Dissertation Summary
The role of community mobilization in the promotion of maternal health of women living with HIV in Zambia - Summary

The main aim of this dissertation is to investigate the role of community mobilization in the promotion of maternal health in women with HIV in Zambia. **Community mobilization** in maternal health is defined as any maternal health promotion strategy which makes use of a) *indigenous resources* (such as Traditional Birth Attendants-TBAs), b) *peer support*, and c) *community involvement* in designing and implementation of maternal health initiatives. Maternal health remains a challenge in low income countries. Studies show that on average, in Sub-Saharan African (SSA) countries, 720 women die each day during pregnancy and childbirth from causes which are largely preventable. The situation is even worse for women living with HIV. It is estimated that women living with HIV are four times more likely to die during pregnancy and childbirth than HIV negative women. HIV positive women suffer intersecting vulnerabilities. This is through a combined burden of pregnancy-related complications and HIV status (which predisposes them to optimistic infections including stigma and discrimination). The traditional response to this predicament has been to recommend the evidence-based biomedical response which normally focuses on modernizing and improving quality of care through the provision of drugs, advanced equipment and skilled personnel, improved infrastructure etc. However, although these recommendations are useful, evidence has consistently pointed out that these recommendations are costly and as such they are never sustainably implemented in poor settings. It is for this reason why community mobilization is being suggested as a useful approach in such contexts. Gaps in knowledge still remain regarding how useful community mobilization is to women living with HIV.

Therefore, the main aim of this dissertation is to provide insights on the role of community mobilization in the promotion of maternal health in women with HIV in Zambia.

**Chapter 1**

In this chapter we provide an exploration of the concept of community mobilization. The chapter further shades light on the maternal health outlook of Zambia including the health system in Zambia in general and Mfuwe (our study area for the qualitative part of the dissertation) in particular. Further, we explain the objectives and methods used in subsequent chapters of the dissertation. The following are the objectives of the dissertation highlighted in chapter 1:
Objective 1: To outline the role of community mobilization in SSA countries:

Given the fact that, currently, there is a lack of synthesized empirical evidence of the role of community mobilization on maternal health outcomes of women living with HIV in SSA, a thorough search, analysis and documentation of this evidence was necessary. This was an important basis for demonstrating what has been studied and not studied, and where exactly the main gaps lay vis-à-vis community mobilization and maternal health in SSA. Thus by relying on systematic review technique, the first objective was to map-out the evidence available in the extant literature, and to also gain insists into the general operationalization of the concept of community mobilization.

Objective 2: To investigate the role of community mobilization in women living with HIV in rural areas in Zambia:

While the evidence on the role of community mobilization was more conclusive in HIV-negative women, similar evidence for women living with HIV was missing. Therefore, we use a qualitative study design to investigate the role of community mobilization in women living with HIV in resource-poor settings by using Mfuwe, Zambia, as a case study. Mfuwe is a rural settlement located in the South Luangwa national park in the Eastern province of Zambia. There exits only one hospital in Mfuwe (Kamoto hospital) catering for a population of over 207,000 people spread roughly around an area of 370 km². The settlement retains some of the highest HIV rates, including very high maternal and under five mortality rates in the country. It is for this reason that Mfuwe was selected as a case study. This specific objective was expected to yield useful insights by detailing specific ways community mobilization is useful for women with HIV in Zambia.

Objective 3: To investigate the usefulness of TBAs on maternal health care of women living with HIV in rural areas in Zambia:

Out of the three components of community mobilization, indigenous resources, and in particular TBAs, play a dominant and controversial role in maternal care of women with HIV in Zambia. Thus it becomes important to provide more insights on the role of TBAs on the maternal care of women living with HIV. This objective is achieved through the use of a qualitative research design to investigate the relevance of TBAs to women living with HIV in resource poor settings by using Mfuwe, Zambia, as a case study.
• **Objective 4:** To investigate and compare factors affecting choice of care (TBAs or professional care service) between HIV negative women and women living with HIV:

There is growing evidence which suggests that HIV positive women are more vulnerable than those who are not. However, the relationship between HIV status and maternal-care-utilization is not very well understood. It is not clear whether factors associated with professional maternal care utilization are similar for HIV positive and HIV negative women. Thus it becomes important to investigate the differences in factors affecting choice of maternal care (TBAs or professional care service) between HIV positive and HIV negative women. Other than that, it is also necessary to investigate the effect of HIV positive status on the utilization of professional maternal care. For this reason, we make use of the 2013-2014 ZDHS and quantitative methods to investigate factors which affect the choice of maternal care service between women with HIV and those who are HIV negative.

• **Objective 5:** To investigate and compare the effect of choice of care (TBAs or professional care service) between HIV negative women and women living with HIV on under-five mortality:

After establishing factors affecting choice of care between HIV negative and women living with HIV, it becomes necessary to assess the effect of this choice on biomedical outcomes such as under-five mortality. For this purpose, we take the discussion further by investigating the impact of choice of care on under-five mortality by comparing outcomes between women with HIV and those who are negative. Here we also make use of the 2013-2014 ZDHS and quantitative methods.

