Responding to chronic illness

A case study from rural Uganda

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Abstract

This thesis explores the individual and household-level factors that determine households' responses to and ability to cope with chronic illness of adults, as well as with the stresses from the wider environment, in a rural Ugandan context. Over a period of one year, in 2009/2010, monthly visits were made to 22 households that were part of a cohort that accessed free healthcare from the Medical Research Council of Uganda. Data was collected through in-depth interviews including life histories and observations. The material was continuously analysed and data collection refined over the course of the year, and later the three most important themes arising from the material were developed into papers.

The three major findings were; 1) the lifecycle-stage of a household influenced response strategies and outcomes during chronic illness, and households headed by the elderly (those with household heads over the age of 60) were an especially vulnerable group, 2) Social relations and broader social protection is key for minimising financial hardships in households with chronically ill individuals, even with free healthcare, as locally prevailing factors such as poor transportation services, food shortages and droughts still cause economic loss during ill health, and 3) the elderly are in an especially vulnerable situation due to their shrinking asset base as well as due to trends in the wider environment, such as increased schooling of children and out-migration of young people, which means they risk being left in rural areas with inadequate access to care and support.

Addressing the needs of individuals and households with chronic conditions requires health systems to focus on both medical factors and the broader context-specific social determinants of health. The unique case of a population accessing free healthcare made it possible to observe the factors that could still hinder access to the available care, and the needs, aside from purely medical concerns, that had to be met in order to cope with illness. The highlights from the thesis help to fill gaps in knowledge on how health systems could improve and maintain health outcomes during chronic illness in similar low-income settings. It must also be acknowledged that households are all different, and that solutions that are successful at one point might prove less suitable in a changing context that demands continuous attention and flexible policies.

Key words: Rural, Households, Chronic Illness, Life Cycle Stage, Universal Health Coverage, Social Determinants of Health, Contextual Factors, Socioeconomic Changes, Uganda.

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Preface

I grew up in a rural area in eastern Uganda as the ninth of 10 siblings. My father lost his job due to the restructuring of the public sector. He later disappeared or was kidnapped during the political instability of the 90s, leaving my mother to raise the family alone. It was a challenging start to my life: being female, living in a rural, low-income area, and losing my father (the major breadwinner). I survived thanks to my mother. Although she did not have the benefit of a school education herself, she had a number of values that she believed were basic for survival – one of these was the importance of education. Despite our family's financial difficulties, she believed that investing in education would contribute to her children having a better future. She said;

> Setting your foot on a school ground is an eye-opener. Everyone should receive an education enough to read at least the billboard on the highway that says, 'Welcome to Kampala'; to be sure they can find their way.

She focused on giving every family member the opportunity to acquire a minimum level of education. This included taking some drastic decisions such as fostering out some of my siblings to relatives who needed help. In exchange for this help, these relatives provided food, shelter and school fees to my siblings. Because of my mother's commitment to education, I was able to go to school and then continue my studies all the way up to university. This is an unusual trajectory, especially for a girl, from the rural areas in Uganda. My personal experience is directly responsible for my enthusiasm to engage in research that could contribute to evidence-based policy development in Uganda and other developing countries, particularly regarding health issues in rural areas.

Health policy makers around the world are interested in maintaining and improving the health and well-being of populations. Approaches and strategies, such as improving access to healthcare, vary across countries, but also within countries, for example between rural and urban areas. My personal experience has been that a number of factors play an important role in health and well-being. Having healthcare facilities, which provide free treatment, in the vicinity may be effective in urban areas where other infrastructure is in place. In rural areas, however, health facilities also need additional infrastructure such as roads and public transport, and if travel distances are great, food and accommodation facilities may also be necessary to improve access to healthcare. Equally important is investment in health promotion measures to improve other aspects of health and welfare, which can help to limit the demand on healthcare services.

For example, my mother believed in the importance of having a health facility in the vicinity, which could provide timely treatment for malaria, and helping women to give birth. This was underlined when she lost her 11th child a few hours after delivery due to the long distance to the closest healthcare facility. She also understood that access to sufficient food was important for health and wellbeing. In my family's case, having no breadwinner and thus no income, we had only one, or even half a meal a day. My mother addressed this challenge by starting to farm, an option which is possible in rural areas. She relocated the family from the city where we were living, to a country farm. She understood that by having the family in a rural area there would be more opportunities to grow enough food, part of which could be sold to pay school fees.

Living in the village had its challenges, however. The schools were far away. The distance to the closest healthcare facility was more than 15 kilometres, and the facility itself was poorly equipped. Roads were poor and public transportation was not easily available. The common means of transport in rural areas is by bicycle, which families borrowed from each other in case of emergencies such as complicated child deliveries, or high fevers in children. Once my mother carried me on her back to the health centre, but when we arrived there, there was neither a doctor nor medicine. The journey took 12 hours. In acute health situations, every minute that passes may be critical for survival, and if a hospital lacks basic resources, it may not be able to provide any help. I experienced this when one of my brothers was involved in a motor accident. Although we were able to get him to a local hospital, he died after 2 days, as the facility had no electricity, no water, no medicines, and only a nursing assistant.

There is a growing trend of young people moving to more urban settings both for further schooling and later to obtain formal employment. This was also true for my siblings and me. However, this means that older family members are then left alone to deal with issues such as poverty and poor health, which become increasingly problematic with age. The elderly are also less able to manage the physical tasks of farming, and are more vulnerable to hunger during drought and disease. The sole sources of income for these ageing family members are the remittances sent by family members who have moved to the city. This was the case in my family as well, as my mother remained alone in her rural home, and in poor health. Apart from remittances from my siblings and me, she has no formal social security earnings, such as a pension. Having access to remittances is therefore important, especially as the harvesting potential for ageing people decreases, a situation that is aggravated by poor rain, less fertile soil, and less energy for performing farming activities.

My family situation is not unique, rather it is common in many rural families in Uganda. In a time of increasing interest in national health systems and health

policy, I became interested in investigating rural health in Uganda, particularly with respect to how households respond to challenges such as access to health care and ageing. While the area where the data for this thesis was collected is not my home area, I recognise many of the experiences that people narrated as experiences that are common in rural Uganda.

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I am grateful to the Medical Research Council, specifically the Head of the Social Science Unit Janet Seeley and the Executive Director of the Uganda Virus Research Institute, Pontiano Kaleebu, for the funding and for allowing me to collect data from the General Population Cohort, which was used in this thesis. I also wish to thank the two Research Assistants, Grace Tumwekwase and Fatuma Ssembajja, who worked closely with me in the data collection process. Special thanks go to the households that participated in the study. I also want to thank the International Foundation for Science (IFS) for awarding me the Young Scientists Fund which was used for collecting data for this thesis.

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Contents

List of publications

This thesis is based on the work contained in the following papers, referred to by Roman numerals in the text:

I. Amurwon, J., Hajdu, F. & Seeley, J. (2015). The relevance of timing of illness and death events in the household life cycle for coping outcomes in rural Uganda in the era of HIV. *International Journal for Equity in Health*, 14 (105). Open Access.

II. Amurwon, J., Hajdu, F., Bukenya Yiga, D. & Seeley, J. (2017). "Helping my Neighbour is Like Giving a Loan . . ." –The Role of Social Relations in Chronic Illness in Rural Uganda. *BMC Health Services Research*, 17 (105). Open Access.

III. Amurwon, J. (2018). "It's like I never had a child of my own": Care and support for the elderly in a changing socio-economic context in rural Uganda. *Gerontology Series b*. doi:10.1093/geronb/gby094.

My contribution to the papers included in this thesis was as follows:

I. I collected the data for the paper, in cooperation with the research assistants. Janet Seeley was in charge of the larger study in which my study was a part. I had the idea for the paper and developed it in discussion with Flora Hajdu. I did the data analysis for the paper, discussed the results with Flora, and wrote the first draft of the paper. Flora Hajdu commented extensively and added to the text. Janet Seely commented on the final version of the paper. I was communicating author.

II. I collected the data for the paper, in cooperation with the research assistants. Janet Seeley was in charge of the larger study in which my study was a part, Dominic Bukenya Yiga was the Social Science Unit Coordinator. I had the idea for the paper and developed it in discussion with Flora Hajdu. I did the data analysis for the paper, discussed the results with Flora, and wrote the first draft of the paper. Flora Hajdu commented extensively and added to the text. Janet Seely and Dominic Bukenya Yiga commented on the final version of the paper. I was communicating author.

III. I collected the data for the paper, in cooperation with the research assistants. I had the idea for the paper, did the data analysis and wrote the paper. Flora Hajdu commented in the role of supervisor. I was communicating author.

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral
DFID	Department for International Development
GPC	General Population Cohort
HIV	Human Immunodeficiency Virus
IFS	International Foundation for Science
MRC	Medical Research Council
NGO	Non-Government Organisation
RLS	Rural Livelihood Study
SAP	Structural Adjustment Program
SDH	Social Determinants of Health
TB	Tuberculosis
TASO	The AIDS Support Organisation
UHC	Universal Health Coverage
UVRI	Uganda Virus Research Institute
VHT	Village Health Teams
WHO	World Health Organisation

1 Background

> With this sickness, I will be dead from hunger by the time I am found. Even if I find transport to take me to hospital, they may not admit me because I have no one to look after me during a hospital admission. These days no one can give you his or her child to live with. The grandchildren who lived with me left and joined their father who lives in town. The children used to help me with everything including washing clothes, fetching water and firewood, and cooking. During this sickness, my neighbour's wife gave me food to eat. When I was unconscious, that same woman found someone from the community who treated me, a treatment I will pay for when I get better. Before the swamp dried, I also used to go fishing and gave some [fish] for free to the neighbour, even when they wanted to pay...
>
> *Kalooli, in his 80s*[1]

This thesis investigates how individuals in households in a rural setting in Uganda experience three things: living with chronic illness, the factors that determine responses to chronic illness, and the resulting outcomes. Individuals with chronic illness – a health condition that persists over time and becomes a part of a person's everyday life (Bentzen, 2003) – have exceptional care needs that extend beyond the usual medical care provided. The quotation cited above underlines some of the needs chronically ill individuals have that are not addressed by the healthcare sector, such as bedside care or food. Such factors compound the ability of individuals to cope with chronic illness and even to access healthcare services. As the quote also illustrates, chronically ill individuals also face wider issues such as food shortages, poor transportation possibilities, poor social networks, changes in cultural values (e.g. who is responsible for caring for the elderly and sick), loss of assets (e.g. land), and

[1] Quotes and stories are all from the data, see Paper I. Names used are pseudonyms.

environmental issues (e.g. drought). Finally, the quote also indicates how social networks are crucial for accessing support and care in difficult times, and how complex relationships of reciprocity, beyond kinship relations, are becoming increasingly important to combat the challenges of chronic illness. These issues are at the centre of this study.

Chronic illness is one of the main causes of mortality and morbidity worldwide(World Health Organization, 2003). In low-income settings, chronic illness constitutes a major public health challenge and impedes social and economic development(Nugent, 2008). At the household level, ill-health may result in impoverishment through asset depletion, indebtedness, individuals withdrawing from school and work, and skipping meals. For chronic illness, it is the sum of these individual and household-level needs that shape health outcomes across a wide range of populations and settings (Link and Phelan, 1995; Agyepong et al., 2017). Countries are increasingly recognising the health of their populations as a human right following declarations such as the Universal Declaration of Human Rights in 1948 (United Nations General Assembly, 1948), the MDGs in 2005, and the Sustainable Development Goals (SDGs) in 2015 to be achieved by 2030 (United Nations, 2015). One of the strategies for achieving this goal is to avail the populations with universal access to healthcare services (Maeda et al., 2014), including free healthcare where necessary. To target populations in low-income settings, who are mostly rural based with poor existing healthcare and social services, with universal access policies is a challenge. To do this, it is important to understand the context, including the social and economic burden of illness on individuals and households as described above, as well as how policy measures may influence this burden. Research into these factors necessitates considering factors beyond medical needs, collecting context-specific data (Russell, 2005), and requires using appropriate approaches such as qualitative methods, and longitudinal data collection (le Roux Booysen and Arntz, 2003).

