt and self-manage their conditions under these circumstances. The generated evidence underscores the critical role patients play in their own care and the relevance of moving towards a patient-centred care approach in the health care settings we studied. Peer-driven initiatives and volunteer-led community-based programmes play an important complementary role in offering patients with self-management resources and positively impact self-management outcomes. However, their optimal performance depends on strengthening their resource-base and linkages with frontline health facilities. As Malawi and many other African countries reorient their healthcare systems towards the provision of chronic care in a more consolidated and coordinated manner, there is a growing need to integrate the different disease-specific programmes through accommodative policies, and build on the synergies between public and private sector providers. Additionally, establishing a critical mass of multi-purpose care providers, both within and outside healthcare facilities, who are equipped with the knowledge and technical skills to serve chronically-ill patients, regardless of the nature of their condition.