**Chapter 2**

Chapter 2 provides a systematic review of the literature on the existing empirical evidence on the role of community mobilization in maternal care provision of women living with HIV in SSA. The evidence on the role of community mobilization in maternal care provision in general (both HIV positive and HIV negative women) is also reviewed. This was done through a systematic search of existing literature on the role of community mobilization in PubMed, Scopus, Web of Science, MEDLINE, COCHRANE, Allied Health Literature, and Cumulative Index to Nursing. We only include studies with an experimental design in order to identify causal effects. Strong evidence for causal inference is a useful basis for establishing definitive conclusions. Our review identified 14 publications for analysis. These papers were divided into two categories: those that involved HIV negative women (category 1) and those that involved women living with HIV (category 2). For
category 1 (HIV negative) we had nine articles, and for category 2 (women living with HIV) we had five articles. Results from this chapter show that regarding HIV negative women, community mobilization is a useful strategy for promoting both positive maternal process results and maternal health outcomes. However, most of the literature on women with HIV has focused only on demonstrating the causal link between community mobilization and process results. There has been very little focus on demonstrating the causal link between community mobilization and maternal outcomes for women living with HIV. Overall, the results from this chapter show that while there is strong causal link between community mobilization and maternal health outcomes for HIV negative women, this kind of evidence is still missing for HIV positive women. Moreover, as shown by the studies, community mobilization as a maternal health strategy is still in its infancy. The chapter therefore concludes that given the gaps identified in our review, there is a need for further research which should aim at providing sound evidence on the role of community mobilization on maternal health outcomes of women with HIV in SSA.

Chapter 3

On the basis of recommendations from chapter 2, chapter 3 provides a qualitative study exploring the relevance of community mobilization in the promotion of maternal health care among women living with HIV in resource-poor settings by using Mfuwe, a rural district in Zambia as a case study. For this purpose, we collected data through Focus Group Discussions (FGDs). Our participants included 37 women living with HIV. Our results showed that within their social fabrics, resource-poor communities often contain unrecognized and sometimes ignored strategies which are contextually-feasible and have been used for generations to promote maternal care of HIV positive women. Further, it was evident that although the three forms of community mobilization were largely useful in promoting maternal health care of women living with HIV, they also presented unique and various shortcomings. This chapter therefore shows that women living HIV characterize community mobilization as a force for good (e.g. providing support, improving access to maternal care etc.) and sometimes for bad (e.g. reinforced harmful misconceptions, superstition and clichés). Thus we recommend that community mobilization needs to be factored into maternal health care policies for HIV positive women in resource poor settings either to optimize its potential benefits or to minimize its potential harm. This chapter also highlighted the unfinished debate on one of the three components of community mobilization; namely, use of indigenous resources and in particular, TBAs. The debate is on whether it is beneficial to HIV positive women for the
government of Zambia to ban TBAs from the line of care. This debate informs the aims of the next chapters.

Chapter 4

In this chapter, we take the discussion on TBAs further by assessing the relevance of TBAs to women living with HIV in resource poor settings by using Mfuwe, Zambia as a case study. For this purpose, we undertake a qualitative study in Mfuwe consisting of two FGDs, one involving HIV positive women utilizing TBAs and the other with HIV positive women not utilizing TBAs. Additionally, in-depth interviews were conducted with TBAs and health workers. Our findings from this chapter suggest that in the face of an inefficient health system, TBAs were seen to be useful in providing efficient, cheap and quality care. This was exemplified through counselling, referral and logistical support to HIV positive women, including treatment-adherence support which are collectively known as ‘soft-services’. This chapter also establishes that HIV positive women do indeed need professionals to handle complications and access antiretroviral treatment to ensure Prevention of Mother to Child Transmission (PMTCT). However, additional “soft” services offered by TBAs are equally important in the promotion of maternal health care for HIV positive women. Thus, it seems there is more to gain by systematically allowing TBAs work alongside professionals in a well-coordinated and complementary manner.

Chapter 5

Chapter 5 focuses on investigating the differences in use of antenatal, delivery and postnatal health service between HIV positive and HIV negative women. We also investigate the effect of HIV positive status on the utilization of professional maternal care during antenatal, delivery and postnatal periods. To do this, we use the 2013-2014 ZDHS to perform two different quantitative analyses: a) Regression analysis: to identify and compare factors associated with the likelihood of utilizing professional care during antenatal, at birth and postnatal periods between HIV positive and negative women. b) Propensity score matching: to investigate the effect of being HIV positive on the choice of care (Professional care or TBAs). Our findings in this chapter show that there are no differences between HIV positive and HIV negative women in factors that are associated with choice of care during antenatal, at birth and postnatal periods. More wealth, high level of education and urban-residence seem to increase probability of utilizing professional care in both HIV positive and HIV negative women. Further, we showed that although the probability of utilizing professional
care for HIV positive appears to be slightly higher than those who are HIV negative, the difference is small. We also show that although institutional care is desirable and an ideal solution for HIV positive women, insisting on exclusive institutional care (which is ideal) while ignoring the many challenges and barriers that exist within professional care in Zambia is counterproductive. The chapter ends by recommending further investigation on the effect of choice of care (skilled or TBAs) on maternal outcomes such as under-five mortality.