In sub-Saharan African countries, chronic illnesses affects not only the health of the individuals involved, but also the wellbeing of whole households (Okediji et al., 2017). In Uganda, households in rural areas dependent on manual labour on farms are particularly affected by the illnesses and death of adults, especially those in their prime years (Rugalema, 2000; Seeley, 1993; Barnett and Blaikie, 1992). Family members in the households studied reported for example forsaking farming duties and withdrawing children from school to care for their sick, and selling off land, assets or animals to address treatment needs. The extent to which households respond to the needs of individuals during chronic illness may vary, and some might not be able to meet the basic needs of the ill household members. Households can in some cases draw on wider social

networks for help but not all households have access to such safety nets and the system needs to be able to address the specific and differing challenges rural individuals and households experience.

Furthermore, health policy makers, social services, and welfare planners need a better understanding of the intermediary solutions that households and communities have developed to deal with stressful life situations (Wolffers, 2000; Maes, 2003), such as joining other households for support. Insufficient knowledge concerning the challenges of households with individuals with chronic illness, and the response strategies that individuals and households employ may make it difficult for policymakers to predict outcomes and put response strategies and initiatives in place. For example, policy-makers targeting universal access to health to protect households from catastrophic healthcare expenditures(Evans et al., 2013) have been criticised for focusing only on abolishing user fees or provision of free medication, while not including food and transportation, factors that provide people with challenges in accessing care.

Research from the early 1990s on the impact of HIV in Africa predicted that illness and death due to AIDS would have a devastating impact on, among other things, household labour availability, social networks, household structure and composition, and assets (Rugalema, 2000; Seeley, 1993; Barnett and Blaikie, 1992; Barnett and Whiteside, 2002). These predictions and findings were important for drawing donor community attention to immediate actions, such as the provision of HIV medicines, free schooling for orphans(Bryant et al., 2012), and exploring livelihood alternatives, like quickly-maturing and less labour-intensive crops (Karuhanga, 2008; Datta and Njuguna, 2009). However, the predictions and findings were mostly drawn from cross-sectional data collected during brief encounters with the respondents (le Roux Booysen and Arntz, 2003), and there was a lack of in-depth qualitative studies that would have provided more understanding of experiences at household and individual levels. The variation in the characteristics and vulnerabilities of affected households over time could not be captured by these early studies, and the socioeconomic context, as well as the extent to which households managed to address their needs, could thus not be fully understood. Indeed, households responded to adult illness in very different ways from those predicted, for example, by adjusting social relations in various ways to accommodate the new challenges. In some cases, ill individuals moved to other households that could care for them, while in others, social networks were widened to increase the support base per household. Such socially fluid responses to stresses are common in rural Uganda and in other societies where scarcity of resources is a prominent feature (Wolffers, 2000; Becker, 1993; Link and Phelan, 1995; Du Toit and Neves,

2009). Existing knowledge about this, however, was not incorporated into either the research from this period or the resulting predictions.

Longitudinal studies with a long-term follow-up of individuals and households have attempted to examine the effects wrought by adult illnesses, such as those due to HIV (Bray, 2003; Ekoru et al., 2010; Hosegood, 2009; Meintjes et al., 2009; Mushongah, 2012; Richter et al., 2009; Barnett, 2006; Barnett and Whiteside, 2007; Seeley et al., 2010; Beegle and De Weerdt, 2008; Madhavan and Schatz, 2007). These studies have shown that establishing a link between adult illness and the changes observed in households, such as the movement and relocation of individuals, child fostering and changes in agricultural productivity, is complex (Madhavan and Schatz, 2007). Factors in the wider environment, such as increased schooling, rural-urban migration and drought, may determine how well households are able to respond and cope with illness, in addition to continuing to meet other household needs. Not enough is known about the nuanced mechanisms through which individuals and whole households in resource-limited settings respond to needs during chronic illness. At the same time, the contextual changes that affect a household's ability to respond and address household needs, including chronic illness, are not well understood. Hence, health policy interventions that have proved effective in affluent contexts may be less so in low income contexts with non-functional healthcare infrastructures (Benda-Beckmann and Midgley, 1997), where there may be limited social services, poor physical infrastructure such as roads, and low economic status of individuals.

This thesis attempts to fill the research gap outlined above by highlighting the individual and household-level contextual factors that determine responses and ability to cope with chronic illness of adults, as well as stresses from the wider environment. The thesis is based on data collected from households that were part of a much larger study, the General Population Mixed Cohort of the Medical Research Council of Uganda (MRC). This larger study collected data from individuals of varying ages, genders and socioeconomic statuses. This quantitative data provided a solid foundation from which I drew a sample to base the life trajectory analysis for this thesis. The composition of households in this study is mixed. It includes those who experienced HIV as a shock in the early 1980s, as well as those who are currently experiencing HIV as a chronic disease. The difference in their responses at different times can be observed in their life histories.

The fact that the study took place in a region where the MRC, an NGO that provides free healthcare and medicines while conducting their research into health issues of relevance to the population, makes it a unique setting for a case study. While most areas in rural Uganda have problematic healthcare and medicine availability even when ill individuals do access the hospitals and clinics, the MRC

provides high quality healthcare to the population served (Photograph 1 (of the MRC field clinic) and 2 (of a public health clinic)) illustrate the different resources available to upkeep of buildings, which is reflected also in healthcare and medicine availability). This means that the factors that still present problems, even in a setting where free good quality healthcare is provided, can be isolated and observed. The data shows that, even though the households could rely on receiving healthcare when reaching the facilities, they still struggled to gain access to care for various reasons that are further explored in this thesis.

The following section provides an overview and background information on chronic illness and access to healthcare in Uganda. It starts with an overview of the Ugandan health system and how it addresses chronic illness, and also shows the importance of considering context in health policymaking. The role of the private sector in improving the health of populations in low-income countries is also highlighted. The next section further gives an overview of universal health coverage as one of the global interventions to improve health outcomes, followed by a section on the social determinants of health. I then present the main concepts used in the thesis and a conceptual framework to illustrate factors influencing a household's ability to cope with a chronically ill adult. I explain the location of the study and present the methodology and methods used. The most important results from the three published articles are then presented. The thesis ends with a discussion and conclusion.

1.1 Health systems and chronic illness

The World Health Organization (WHO) defines health systems as consisting of all the organisations, people and actions whose primary purpose is to promote, restore or maintain health (World Health Organization, 2007). Health systems have the responsibility of maintaining the health of populations in order to achieve well-being as well as contributing to economic progress (Sachs, 2001; Bhargava et al., 2001; McKee et al., 2009). For low income-settings such as Uganda, healthcare systems have fought, and continue to fight, acute problems related to infectious diseases, and maternity and childcare(Institute for Health Metrics and Evaluation (IHME), 2014.). Hence addressing the double burden of acute problems, including infectious diseases such as HIV, and chronic illness causes challenges for the healthcare system. Managing chronic disease is more complex as it entails multiple causes over a lifetime. It may require a more horizontal and integrated approach, with active participation from the patients, the households, and the whole community, as well as the government and private organisations. The health system should also be able to match health policies with changes in the wider environment that are important in determining health,

e.g. challenges resulting from changes in the education system, rural-urban migration, and declining asset ownership (especially land).

1.1.1 Organisation of the health system in Uganda

The health system in Uganda consists of public and private actors. Ideally, public health services are supposed to be provided for free (Basaza et al., 2008; Orem et al., 2011), and there are well-developed visions of how the health system should be arranged. These visions are however far from fully implemented. According to the formal structure, the health services are implemented through four levels of healthcare in the country (Ministry of Health, 2010; Orem et al., 2011). The village health teams (VHT) are the first contact for someone living in a rural area, also referred to as "Health Centre I" (HCI). These are medicine distributors, usually volunteers, going around the community by bicycle. They work as a link between the community and the health facilities. They may not have medicine, but they are in a position to advise patients and refer them to health centres. At parish level there is "Health Centre II" (HCII), usually nurse-led and formally serving about 5,000 people, although in reality, their coverage is wider. This level manages common diseases, antenatal care, immunisation, referral and outreach. At sub-county level there is "Health Centre III" (HC III), which is managed by a clinical officer and serves about 25,000 people. Usually it has a laboratory for basic tests such as malaria and HIV, and offers other services including uncomplicated deliveries, antenatal care, tuberculosis treatment and public health inspection services (however, as shown and mentioned in relation to Photograph 2, these services are sometimes not available). Most rural and peri-urban based households, especially with small children and older people, utilize health-care services at these lower levels. "Health Centre IV" (HCIV) is the district referral hospital equipped with medical doctors, which serves about 100,000 people. It provides technical support to lower level facilities and plans service delivery in the zone. As mentioned above, the government and the population still meets challenges with provision and access to healthcare services partly due to, among other things, a dilapidated infrastructure, and, especially at district and sub-county levels, a shortage of medical personnel and poor funding (World Health Organization, 2008; Ministry of Health Uganda, 2015; Katende et al., 2015). It is therefore common for individuals to seek care starting at the higher levels, such as HCIV, which are usually better equipped with medical personnel and other medical equipment such as a laboratory (Settumba et al., 2015). However, the cost of seeking care from the higher levels is high for most Ugandans and involves travelling long distances. As photo 2 shows, the main mode of travelling a longer distance is

often paying for transport by bicycle or motorcycle, which can be costly for a resource poor household. Therefore, many people needing healthcare are left with little choice but to go without treatment due to the unaffordable associated costs. Those who can afford the expenses can purchase medicines from local drug shops or seek care from private clinics that are more accessible (Wanyenze et al., 2010).

The ideologies that prevailed in the 1980s and gave rise to structural adjustment programmes (SAPs), among other things, promoted the privatisation of healthcare services (Sen and Koivusalo, 1998) giving rise to a private health sector (Moore, 2008; Mundial, 1993). The private sector includes "for-profit" and "not-for-profit" providers. The "for-profit" providers focus mainly on curative services and include private clinics and hospitals, which most Ugandans cannot afford. The "not-for-profit" providers, usually non-governmental organisations (NGOs) and some faith-based organisations (FBOs), provide both curative and preventive services, usually at subsidised prices or waiving fees where needed. They usually have more adequate medical supplies and staffing, and are typically supported by development partners (Reinikka and Svensson, 2010). It is believed that NGOs fill the gaps in the public health system in terms of geographic coverage, supplementing state health budgets and being efficient at their work (Desai, 2015). The NGO ideology of being community-based gives them a competitive edge in healthcare service provision. Most NGOs have the ability to reach the peripheries where poor and vulnerable populations, such as women, children and the elderly, are based. In this way, NGOs are in a position to understand the social processes of their constituent communities, as they are engaged in the community for extended periods of time (Olivier et al., 2015; Desai, 2015). This makes them more adaptable to the needs of the people they serve, as well as more aware of the broader social and economic factors, that interact to influence health and wellbeing (Cumper, 1986; Kamat, 2004).