Chapter 6

This chapter concentrated on investigating the effect of using professional maternal care or TBA care (during antenatal, delivery and postnatal) on under-five mortality. We also compare these outcomes between HIV positive and HIV negative women. By relying on the 2013-2014 ZDHS, we use Propensity Score Matching to investigate the effect of utilization of professional care or TBA during antenatal, childbirth and postnatal periods on under-five mortality. Our results show that the use of professional care (as opposed to TBAs) in all three stages of maternal care increases the probability of children surviving beyond five years old. However, although there is a positive impact when mothers choose professional care over TBAs, the difference at all three points of maternal care is small. We therefore conclude that indeed, professional care is desirable and appears to be an ideal solution for reducing under-five mortality of children, but completely excluding TBAs and insisting only on professional care when the health facilities in Zambia, especially in rural areas, continue to lack adequate trained personnel, drugs, and equipment seems counterproductive. Our results in this chapter highlight an opportunity for improving maternal care by incorporating, regulating and making use of TBAs in a complementary manner. From this end, it seems plausible that integrating TBAs in the response unit rather than excluding them may make it easier to mitigate their shortcomings, amplify their potential benefits, regulate, and monitor them in a manner that complements institutional care.

Chapter 7

This chapter focuses on discussing the main findings of the dissertation (Chapter 1-6). We also highlight some policy implications and recommendations for future research. Firstly, overall findings from chapter 1-6 indicate that in the face of a poorly-resourced government and inefficient health system, women living with HIV in Zambia rely on community mobilization (support from peers, TBAs, and community-led and collaborative initiatives) to improve maternal health outcomes. In
this regard, we show that that even though local communities in Zambia lack proper health centers, their survival over generations has been dependent on social networks, reliance on locally-available resources and collective action. Relying on these resources in the face of weak health institutions made access to the much-needed care possible. This argument is presented not as a critique to highly-functional and accessible professional care, but rather as a confirmation that local people are not passive victims of failed health systems. Communities are aware of the importance of professional care, but their attachment to community resources (in the absence of professional care) reflects the need to develop useful local alternative strategies nonetheless.

We further demonstrate that community-strategies are characterized as “useful and effective” by local people and in some cases they produce under-five mortality results that are not all that different from those of professional care. Locals remain loyal to practically feasible and locally-available solutions (albeit their limitations) rather than putting their faith in attractive yet unavailable solutions (in the form of efficiently operational facilities). We further highlight that TBAs and skilled care givers have comparable effects in so far as under-five mortality is concerned in both HIV positive and negative women. It is for this reason that we demonstrate that the policy to exclude TBAs on grounds that they produce significantly worse outcomes is misplaced in the absence of good quality professional care. This finding reflects the fact that taking into account local worldviews and context-specific realities is crucial in handling maternal health challenges especially in women with HIV in resource poor settings.

We also show in chapter 7 that ignoring or excluding components of community mobilization in maternal health care of women with HIV obliterates the opportunity to maximize their benefits and minimize their costs. It is effectively a ‘lose-lose’ situation. The dominance and subsequent universalization of the evidence-based biomedical approach in maternal health has become pervasive in resource-poor settings. ‘Wholesale’ transposition of global initiatives in local settings in SSA in maternal health policy should be looked at critically. In this sense, future policies need to depart from top-down global prescriptions which do not take into account localized-realities. The idea that ‘because it worked there it must therefore work here’ is pervasive in the fight for better maternal health outcomes for women with HIV in SSA. Policies on maternal health should take into account the contrasting outcomes and characterization of popular global maternal health initiatives between wealthier and resource poor settings. Rather than establishing the biomedical approach as an
incontestable good for all contexts, it is important to interrogate its suitability for different contexts especially in resource poor settings.

We end by demonstrating that community mobilization offers space for engagement between externally-imposed interventions and local people in a manner that allows for improved maternal care and outcomes in women with HIV in resource-poor settings. It was clear from the dissertation that both local and global strategies have useful elements and shortcomings; the two are also not mutually exclusive, meaning that they can complement rather than replace each other. As such, responding to maternal health needs in Zambia requires cooperation between professional care and the community. Community mobilization offers an opportunity for open recognition and dialogue between local and global strategies in an effort to build partnerships. This leads to strengthening of maternal health response in a manner that is regulated, feasible, contextually-suitable and beneficial. It was clear that maternal health policy would benefit from community mobilization which offers space for engagement between local and global in a context-specific way. There is more to benefit from sustained and careful engagement of local and global initiatives via community mobilization.