While Uganda, like many low-income and middle-income countries, is still facing great burdens of infectious diseases, the health system there is facing a growing challenge presented by people living with chronic diseases. With HIV infection becoming a chronic disease (Russell and Seeley, 2010) like diabetes, hypertension and others, those afflicted by it require life-long care. Chronic diseases require long-term follow-up for adherence to treatment and timely assessment of risk factors, among other things. Social policy strategies, such as strengthening primary healthcare, may combine both pharmacological and psychosocial interventions (Beaglehole et al., 2008), but given the absence of well-developed publicly-funded primary healthcare services in Uganda (Katende et al., 2015), the outcomes of such strategies have not been tested. Therefore, organisations such as the MRC that offer free basic healthcare services in a rural

population provide an opportunity to learn from these households about their experience accessing free healthcare, and the social and economic determinants of responding to needs in chronic illness. As mentioned, the community in which this study is conducted is privileged to access free treatment, and can therefore provide important lessons for healthcare policy on what other needs still have to be met, apart from purely medical needs. More about this community and their situation is described in chapter 4 on study setting.

1.2 Universal health coverage and chronic illness

The fundamental role of health and wellbeing in social and economic progress underpins the global health community's commitment to universal health coverage (UHC) (Watkins et al., 2017). The Uganda Health Sector Development Plan for 2015 aimed to accelerate movement towards UHC with the essential healthcare and related services needed to promote a healthy and productive life (Ministry of Health Uganda, 2015). Universal health coverage has the ambitious goal of enabling everyone to access the health services they need without risking financial hardship from unaffordable out-of-pocket payments – defined as when total out-of-pocket health payments are equal to or exceed 40% of a households non-subsistence expenditure i.e. income available after basic needs have been met (Xu et al., 2007; World Health Organization, 2005). The basic philosophy in UHC is that health services should be accessible to people when they need them (Evans et al., 2013). The implication of this is that health services need to be accessible, in terms of travel distance and financial affordability (including indirect costs), and that they are acceptable to the targeted population, *i.e.* they seek out the services, there is trust in the providers, and services are provided in a culturally acceptable way. This last point could include issues relating to gender, religion, or social or economic status. In the community studied, challenges with access presented in various ways. While some could not go to hospital due to lacking a personal attendant necessary to provide food during admission, others felt they lacked the time and energy to get to the faraway clinic.

This thesis aims to explore and understand how households experience access to free medication during chronic illness, as well as exploring the other factors that plays a role in addressing their care needs. Given the multiplicity of stresses that households experience, it is important to strengthen their capacity to respond and adapt. Vega et al. (Vega and Frenz, 2013) emphasise positioning UHC in the context of action on wider social determinants of health. It is important to support other social, economic and structural arrangements and mechanisms and

include these in strategies for addressing the resource needs of chronically ill individuals living in low-income settings.

1.3 Social determinants of health and chronic illness

Some research has highlighted that the promotion of UHC is not enough if the goal of healthcare access and financial protection is to be achieved (Vega and Frenz, 2013; Fried et al., 2013; Gwatkin and Ergo, 2011; Donkin et al., 2018; Ata Alma, 1978; Lönnroth et al., 2014), and that a health benefit package that reflects the needs in each context is necessary (Glassman et al., 2016). Other studies that have explored strategies for access to care and financial protection advocate a focus on people's living conditions and the social determinants of health (SDH) (Evans et al., 2013), which they identify as central to addressing a population's health needs (Vega and Frenz, 2013; Fried et al., 2013; Hosseinpoor et al., 2014). Improving access also implies improving the conditions in which people are born, live, work and age, hence addressing the broader SDH (Evans et al., 2013). Investing in social programmes that protect the vulnerable, and equipping people with the necessary awareness to demand and obtain quality health services are examples of this. Indeed, the 2030 Agenda for Sustainable Development (United Nations, 2015) has broader approaches aimed at SDH, including the achievement of UHC by providing free healthcare.

In sub-Saharan Africa, changes that are transforming livelihoods also have a negative impact on health and wellbeing. These changes include diminishing land size per household, rural-urban migration, which usually deprives households of labour, and chronic illness caused by non-communicable diseases and HIV infection, among others. In countries such as Uganda, owning sufficient land is central to providing a livelihood, since 84% of the population lives in rural areas and depend on subsistence agriculture for food and income. In the community studied, the amount of land accessible to each individual in the household changed partly due to inheritance over generations, but also due to selling of land to in-migrants (Kasaija, 2015). At the same time, agriculture was strongly affected by factors such as drought, pests and diseases (Anyamba et al., 2014; Okonya et al., 2013). As a result, individuals have had to diversify their livelihoods to non-agricultural activities. Such activities are mostly found in urban areas (Ellis, 1998). Consequently, prime-age adults fuel the rural-urban movement as they move to find non-agricultural work (Mukwaya and Bamutaze, 2012). Thus, certain groups of individuals such as widows, the sick and the frail elderly, are left in the rural areas without care or adequate help to find food or transportation to health facilities (Wandera et al., 2017).

Photograph 1: The Kyamulibwa field station clinical rooms. Credit: MRC archives.

Photograph 2 (left): A Level III health center. Not many patients due to lack of medicines and personnel. (Credit: Betty Kakia). Photograph 3 (right): A motorcycle and bicycles waiting to transport patients back home. Credit: Betty Kakia.

Photograph 4 (left): A goat for share-rearing. After weaning, one kid is kept by the household while the goat and other kid is returned to its owner. (Credit: Jovita Amurwon). Photograph 5 (right): Transporting a sick woman in rural south-western Uganda. Credit: Betty Kakia.

2 Aim of the study

The overall aim of this thesis is to explore and describe the social aspects that determine responses to chronic illnesses and access to care in the context of rural Uganda in sub-Saharan Africa. To achieve this aim, the qualitative data collected from 22 households was iteratively analysed, and three topics that emerged strongly as important were selected for specific focus. These were how household characteristics, such as life cycle stage, influence responses and coping outcomes (Paper I), the role of social relations for responding to chronic illness (Paper II), and how changes in the wider environment undermine elderly individuals' ability to cope (Paper III).

2.1 Specific objectives

The specific research questions are:

1. How do household characteristics, including composition and household life cycle, influence the ability to respond to chronic illness in this setting?
2. What are the factors that still hamper access to healthcare in a rural setting with free quality healthcare available, and what strategies and responses enable households to overcome these barriers?
3. What is the role of social relations in facilitating access to health care and ensuring that wider needs of social protection are met?

3 Conceptual framework

3.1 Household life trajectories

Although the term 'household' has had many different definitions over the years (Nasirumbi et al., 2013), in this thesis a household is defined as a group of individuals who regularly eat from the same 'pot' of food and either live together or in close proximity. This thesis uses the household as a unit of analysis as the household is analysed as a whole in relation to its responses to a given circumstance, such as chronic illness.

The application of the life trajectories perspective in social sciences began in the 1960s with Glen (1975) in his study of the impact of the Great Depression on individual and family pathways in the 1930s. Since then, consideration has been given to the role of historical forces in understanding individual health behaviours and outcomes, as well as predicting social patterns of stability and change (Evans et al., 2009). A life trajectory approach attempts to understand the links in complex individual life pathways, relationships within and between households, and the social and cultural factors seen over time (Turner et al., 2004). For example, it takes into consideration temporal experiences, individual and household adaptation to changes, social and cultural factors influencing adaptation and choice when faced with external stresses, and how all these evolve to result in the observed consequences. This temporal, historical context gives researchers an understanding of how the accumulation of advantages and disadvantages influence health and health outcomes in the life course of individuals and households (Wethington, 2005).

This thesis has been influenced by life trajectory approaches in the analysis of understanding how households respond to chronic illness and its outcomes in rural Uganda. Chronic illnesses are long-wave in nature, with effects that unfold over decades, and the responses to these effects also change over time as more knowledge and understanding is generated. The thesis highlights the social and

economic advantages and 'turning point' experiences that individuals and households go through over time. In analysing the data, timelines of important events in each household have been constructed and used to explore how events unfold over time and link to each other over a life trajectory (see appendix 3). These timelines were integral to the analysis of events and life histories, especially for Paper II and III. Paper II deals with social interconnectedness, a factor associated with health outcomes, and how these relations develop and persist over time. From the timelines developed, events such as illness, relocation of adults, changes in land use, and sources of food, were among the important factors when exploring access to care and treatment. Paper III explores the transforming social and economic environments in which health related events happens over the life of the household, and how the responses of individuals change over time to determine the capabilities and vulnerabilities experienced at household level. When exploring the timeline data (which is also shown in Paper III), issues that emerged were that assets, mainly land, reduced over time, and that household members relocated to urban areas. In addition, the timelines for older households show young children joining, mostly to help with care, and leaving to study or during a famine.

While life trajectories may differ, they also follow some predictable patterns over time, as individuals go through a life cycle experiencing childhood, youth, middle age and old age. The focus on life trajectories of households as well as individuals also makes it relevant to discuss household life cycles (as is done in Paper I). The life cycle of a household is different from the life cycle of individuals in specific ways – specifically a household starts not with the birth of an individual but with young adults moving away from their parents and establishing a new household, or taking over a household after the passing of the older generation. The household then typically grows as children are born, after which children age and eventually leave the household, leaving it smaller yet again (or sometimes caring for grandchildren). Some studies have assessed the life cycles of the chronically ill individuals and families to characterise a resilient family (Rolland, 2005), the degree of demands (Rolland, 1987), and assess cycle related adaptation capabilities (Newby, 1996). From a low income context, others have explored whether chronic illnesses such as HIV disrupt the normal household life cycle development and the effectiveness of policies targeting support to the vulnerable individuals in these households (Hosegood, 2009). This thesis similarly applies the life cycle perspective to explore the ability to cope with and adapt to household demands such as healthcare and food during ill health. There can be variations and overlaps in life cycles, and there are also non-traditional household structures such as single adults or adults who do not leave the parental home. Several household life cycles have been merged to

come up with three broad stages that reflect the issues arising from the empirical material: 'young', 'middle-aged' and 'old' households. The demarcations are mainly based on the age of the household head and the presence and age of dependents. For example, a middle-aged household usually has older children who may help out with labour or remittances, and sometimes grandchildren, who may offer help but also need support. Conversely, the children of an old household have usually established their own households and may not offer the same kind of help or support to the elderly. Typifying households as young or old rather than merely looking at young or old individual's characteristics give a different dimension to the analysis and illuminates specific challenges. The life cycle analysis in Paper I discusses how advantages can accumulate over time as a household develops and as the head of the household ages, as well as how vulnerabilities are formed in the same process. Such processes determine how well the household can respond to stressful events and adapt to address its needs at given points in time.

3.2 Household responses to chronic illness

In analysing the household trajectories, there has been a specific focus on household responses to chronic illness, in relation to how health systems are able to cope with this new dynamic. Although I explore all illness and death events in the households, it is often evident from the life stories that recurring events and chronic illness trigger a different type of stress that generates different responses. Categorisation of chronic illness is often used interchangeably in the literature, for example chronic illness, chronic disease, chronic conditions and long-term medical conditions. Chronic disease is defined as a condition of long duration and generally slow progression, usually requiring periodic monitoring and supportive care in order to reduce illness and facilitate functioning (White et al., 2018). The term 'chronic' may be mistaken to imply constant illness, however many diseases can have long periods of remission, such as HIV (after ART rollout) (Nakagawa et al., 2013), and hence, are sometimes perceived as temporary by the individual involved. The term 'chronic' is only used here to indicate the temporal nature of the disease. The author refers to "coping with chronic illness" to mean the adaptation of household activities and plans in response to daily basic needs given that a household member is either ill or likely to be periodically ill in the future. This thesis includes households that have members with chronic diseases, both according to the cohort survey database as well as self-reporting from the individuals interviewed who describe illnesses with no specific diagnosis mentioned.

This thesis has focused on how households respond to chronic illness events, including how they adapt to such events and the outcomes (which can include anything from coping well to struggling to cope). Previous studies have pointed out various response strategies in households with chronic illness events, such as children taking on parenting responsibilities (Andersen, 2012) or individuals migrating in or out to relieve the care burden on affected households (Ansell and Van Blerk, 2004). The thesis author, in agreement with other researchers, such as Rugalema (2000), has chosen to use the term 'response to chronic illness' rather than using 'coping with' in order to underline that some responses used by the household may lead to negative outcomes, while 'coping' has a more positive connotation. For households in poor rural areas where there is a lack of savings or regular incomes, predicting individual or household responses is complicated, as the strategies employed are likely to be more diverse and random. The term 'coping' has, in this thesis, been used to indicate a specific positive outcome of responding to chronic illness. Despite ill health and other stresses, some households are able to cope, meaning that they are able to address their needs amid external pressures including care, food and education. In Paper I 'coping well' is opposed to 'struggling' where the latter may mean that the household cannot meet all its basic needs for an extended period of time or, more often, that the household initially manages to cope, for example, by selling assets or relying on support from outside, but in the long term is unable to meet its basic needs.

The extent of support and care that an ill individual can receive from their household depends on household characteristics such as socioeconomic status, stage in the life cycle and age of the household's head. This influences how dynamic and innovative the household is at absorbing the shocks and stresses it encounters, including the illness of its members. Some studies on the economic effect of health shocks, including death, find that rural households are able to address their needs such as food and care, for example by supplying more labour on the farms (Wagstaff, 2007; Townsend, 1994). Other studies find that households are sometimes not able to address the needs of their ill members due to costs involved.

The household decision to seek care for ill individuals is important. To obtain care from the healthcare organisations, households incur costs, which they cover using internal resources such as saved income or crop harvests, and their own labour. Alternatively, the household may draw from resources in their social networks, such as kin and friends. It is the totality of the various responses that individuals in these households apply as response strategies that act together and determine the household's health, social and economic outcomes. This capability to respond develops and changes over time, is enhanced by protective factors

within the individual and the environment, and contributes to the maintenance or enhancement of health and wellbeing (Stewart et al., 1999). In contexts where there are no formal mechanisms for social protection, it is important to identify and support existing informal mechanisms that seem to provide protection and place the household in a resilient position where it can adapt to health shocks and other stresses.

This thesis also uses the concept of adaptation when exploring household responses to chronic illness and outcomes. Adaptation to chronic illness is complex (Moss-Morris, 2013). It includes both adaptation to the illness itself, e.g. in terms of taking medications or securing care, as well as adaptation of life in general, e.g. making sure that the household can still be looked after and food can still be produced in times of illness. Adaptation is applied in this thesis to imply that ill individuals and household members adjust and adapt to changes brought into their lives by illness and other stresses. The outcomes from the adaptation processes vary due to a number of factors such as age, gender and socioeconomic position, among others. If conditions are favourable, adaptation may lead to the household 'coping well' with the events.

3.2.1 Social relations and informal social protection during chronic illness

Social relations are the interpersonal relationships and exchanges in which people engage within and between households, friendships and group affiliations (Antonucci, 1994). They include social networks of individuals (which can differ in terms of size, composition, frequency of contacts etc.), social support (the support received from individuals, exchanged among individuals and small groups, and support provided by clubs and organisations) and social inclusion (enhancing individuals' participation in society, e.g. through accessing or giving support). These social connections are broadly referred to as 'social relations' in this thesis, and the key importance of these in responding to chronic illness events is investigated in detail specifically in Paper II. Only a minority of the population in low-income settings like in rural Uganda is covered by formal institutionalised social protection mechanisms, which usually focus on the urban formal sector and providing social protection in the form of social security to those in employment, as well as pensions to those retired from formal employment. The bulk of the population, including the rural based, the elderly, and most women and children derive the needed support through social relations, which acts as a form of informal social protection, and is key in times of shocks such as chronic illness and inclement weather (Platteau, 1991). I find the definition of informal social protection by the DFID relevant for the context studied; "those actions to minimise risks or transfers between individuals or

households to cope during difficult times" (Dfid, 2006). Some studies have found that household consumption remains stable despite shocks such as illness (Townsend, 1994). This could be a result of support from the informal individual and household networks, which are known to protect consumption and prevent household expenditure from becoming catastrophic during illness, death, or other stresses. Some health service providers in Uganda, such as The Aids Support Organisation (TASO), have relied on the availability and support of kin to ensure adherence with treatment protocols (Foster et al., 2010). This is common in low-income contexts where healthcare institutions may have limited capacity to fully provide a range of services, such as care and food for the hospitalised, indicating the need for a complementary mix of support from both formal and informal arrangements to achieve the well-being of individuals and households. From the opening quote in the introduction of this thesis, we learn from the participant that a service such as a hospital admission that was free in the community was only possible if one had private carers to provide bedside help, including cooking food, during hospitalisation.

This is not to imply that informal social protection fills the gaps left by lacking social services, or that it benefits the whole community equally. The need for formal institutionalised social protection mechanisms remains if equal care is to be guaranteed. Some researchers have indicated that where similar social and economic conditions, e.g. poverty or droughts, are experienced by everyone, the 'safety net' from the extended family and networks is inadequate for providing material needs such as food and care (Seeley et al., 1993; Dawson, 2013; Booth and Milimo, 1995), requiring other forms of support such as cash transfers for healthcare, education, and food. The flow of informal support and exchange may be unfairly distributed, and hence, providing partial social protection to some groups, such as women, children and the elderly, is needed. For example, in Uganda, women generally own less land (Okonya et al., 2013), and in the study area a number of them had 1.0 acre or less (see appendix 4). This drives women to depend on social relations to access the resources they need, sometimes requiring them to provide much more support than they probably receive, such as care for the sick and frail. At the same time, one should be aware that access to support from the household's kin, as well as from neighbours, is not always guaranteed due to other issues, e.g. when mistrust exist. An individual or household with a tarnished relationship with the wider community will have limited possibilities of engaging in reciprocal support. Hence, policymakers need to be aware of differences in the extent of informal social protection and create strategies for social services that are non-discriminatory.

The thesis explores the care and support that individuals and their households' access and the extent of their involvement in social relations, including those outside the immediate family, and reciprocal exchanges. The support provided may include borrowing or lending a bicycle or wheelbarrow to transport the ill, nursing care for the ill person, or food and accommodation. These social relations can contribute to protecting households from a downward spiral when experiencing stresses, such as chronic illness, death and erratic climate conditions. This in turn creates and strengthens social trust and norms of reciprocity between households, and in the community. For example, an individual who receives care when they are ill may repay this social debt with food for someone in need, rather than to the person who provided the care. These social relations are also characterised by trust that individuals will comply with group expectations in order to maintain their standing in the community (Hart, 2000), and that everyone contributes to reciprocal relations, including children (Manderson et al., 2016; Abebe and Skovdal, 2010; Skovdal, 2010; Foster et al., 2010). Some anthropologists refer to this type of exchange as generalised reciprocity (Sahlins, 1972; Malinowski, 2014), which is based on the assumption that any good turn will be repaid at a time of need by someone in the group who has the ability to help at that time (Evans-Pritchard, 1940). Through these social relations, individuals and households are able to access a pool of resources embedded in the community when the need arises, in ways that match their needs.

3.2.2 Responses of the elderly: an especially vulnerable category

Characteristics of the person heading the household that influence how they respond to chronic illness include age, gender and social position. Paper III of this thesis focuses specifically on how the elderly respond to chronic illness events. In the data collected, 10 of the 22 households are headed by individuals over the age of 60. In order to understand why these households are in a special situation when coping with chronic illness, it is important to look at some of the insights offered by the literature on how Ugandan households are organised to provide care and support to elderly or otherwise weak or frail members.

Ugandans have traditionally cherished elderly household members as valuable resources of information and experience (Nzabona and Ntozi, 2017). The elderly are also key as they own important assets such as land. These contributions from the elderly accrue in contexts with limited resources, providing few effective alternatives for addressing needs such as healthcare and maintaining basic livelihoods. There has been a tradition of intergenerational exchange of support, a value that has contributed to making individual households relatively resilient, particularly in times of adversity, such as during droughts and the HIV pandemic.

An example from the households interviewed include a pregnant teenager being sent to live with her grandparents, which ensured help with care for the elderly as well as support for the woman and her child.

Elderly women carry out activities such as childcare and cooking, and, on a small scale, cultivate the land, depending on their health and physical abilities. Elderly men are mostly involved in planning and making decisions, for example what, when and where to plant and who should do it, as well as who should take care of who. The elderly usually access care by living with their older children or grandchildren (Zimmer and Dayton, 2005), and exchange non-financial support (Kohler et al., 2012) such as advice and childcare.

As in most of Africa (Doron et al., 2016), Uganda has undergone social and economic transitions that could undermine traditional values and organisations that have provided household members with social and economic security, including care during chronic illness. On the other hand, some anthropologists who have explored care in African contexts find that the functionality of kin and kin boundaries are flexible and provision of care reflects the current changes that society is undergoing (Manderson and Block, 2016). I encountered a similar situation in my own fieldwork. For example, there were instances of non-relatives, such as a neighbour, who had performed caring roles for older people and were absorbed into the kin group by the relatives who lived away from the study area. This shows how strongly kinship is associated with care values, so much so that even non-relatives who perform expected care may be absorbed into the group.

In 1997, the Ugandan government launched the Universal Primary Education (UPE) programme, which was followed in 2007 by the Universal Secondary Education (USE) programme (Kristen, 2012). These initiatives have provided opportunities for most children to attend school and have increased the mobility of young people to nearby towns. While the out-migration of adult children from rural areas, to continue education and find work, has the benefit of remittances for the rural household left behind, the migration phenomenon may increase distances between the rural-based sick or elderly and their migrant children and grand-children, making it hard for those left in the rural areas to receive necessary support. In rural areas, increased schooling and out-migration has meant that the elderly are left alone most of the time, lacking the support that children have previously provided such as cooking, fetching water and firewood, and hoeing in the gardens. Furthermore, assets such as land decreases as the elderly pass them over to younger generations. The younger people may then continue cultivation or even sell the land, particularly if they have to meet needs like healthcare. This leaves the elderly with insufficient land (Nzabona and Ntozi, 2017) to attract young people to stay with them and, in exchange, provide them with support.

4 Study setting

4.1 Uganda and the study area in the Kalungu district

Uganda is located in East Africa. It straddles the equator and is divided into three main areas: swampy lowlands, a fertile plateau with wooded hills, and a desert region. These regional differences determine the nature of livelihoods and socioeconomic outcomes. Agriculture provides a livelihood for over 87% of the population (Wichern et al., 2017). Both food and cash crops are entirely rain fed. Agricultural production is mostly small-scale for income and food. Over time the soils have lost fertility due to poor soil management (Nkedi-Kizza et al., 2002), resulting in low farm output. The practical soil management options for rural farm-based populations are limited by the high population growth rate, resulting in food shortages and the rural-urban migration of individuals in search of non-farm livelihood strategies.

The total population of Uganda in 2016 was 41.5 million and life expectancy at birth in 2016 was 60 years for males and 65 years for females (World Health Organization, 2019). That is a great improvement from the life expectancy of 42 years following the outbreak of the HIV epidemic in 1988 (Mills et al., 2011). The gross national income per capita in 2016 was US$ 630. Total expenditure on health per capita was US$ 133 and total expenditure on health as a percentage of GDP was 7.2% in 2014 (World Health Organization, 2018), with the remainder of the healthcare budget funded by donor funds. Universal primary education (UPE) was introduced in 1997 and in 2007 tuition fees for secondary education were removed (students still pay exam fees, and parent and teachers association fees), increasing rates of school attendance.

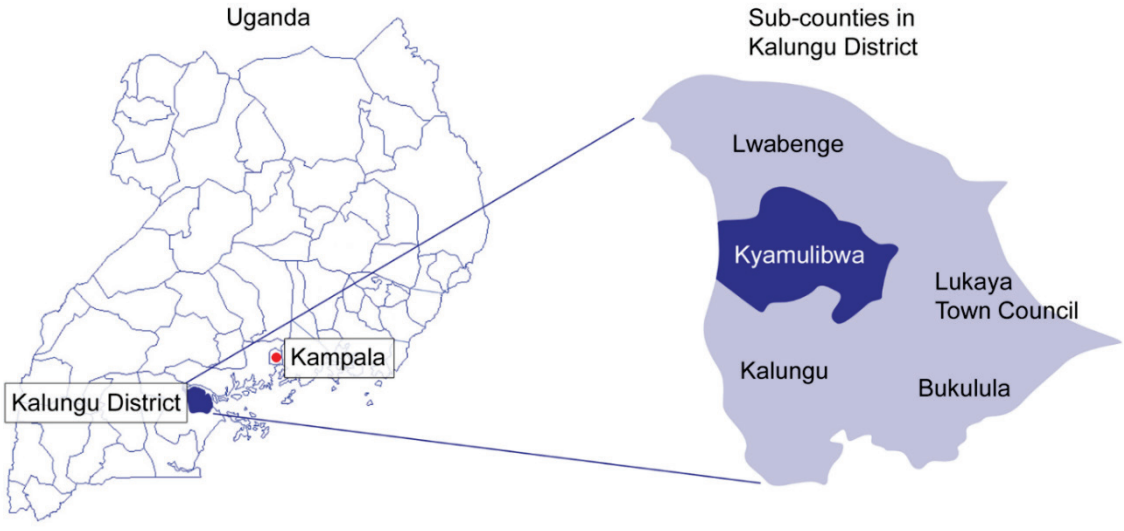

Figure 1. Map of Uganda showing study area of Kalungu district and the General Population Cohort study village, Kyamulibwa. Credit MRC-archives.

The research for this thesis was conducted in a rural sub-county in Kalungu district (Figure 1), in south-western Uganda. Kalungu district was created in 2010. In 2019, the population in this area was estimated to be around 192,400 according to the Uganda Bureau of Statistics. People living in the area are largely subsistence farmers who produce small amounts of crops, such as bananas, beans and coffee, for home consumption and cash. They also farm livestock and fish in Lake Victoria and the marshes of the Katonga River. The majority of the population are ethnically Baganda (75%), but there is a large representation of immigrants from Rwanda (15%). Just over 50% of the population is under the age of 15, and the ratio of females to males is roughly equal (Asiki et al., 2013).

4.2 Household activities and access to resources

Daily life and access to basic resources are organised around clan lineage and marriage in this area. Generally, the clan collectively owns land, and sons utilise their father's land and may share the harvest with each other, especially during good harvests. The clans are usually headed by elderly menfolk, an authority that confers respect and honour on the elderly. The kin group oversees the activities of the extended family to ensure resources, including land and labour, are distributed. Patrilocality, where a woman moves to join her husband in his father's home or compound upon marriage, is common, while a woman may live close to her parents if she is unmarried or after a marriage ends (Kandiyoti,

1988). Women are economically dependent on the male next of kin (husband, father, brother or eldest son), who is important for their own and their children's sustenance. This arrangement may however jeopardise the ability of women to control resources, mainly land, and has implications for access to support and care in the future, as can be seen in the households studied. Through these structures, marriage and property inheritance are organised, care for the elderly and sick given (Manderson and Block, 2016), young mothers are protected, and vulnerable children are given home (Cheney, 2016). These structures also ensure that there is enough labour to produce food for the households. In this way, the clan serves as a social safety net for households and individuals, even if different individuals do not have equal powers within this system.

Household members usually have age-based and gender-based roles in the household. Women and children usually fetch water and firewood, cultivate and harvest food in the fields, prepare food, keep the house clean and take care of small children, the sick and the elderly. Men and boys aged over twelve years have authority in the family and are expected to engage in economic activities to ensure the family has food, among other basic needs (Tamale, 2004). Prime-age, mostly married, men carry out cultivation (mainly of cash crops) and are sometimes involved in income-generating activities such as selling charcoal or trading food (Republic of Uganda, 2013). It is also common for prime-age men and women to live and work in other towns and send remittances to their rural-based households, usually to support the elderly as well as the younger children that the elderly live with (Ellis, 1998).

The labour for gardening can be from the household, or hired for cash or in exchange for the crop when the harvest is ready. Strategies for acquiring food includes harvesting from the farm, purchasing from the market, working for food from a neighbour, or rearing a goat for a neighbour and sharing the kids that are born (see Photograph 4). Some households rent out the land to able-bodied or healthy people and share the harvest. This was common in households burdened by chronic illness, and among the elderly. For example, households where both adults were ill rented out their land to others with whom they shared the harvest as payment. They also often rented out portions of the land to seasonal retail shops e.g. pork sellers. In this way, the household met their needs for food, income to pay fees for school and transport to hospital. Elderly households took in relatives whom they provided for while they worked in the home and in the fields. Water and firewood are not easily accessible, it can take up to two hours to travel to and from the water sources, which are sometimes up to three kilometres away, and firewood is not easy to find especially as the land gets cultivated. The common practice is to carry the water, up to 20 litres, or a bundle of firewood, up to 20 kg, on the head, which is not easy for someone with a body

weakened by illness or age. In some households, the elderly who lack food let their relatives, usually grand or great-grandchildren, work for neighbours with e.g. fetching water and firewood, and use the pay to purchase food items.

4.3 The General Population Cohort of the Medical Research Council

The Medical Research Council/Uganda Virus Research Institute (MRC/UVRI) was established in 1988, based on a bilateral agreement between the Ugandan and British governments. It is a multi-disciplinary research programme for the study of HIV infection in Uganda. The General Population Cohort (GPC) study was established in 1989 in 15 rural villages (expanded to 25 villages in 2000 – all the numbered villages in Figure 1 above) in a sub-county in Kalungu district, described above. This is an open cohort covering a total population, with no age limit, of about 20,000 people. The GPC runs a clinic and clinical laboratory in the field office with two fulltime doctors and one clinical officer and is stocked with most of the drugs on the essential drug list for Uganda, which are available free of charge to the enumerated households. The main objectives of this GPC study are to describe the dynamics of HIV infections within a rural population. It also studies the development and management of non-communicable diseases (Asiki et al., 2013) and includes identification of the major risk factors for contracting HIV, in order to quantify the impact of mortality and fertility and to study treatment-seeking behaviour. Every year since its inception, the GPC has conducted household censuses of the resident population, collecting, among other things, social and economic data. The MRC therefore already had quantitative data, making it easy to identify households for this study. The dataset from the GPC used in this thesis includes age, gender, education, relationships in the households and adult medical surveys.

However, the GPC database uses 1990 as the base year and point of departure, omitting events prior to that time which might be important in explaining current household experiences and socioeconomic status. Another problem is that some variables are excluded from the annual census. For example, household economic data is only captured every four years and statistics on the type of cultivated crops have only been captured in 1990 and 2008. The household definition might be problematic, as it is based on the house structure. However, it became apparent through interviews for this thesis that households are fluid entities located in several geographical places and reconstitute when there is a need to adapt to new situations and opportunities and meet the needs of individuals.

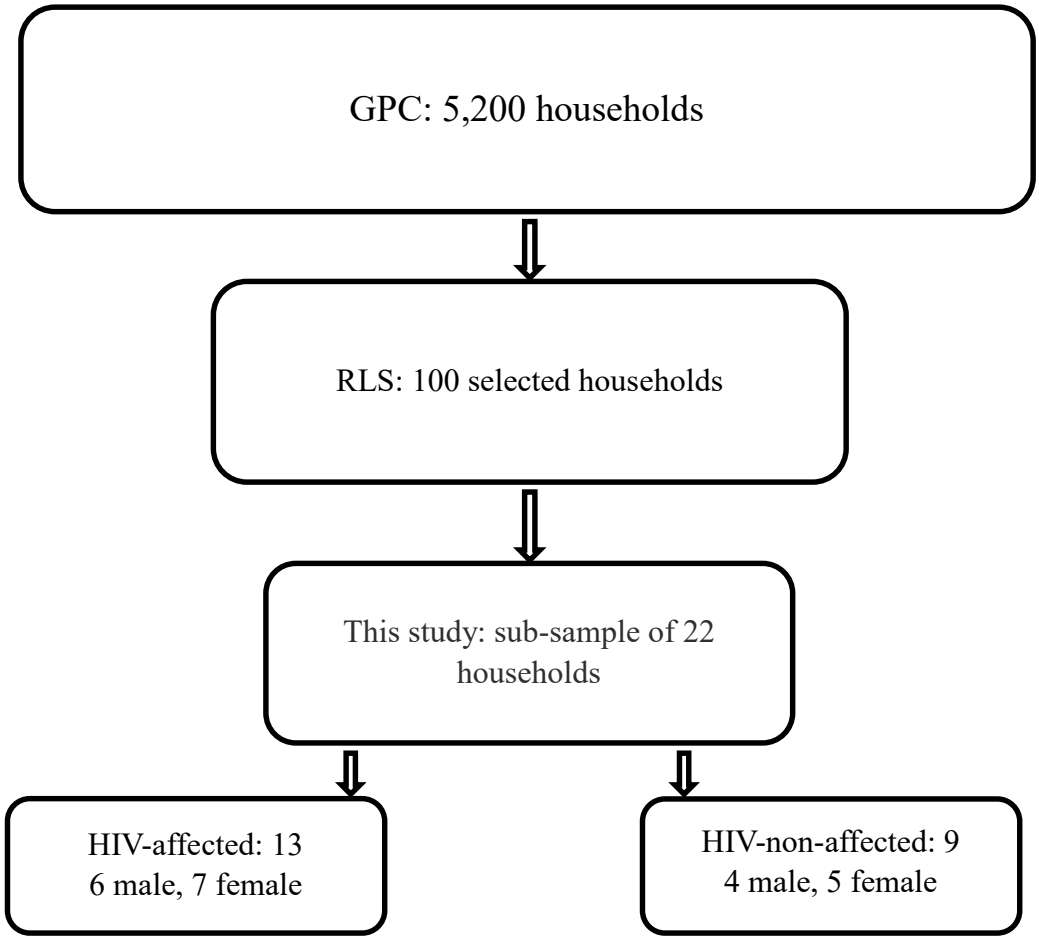

Figure 2. The selection of households for this thesis.

5 Methodology and data collection

5.1 Methodology and research design

The research design for this study is based on a bottom-up principle of generating research questions and an iterative process of analysing each interview and generating new questions to influence the direction of inquiry. In order to gain a broad understanding of the complex life situations of rural households in Uganda, data was gathered using in-depth qualitative and longitudinal data collection methods combined with ethnographic approaches such as observations.

As shown in Figure 2, this study is nested within the Rural Livelihoods Study (RLS), which in turn is nested within the GPC. For the RLS, a stratified random sample of 100 households was taken (50% HIV-affected, meaning they had experienced the illness or death of an adult due to an AIDS-related illness, and the other 50% non-HIV affected). To understand the daily life of individuals in these households and their response dynamics to chronic illness and other stresses, a sub-sample of 22 households was taken for a sub-study, this is the data used in the present thesis. The households included are mainly from five villages, initially selected randomly, and then purposively selected to represent equal numbers of female and male-headed households, as well as equal numbers of AIDS-affected and non-affected households. This was done so as to have findings that are representative and trustworthy (Graneheim and Lundman, 2004). However, during data collection it was found that some deaths in the households had not been captured in the census data, especially where relatives only joined the household to die. The ages of the household heads also varied, with four aged under fifty, nine aged between 46 and 60, and nine aged over sixty.

A qualitative approach was taken with these households as it gave the advantage of generating a wealth of information that could be analysed and

examined from various perspectives to understand important aspects of responding to chronic illness and other stresses (Patton, 2002). During 2009 and 2010, the research team (the author and two research assistants) conducted in-depth interviews combined with observations. Serial qualitative interviews were undertaken due to the need to develop a close relationship with the study participants so as to facilitate discussion of sensitive personal experiences (Murray et al., 2009). Observing individuals in their natural environments provided a rich account of how they experienced and dealt with events from their onset, and of explanations or rationales for their responses (Green and Thorogood, 2009). Follow up interviews to the households were carried out during 2011 so as to fill in any gaps.

5.1.1 Constructivist grounded theory

In this study, I have not started with firstly determining the research questions and then moved on to collect data to answer the questions. Rather, broad life history data was collected around the theme of how households respond to illness and death events in their complex social and rural livelihoods context. The data was analysed in order to determine important themes which were further investigated in the recurrent interviews. When the full dataset was analysed, the research questions emerged as the most important and interesting aspects of responding to illness. Due to the richness of the data collected, I could go into the data and find the answers to the arising questions. Similarly, I did not start with a theory or hypothesis to be accepted or rejected, but reformulated and refined the categories and analysis continuously, looking for theories and literature that could help me explain the findings from the households. In this way, the process is similar to what is prescribed by grounded theory (GT) (Charmaz, 2006), however the process was not guided by the strict methodology outlined for that approach. The basic idea behind the GT approach to data collection is that theory emerges from the data through an iterative research process. Yet, there is no such thing as value free development of theory from the data, and constructivist GT acknowledges the role of the researcher as an active participant in the data collection process, rather than as an objective analyst of subjects' experiences. The constructivist GT also stresses flexible strategies, and the collection of data through multiple sources is encouraged (Taghipour, 2014). I have been inspired by the constructivist GT approach to start my enquiry through focusing attention on the underlying social processes and local perspectives occurring in the context studied, and finding the important themes that emerged from this context over time as the data was analysed and theorised.

5.1.2 Reflexivity

Reflexivity refers to a process where the researcher reflects on the degree of influence that she and her specific positionality have exerted on the research findings (Jootun et al., 2009). Reflexivity introduces a degree of openness on the extent to which the researcher has influenced and been influenced by the research, for the purposes of trustworthiness in the data collected. The fact that I do not come from this community, am an educated woman, and was working at the MRC, meant that I was considered by the community as economically better off, as seen from the way they referred to me as "muzungu" meaning the white-man, and "musawo" meaning the 'doctor'. This raised a lot of expec-tations for support from me. We, the thesis author and the research assistants, informed the participants that we had come to learn from their experiences. This helped to limit potential social gaps between the researchers and researched. This also smoothed interaction during conversations, as the research team was allowed to join in activities, such as farm work, in order to hold the interviews. At the same time, it was possible to observe and engage participants in a conversation in other places, such as the market or other workplaces. This was especially if a home appointment was not successful and the participant was found in a place other than home and was willing to engage in a conversation.

Furthermore, having non-locals directly engaged in interviews in the community was not accepted at the MRC, partly for the same reason of raising expectations of support from the guest interviewer. As a result, during the interviews my role was limited to making notes. I also made observations and asked general questions, mostly related to the observations. For example, when I observed that the bananas, which are a staple food in the area, had been infested by pests and diseases. I inquired what the people in the community had done to ensure continued food production, for which the interesting response was that "in this village one will always receive support, and in return one must support others". Also, based on the rainfall data I got from the meteorological institute, I inquired what the households did in response to a severe drought in the 1980s which dried up all crops and wells.

I am also affected by my personal preconceptions from my own life experi-ences (Charmaz, 2014). I was born and raised in a rural area similar to the one in which I carried out this study, and I have had a similar life experience to some of the households in the study (as indicated in the preface). This meant that I had a specific style in which I carried out the inquiry process, and the way I interpreted the responses that I received. Being of Ugandan origin myself and able to share some aspects of my cultural background and the experience of growing up in rural circumstances was helpful in enriching my understanding of participants' accounts, the language they use and the nuances and subtexts. My

perceptions in this case helped with making judgements about how to explore issues in a meaningful way. Of course my personal familiarity with these contexts might have led me to miss questions or issues that were so familiar to me that I did not think of questioning them.

During my work with microfinance in rural Uganda from 2000 to 2003, I learnt about the social processes that shut out certain categories of people from participating in initiatives that have health benefits, for example access to group loans, and information on health promotion. Having worked as a health economist for the MRC from 2007 to 2010, I learnt about what drives or minimises costs in households during stressful experiences, for example having ill household members. I had an internship with The AIDS Support Organisation (TASO) in 2007, where I participated in needs assessment for people who were HIV positive. In this case, the individuals' household and social network turned out to be key for coping with and adapting to various needs, including accessing medicine, adherence to treatment, transportation, food and personal care. All these experiences have been key to forming my understanding of how individuals and whole households experience and respond to chronic illness in Uganda.

5.1.3 Generalisability and Trustworthiness

The study represents a case that is unique in rural Uganda, in that the population is receiving free good quality healthcare from the MRC. Rather than being generalizable, the case gives indications of issues that could still be problematic even if free healthcare was provided in other areas through UHC policies. The case is thus explorative, rather than generalizable. Comparison with other literature as detailed in the papers however shows that the household experiences in this study are common as far as responding to needs during chronic illness and other stresses in rural low-income settings.

This qualitatively oriented thesis involved a dependence on the testimonies generated from the interviews and observations of individuals, and the texts produced with the research team. Therefore, the directions of inquiry, perceptions and reasoning come from my study participants and me. This inevitably exposes my findings to possibilities of error and lack of honesty. To overcome this shortcoming, different but complementary methodological triangulations were used. Data was collected through interviews, conversations and observations, as well as by participating in activities such as hoeing during fieldwork visits. This study was also enriched by the MRC annual survey database, which is more than 20 years old and provided additional updated information on most of the households. The first two visits to the household were mainly based on building up from the quantitative data. For example, a start was

made by reading out the names of the list of members in the household during the first GPC survey visit to the household several years back. This was followed by the members explaining the changes in the socioeconomic data from the first survey, and hence providing updates on the households' current status, which sparked off a conversation on what would be followed up on during the consecutive interviews.

The qualitative material for the thesis was collected over several visits with each participating household, which resulted in data being more trustworthy compared to data collected during a one-off visit (Thorne, 2008). Collecting data over an extended period provided an opportunity to observe changes in coping strategies over time, as well as follow up where there were gaps in the data. For example, since land redistribution was an issue at the time of the study, participants were hesitant to mention how much land they owned. However, it was possible to find this out after several visits and by 'helping' in the gardens. The same applied when it came to confirming the number of members in each household, as some households had registered more members during the census so that many more individuals would benefit from services such as free medicines. The combination of life histories, interviews and observations made it possible to validate the data, thus increasing consistency and confidence in the findings (Denzin, 1978).

5.1.4 Ethical considerations

This study received ethical approval from the Science and Ethics Committee of the Uganda Virus Research Institute and the Uganda National Council for Science and Technology. The participants were informed about the study and asked if they wanted to participate. Since MRC provides healthcare services, which is highly valued in this community, it was important to inform the participants that participation in the study was voluntary and that they could withdraw at any time without giving a reason, and that it would not affect their access to health services. Indeed, some participants did withdraw. One household withdrew because it was stigmatising to be visited by 'the doctors', as they called the thesis author and the research assistants, particularly as this household was directly affected by HIV since the head and his partner were infected. Written informed consent was obtained from all study participants. Identifying features were removed from the data collected and the names used in the articles and in this thesis are pseudonyms.

The author would like to point out that the households participating in the study and the study villages in general are familiar with the research and expect to receive a token of appreciation for their time from the study team. The

households received two-kilogram bars of soap, a kilogram of salt, and a dozen exercise books, for which they expressed gratitude. In addition to us explaining it at the start of every interview, the MRC held annual information meetings, with the message of voluntary participation in order to decrease the likelihood that people felt pressured to participate in the studies. Even though the gifts meant a lot to some poorer participants and may well have been an incentive to participate, the responses from individuals did not seem to be influenced by the gifts, as people seemed willing to share both positive and negative experiences with no apprehension of being denied the tokens of appreciation or future services. Nakalema always ululated (made a sound of joy) and clapped her hands when the researchers visited. She exclaimed, "ndaba ku ki!" interpreted as "what do I see!". From the author's interpretation, Nakalema looked forward to having someone to talk to, and to receive a gift. Mutebi, unlike Nakalema, was critical about any questions exploring assets, mostly land. Land was a sensitive issue at the time of the study because there was a discussion of the redistribution of unutilised land, or allowing squatters to own the land that they occupied. On several visits Mutebi asked, "what is it again?" before answering questions, despite the fact that we had previously given, and were going to give a token of appreciation for his time. He nevertheless shared his story freely once the interviews had started.

5.1.5 Authorship

The members of the research team who collected data for this study were the thesis author Jovita Amurwon (JA), who was in charge of the sub-study of 22 households comprising the data for this thesis, two local research assistants (Grace Tumwekwasa and Fatuma Ssembajja), each with more than fifteen years of experience with ethnographic research, the Senior Principle Investigator in charge of the RLS study, Professor Janet Seeley, (co-author of Papers II and III), and the MRC Social Science Unit Coordinator, Dominic Bukenya (co-author of Paper II). Being responsible for the sub-study, JA developed the interview guides, coordinated the research assistants, discussed all the interviews and observations in detail with the research assistants and continuously performed data analysis from the time of first data collection, developing the interview guide along the way. The continuation of data analysis and development of the material to produce three papers was carried out while the thesis author was working on her PhD, and was undertaken primarily with the main supervisor, Flora Hajdu (co-author of Papers I and II), at the Swedish University of Agricultural Sciences.

5.2 Data collection and analysis

5.2.1 The RLS and qualitative data

Data were collected from 22 households (important characteristics of the households are detailed in appendix 2) combining semi-structured in-depth interviews and observations. The author also referred to previous studies about the region, known as Buganda, and its culture and livelihood activities.

5.2.2 Interviews

In-depth interviews gave information about the life histories of each household member, a record of changes in household resources, including physical assets and human capital, and major events that the households had experienced and how they had responded and adapted over time (see the interview guide in Table 1, appendix 1). Although data collection was based on this interview guide, the interviews were adapted to the situation around the household at the time of the visit, as well as to developments during the continuous analysis process. For 12 months, each of the 22 households was visited once per month by one of the two experienced research assistants, one male and one female. The thesis author limited her participation in data collection to observations and asking general questions, for example on joint labour activities, weather influences on cropping, general experiences seeking care at the clinic, and following up on interviews that previously proved challenging (e.g. where the household had never accepted to be interviewed). The research assistants could instead engage in deeper conversations with the participants, taking verbatim notes, including untranslated quotes in the vernacular, so as to keep to the respondents' words as much as possible. After each field visit, the notes, interviews and observations were discussed in detail with the research assistants, and adjustments to the interview guides for next visit were made. Interviews were conducted with the household heads and/or their spouses or any other adult if the head of household was unreachable. Altogether, there were 258 interviews. However, after an average of eight visits to each household, the amount of variation in the data levelled off, with few new perspectives and explanations emerging from the data.

During the visits, a life history of the household and of each individual in the household was taken, from which the thesis author generated timelines, (see appendix 3 for examples of timelines). Life history is a method of data collection, interpretation, and reporting using constructions of the past experience of the individual (Ojermark, 2007). Life histories were used because

they are more holistic and provide in-depth knowledge (Ojermark, 2007) about individuals' daily life and various aspects of adaptive responses to changes and opportunities. The life histories were also important for initiating conversations. Some of the stories were sad and resulted in moments of tears, especially if there was loss involved, e.g. death, loss of land, displacement of households. When Tino, in her 60s, narrated the stories of her household she paused to cry because some of her household members had died, and she had lost property. This also raises issues of ethics in research where the researcher should not cause trauma to those researched. Some researchers consider this experience as an opportunity for the participant to complete the bereavement process (Rubin and Rubin, 1995). However, in such moments, the participant should have the option to withdraw (Robson, 2001). In this case, Tino said we could not talk about the members who had died. The life histories also provided grounds for follow-up visits later to find out more from the stories told. Details were obtained about the establishment of the household, status of assets owned over time, changes in household membership size and structure, major events including death and illness, and weather patterns. An account of individuals' lives included movement in and out of the household, births, illnesses and death, education and work events. It was also through life histories that the author found some mismatches with the survey GPC data, for example, deaths (affected versus non-affected households) and property ownership.

The interviews were conducted in the local language, Luganda, but notes were mainly taken in English. The visits lasted an average of two hours and time was spent with the household head, spouse or any other adult household member, walking around the compounds, cultivating fields and participating in activities such as harvesting or threshing harvested crops, while holding conversations about on-going activities and recent and past events. Details of events and changes that households had experienced were derived as far back as individuals could remember.

An emergent design (Denzin and Lincoln, 2005) was used whereby the direction of the questions was not predetermined. The broad focus of the study was to understand the daily living experiences of individuals, how this has changed over time and what the factors that influence these changes could be. Such a broad focus generates diverse responses from households due to varying individual experiences, which the study needed to explore. Asking open-ended questions, such as "Tell me how you came to live here?" gives individuals the freedom to respond spontaneously in a direction that was relevant to them. This was followed by iterative questions that were developed based on previous responses and observations. Over the study period, new and emerging themes from households were identified during investigations that were applied across

households. Common themes were identified as well as uncommon themes. The uncommon themes were examined for uniqueness to the households, as well as to explore such themes across other households during subsequent visits.

The thesis author gained a lot of knowledge by using locally based and knowledgeable research assistants. Their contributions enriched the study. For example, they knew that younger study participants could be visited mostly later in the afternoons as they stayed out until late on their farms, while it was almost certain to find the elderly study participants home in the later hours of the morning. They were also knowledgeable about the common local expressions, for example: "Kyemwagaliza embazi kibuyaga asude" translated as "the tree that you required a saw to cut was brought down by the storm" (meaning that unpredictable events saved someone a lot of work) was used by a respondent and needed to be explained by the assistants. Discussing such specifics of the local language and local expressions with the assistants enabled the author to gain detailed insight into how households expressed their experiences and responded to their needs during chronic illness.

One research assistant, Grace, explained his experience that good coffee harvests resulted from cutting down the old coffee bushes that were pest/disease infested. This made it easy to appreciate when one household head, Kakooza, complained that his grandchildren had not helped to cut down the coffee trees, and that the resulting poor coffee harvest had contributed to the food shortage that the household experienced. Using these two sources of information guided further probing on the importance of coffee tree cutting in the rest of the interviews. Concerning bedside care such as washing and toilet visits, the thesis author learnt that grandchildren are obliged to care for their grandparents in ways that are not seen as culturally appropriate for children to do, as Fatuma explains, "Because grandchildren are [seen as] 'wives and husbands' of their grandparents and have to care for them like they would to their own partners." This enriched the author's understanding of the extent to which grandchildren were important in this community, and the implications of modern developments such as universal education. Engaging the research assistants in this way increased their voice and commitment to the research, which was essential given the lengthy research exercise.

5.2.3 Observations

Observation is a data collection approach where the researcher examines people in natural settings as well as naturally occurring situations. It is used as an additional source of information to understand interaction and practice in everyday life (Mays and Pope, 1995). The thesis author conducted both

participant and non-participant observation. Observation of the home during interviews added rich information to the data collected. In a conversation with Jane, in her 50s, she had mentioned that her only son was too ill to come and help her. However, as the thesis author observed around the compound, a new dish-rack had been constructed. On inquiring, we found out that the seven-year-old grandson had built it for her, in exchange for a school uniform so that he could go to school. During fieldwork, the author also observed the crops grown in the season, and their quality, i.e. if they were affected by pests or dry spells. Non-participant observation also took place in the office when individuals from the community came to the clinic for appointments or consultation. During such visits the thesis author listened to conversations from patients who sat on the veranda outside the office. It was from such conversations that perspectives from the local community on chronic illness could be understood. For example, watching a clinic visit added an understanding on how transportation was important. The author observed that youth in brightly coloured school uniforms brought in sick relatives on bicycles in the morning, and came at the end of the school day to ride them back home.

At the end of each field visit, the two research assistants and the thesis author discussed and reflected on the observations from the field visits, the notes were re-written in the field office and transcripts were kept by the author of this thesis. Meeting regularly following each visit was also important as the households were visited simultaneously. In this way, the author kept in close contact for updates from the research assistants by holding meetings at the end of each field visit to discuss what was observed and talked about with the households. Any challenges were also reflected upon, discussed and resolved during these meetings. Observations that needed deeper exploration in subsequent interview visits to the households were also agreed upon during these meetings. For example, Mutebi, in his 40s, was not willing to hold a conversation during the 3rd and 4th visits. Exploring this behaviour during the 5th visit, the author found out that he wanted support to roof his house as he was ill and not economically active. He said, “deliver this report to your office, I need eight iron sheets…”. The fact that the gift did not vary between visits was important in order to discourage people from thinking that their positive or negative stories influenced the gifts. We did therefore not give him iron sheets, but thanked him for his feedback and emphasised to him that, as mentioned earlier, his experience and feedback was an important contribution to understanding people’s situations in order to improve future support to the community. Having research assistants who were known to the community made the interview visits possible even on non-scheduled days. For example, Jacob, in his 50s, and the wife were often out doing business, selling charcoal

and coffee. On two visits, the conversation was with their older children. However, Grace the research assistant met Jacob in the market on a market day and he was willing to have a follow up conversation there.

During subsequent monthly visits, any visible changes such as household composition, health status of household members, types of food consumed, income sources and livestock changes were noted. Follow-up interviews were also conducted to fill gaps from previous visits and explore issues that had come up during previous visits and in discussions with the research team. From these unstructured, open-ended, serial interviews and observations, data was generated on events and changes in households, including sources of food, healthcare, labour, movement of individuals, household composition and structure, and livelihood activities and strategies.

Conducting continuous observations and in-depth interviews had the advantage of building a relationship and trust with all household members. This enabled interviews to be carried out and observations made with limited hindrance, even during the absence of the household heads, because 'friendship' bonds developed. The trust that study participants developed for the research assistants over time made it possible to explore in-depth how individuals had experienced their lives over the past 20 years or so, changes and important events along their life paths and responses, as well as reactions to what had transpired during the month following the previous visit. During the first visits to Jane's household, she mentioned that she had left most of her land and the main house to her son who would utilise the resources and provide her with care. That appeared to be a coping strategy for meeting her needs, as she was often ill and weak. However, during the last visit to the same household, the author was curious to know why she was living in the neighbour's dilapidated kitchen with a roof that leaked, and still had to labour for food even when she was often unwell. Jane revealed that her son had married a new wife and needed to cultivate all the land and had actually forced her and her 7-year-old grandson off their land. This gave the author the impression that she was struggling to meet her needs for care and food. At the time of the study, land was a sensitive issue due to fears of land grabbing. Despite the initial detailed explanation about the aims of the study, some study participants became suspicious when questions about changes in assets, such as land, were asked. Some study participants also felt uncomfortable and insecure about frequent visits. Over time, however, and as trust was built up (Corden and Millar, 2007b), all these fears were resolved and at the end of the study some study participants expressed interest for any other similar study, especially the older adults.

5.2.4 Data analysis

Data analysis was a continuous process that began from the start of data collection. Conducting interim analysis (Miles and Huberman, 1994) alongside data collection shaped and gave direction to the inquiry for each household during the study. Identified patterns were explored across households, while contrasting patterns that were also important for the study were identified and examined in-depth. This also made it possible to fill gaps during the study to avoid wasting time and resources at the end of the study.

At the end of each day, the team held meetings where the written and completed interview scripts from the field visits were read and re-read first for consistency and accuracy. The notes were essential in facilitating discussions on meaning and interpretations. The team also agreed how to proceed during the next visit at these meetings. It was during these same meetings that the research assistants typed out the interview notes from their field notebooks using a stationary computer in the field office.

The interview material was sorted and codes developed by the thesis author, and list categories were derived from the coding inductively (Pope et al., 2000). From the data, primary patterns were clustered and then regrouped into categories and sub-categories, and then broad themes were developed (Lincoln and Guba, 1985). The emergent research questions were used to develop broad clusters or content areas. For example, issues related to death (when someone mentioned something about a death, going to a burial, that a child had died, that they gave food to offer condolences) were clustered under the category 'death and related expenses', while those related to illness (someone was ill, bedridden, returned for terminal care, moved in to provide healthcare, moved out to access healthcare, etc.) were clustered under 'sickness'. Death and sickness were then synthesised under the theme of 'health issues'. Some codes belonged to more than one category and theme. For example, death was categorised as 'health issues' and as 'movement', meaning individuals leaving or joining a household. Constant comparisons were made across data from each household so as to come up with categories that captured the most issues from all households.

Due to the wealth of the data generated, categories continued to be refined and new themes developed, also based on the focus of the analysis and the questions or themes for which the data was queried. The author wrote up a thematic summary for each household (see appendix 2) and used the life histories (Corden and Millar, 2007a) to develop timelines in order to illustrate temporal changes and the adaptation mechanisms that individuals in these households have applied to meet their needs during chronic illness and other crises. Three out of the 22 household timelines that were constructed for the analysis are shown in appendix 3. The three timelines were selected to reflect gender as well

as positive and negative trends in households. Tino and Kakoozas stories are discussed in section 6.3. Namara's story illustrates responses to change in the absence of chronic illness. An analytical model was developed for how households respond to chronic illness events in a complex socio-economical context where health policies and local realities sometimes clash (Figure 3 in next section).

The data was developed into three papers with different foci based on the topics that emerged most strongly from the material. It was observed how household life cycle stages seemed to make a difference to household's ability to cope with chronic illness, and this idea was tested in Paper I. It was also evident how social relations were key to helping households cope with illness and cushioning against care expenses that would be catastrophic, which became the topic for Paper II. Finally, the particular plight of the elderly came through very strongly in some of the material and this theme was developed for Paper III. The analytical model shows how these topics are intimately connected and interlinked in understanding social aspects of responses to chronic illness and the outcomes of such responses in the context of rural Uganda.

6 Results

The thesis set out to explore household experience of responding to needs during chronic illness, specifically the social and economic factors that influence the response strategies and outcomes. This aim has been explored through three interlinked research questions explored in three papers (Paper I–III). I first present an analytical model that explains how the themes explored in the three papers are all interlinked parts of the main aim (below). I then go on to discuss each paper and its main results in turn.

6.1 Analytical model of the findings

The model illustrated in Figure 3 explores responses to needs during illness at the household and individual level and how that is determined by different social, economic and institutional factors. The aim is to understand the resource contexts in which the households are located, which mediate their responses to address the need for healthcare and other needs. The model draws from livelihoods and health-related literature, as well as from the empirical data from the household stories to focus attention on the physical assets and the social resources that households revert to in order to address their needs during chronic illness. In the context studied, the resources include those within the household, such as land and labour, and those outside the household, such as the hospitals, and those in the wider environment, such as friends, church community and NGOs that supply food during droughts. In the figure it is also indicated how the papers address different aspects of the main aim.

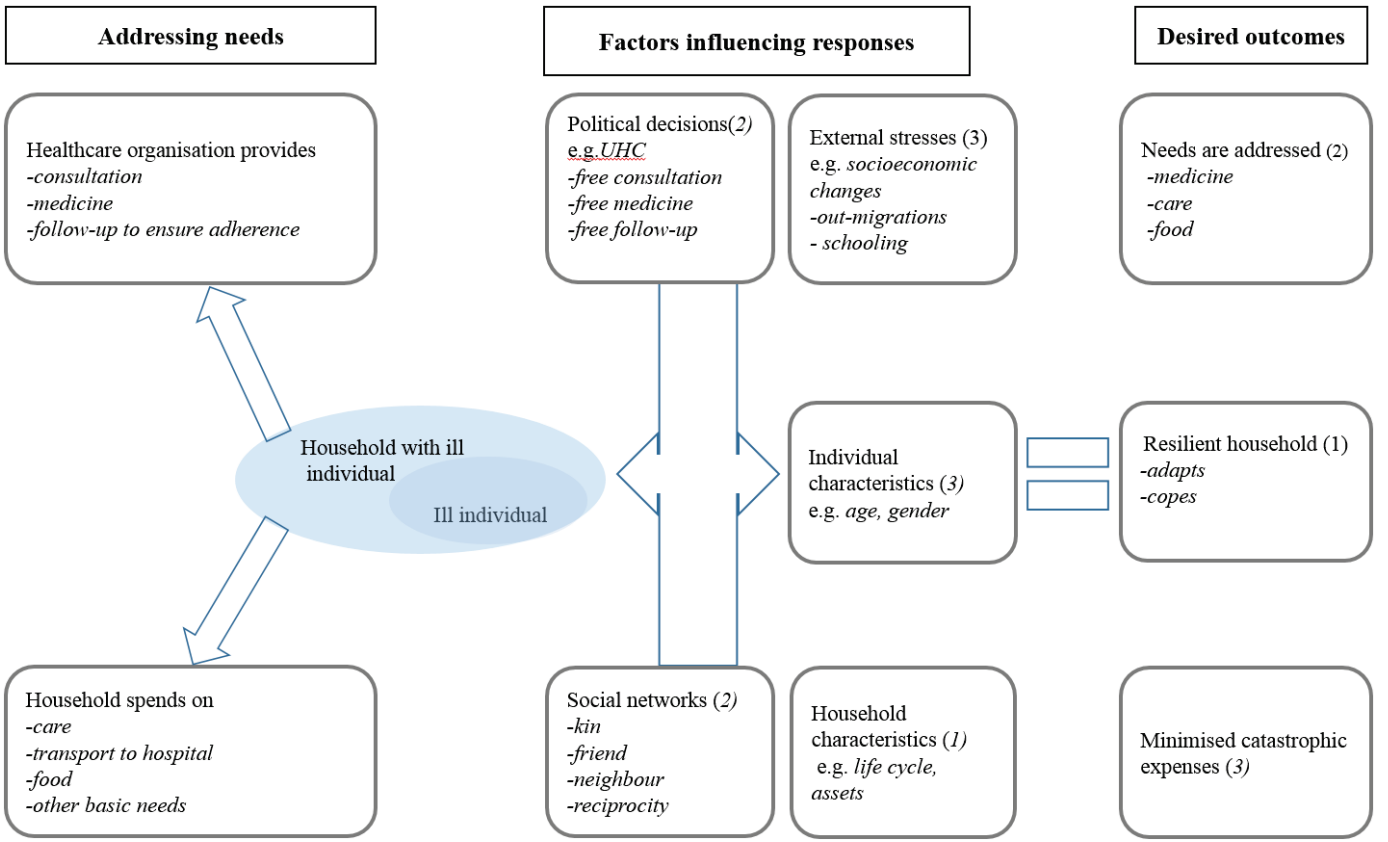

Figure 3. A figure illustrating response goals for households with chronically ill adults. Papers exploring different factors and outcomes are indicated (1-3).

At the centre of the picture in Figure 3 is a household with a chronically ill adult. During periods of illness, the ill individual has two resources. The first is the household, the closest and most important for addressing the ill individual's needs, which include treatment, care, food and transport to hospital. The healthcare organisation is the second important resource the household draws from, which provides consultation, treatment and follow-ups for the ill individual. Factors that influence a household's ability to respond to needs during chronic illness are in the middle of the figure. They include political decisions, such as free treatment for all, other external events that promote or undermine the ability to respond, individual characteristics such as age or gender, as well as household characteristics, such as social economic position and life cycle stage, and community-level factors, such as a strong social network that can be drawn on when needed. On the far right of the figure are the desired outcomes. If all needs are sufficiently addressed, the ill individual accesses medicines and care, and the household becomes resilient and able to respond to its needs during illness, as well as adapting to other stresses from the wider environment, and minimising catastrophic expenses and resultant debilitations such as poverty.

The thesis explored factors such as the life cycle stage, the relevance of social relations in protecting households from incurring catastrophic expenses, and aspects that challenge response strategies such as changes in other sectors, such as education and rural-urban migration, among others. Chronic illness, and other stresses, such as drought, are common to individuals and households in rural Uganda. However, a household's response strategies are highly dependent on a number of factors that are characteristic of the household and events in the wider environment at the time these changes/stresses are experienced. A comment made by a patient in the waiting area in the field station reinforces this: "Silimu mu bwaavu aluma" literally meaning, "the 'slim' disease (a local name for AIDS) is painful in poverty". From this person's perspective, though the disease is a problem, the environment in which the illness is experienced is even more important, and poverty is one of the exacerbating factors.

Paper I shows that the stage of development in the lifecycle of the household determines response strategies and outcomes during chronic illness, and that the group of households with elderly household heads are an especially vulnerable group, which is explored in-depth in Paper III. Paper II explores how the social connectedness of individuals can help them access care and address other household needs during chronic illnesses, but also the limits to this help, especially if all households are poor, and if other resources in the wider environment are undergoing transformations.

This section contains a brief summary of the main findings of the thesis's three papers, each answering one of the research questions set out in section 2.1 and contributing to this overall insight into the social and economic determinants of responding to chronic illness.

6.2 Paper I: The relevance of the household life cycle stage for coping outcomes

Paper I explores how the stage in the life cycle and other household characteristics influence a household's response strategies and the capacity to cope with the chronic illness of adults. The life cycle perspective, as defined in the conceptual framework, recognises that as individuals in households move through their lives over time, their roles, resources, capabilities and vulnerabilities change. In the analysis, the households were demarcated into three broad stages to reflect the empirical material collected: 'young' (those headed by individuals under the age of 45 years), 'middle-aged' (those headed by individuals between 45 and 60 years old) and 'old' (those with household heads over the age of 60). The dependency rate, asset ownership and social networks in general are different for these groups. The most important finding here was that the timing of events in the life cycle seemed to predict a household's ability to cope following the prolonged illness and death of adults, and other stresses. The household stories suggested that middle-aged households coped more easily following a death, as seven out of eight middle-aged households that experienced a death coped well, while five out of seven old households struggled following an illness event.

The paper showed that, partly due to the high dependency ratio and limited asset base, young and old age households had difficulties coping with the illness of adults. Young households had young children who still depended on their parents for food, education and shelter without being able to contribute much to the household livelihoods. At the same time, the elderly in the old-age households were growing frail and had often given away their assets and were dependent on support from their children. The old-age households were also found to foster grandchildren whose parents were living in other towns and the city. Usually this would mean remitting income to support the household. However, out-migration of children and fostering of grandchildren can also increase the number of dependants on the already limited resources of old-age households. Young households have a number of competing demands, such as food, school fees, saving and purchasing assets. Hence, during crises, such as illness, a fall in income presented challenges. In middle-age households, the grown-up children could be a resource, as they contribute to household

economy. Sseba, in his late 40s, had 10 acres of land and 13 children, five of them living and working in the city. The household had remittance support from the city and labour from the rest of the children. Although he and one child experienced chronic illnesses, the household had food, school fees, and could afford to get timely treatment during illness episodes. On a visit to his household two days after he had returned from a hospital admission, the research assistant inquired if his household was experiencing a food shortage like the other households visited. He responded, “It is a rainy season, all the hard-working people have food”. Despite ill health, his children cultivated and those in the city sent remittances.

Assets are accumulated over time, for example, through inheritance from parents and purchases from accumulated savings. Due to population growth, the amount of land inherited is insufficient for all the family members to receive an adequate share of land. When households are still young, they will derive a livelihood from the small area of land they inherited while the children are still small. If there is no crisis there will be sufficient food for the family. As children grow up and household consumption increases with a greater demand for food and school fees, the household should have saved and purchased more land, as in the case of Sseba above. In cases where there is illness of adults in the household or other crises, such as drought, young households will have difficulties meeting their needs. During his 30s, Mutebi was ill and bedridden, and had challenges meeting the demands of his young household. He had sold all his land, except the one acre that he had inherited, so as to meet treatment bills. His children were too young to cultivate or contribute in any way. The household struggled to meet basic needs, such as food.

Factors such as strong and wide social networks, labour contributions and remittances from adult children, and a wider asset base were important for addressing the needs of middle-aged households. Young households had not been in place for long enough to create a strong social network. Middle-aged households were better off in that their own children had grown up and possibly moved to the towns to find jobs and send remittances. These households were therefore able to shift the burden of the crisis in either direction, either parents to children or children to parents. For example, in the event of a crisis such as illness or a fall in income, adults working in the city could send their youngsters to grandparents in rural areas where the cost of living is lower. However, from the study the researcher also learned that this coping strategy might not work in old-age households where assets such as land have been disposed of, as we can learn from Kalooli’s household, and others mentioned earlier.

6.3 Paper II: The role of social relations in chronic illness and protection from catastrophic health expenditure

Paper II explores the role of social relations in providing wider social protection, in a context of accessing free healthcare in the population.

In the face of economic scarcity, which was commonly experienced by households in the study area, accessing healthcare services was also costly for the population. Households containing individuals suffering from ill health may therefore incur income losses as well as face catastrophic health expenses. The households that participated in this study were located in an area that has had access to free healthcare services from the MRC since 1989. At the same time the community had other needs such as transportation to the healthcare facility and food. Paper II examines the impact of social relations on household access to healthcare and addressing these other needs.

The main finding in this article was that in the absence of formal social protection systems, individual social relationships are an asset on which households in the study heavily relied to obtain the resources necessary to meet their care needs and avoid falling into a financial crisis. Hence, the social relationships provided the broader informal social protection that individuals and households needed. These social relations were mainly characterised by generalised reciprocity and sometimes by obligation. Through social relations, a network of kin and friends pooled resources that filled the gaps to meet their needs during illness, including accessing free healthcare. The resources provided included the information, food and transportation that households affected with illness needed in order to access basic social services, such as free healthcare. The relations also enabled individuals to build strong resilience and adaptive capacities when the households encountered crises and adversity. This was done in various ways: individuals who were ill moved to households that would provide care, individuals who were healthy, especially young women, moved to households that needed care so as to exchange support, and individuals helped each other ahead of any need, in other words, investing in others and hoping that the same would be available to them if ever they were in need. The free healthcare available was important in offsetting resources that were crucial to other needs being met.

Social relations were applied as social protection that was generally well received in the community, and everyone was expected to participate by giving to someone in need, as Kalooli, in his 80s commented: “If you do not give [to someone in need], what will happen when it is your turn [to be in need]?”

Expressions such as “muno mukabi” (meaning ‘a friend in need’) were common in households visited, especially when asked if they had supported someone during that month, and the reason for the support. Nineteen of the 22

households studied reported that they had provided care to chronically ill individuals (who were not necessarily HIV positive) at least once in the 20 years preceding 2010. This experience with illness was either direct, involving a household member (16/19, i.e. 84%), or indirect, having to provide support for a household with an ill person (16%). Of the 16 households reporting experience of an ill household member, nine were able to get help from neighbours and friends to fulfil needs, such as bicycle transport to hospital, bedside care in hospital, help with household chores, and gathering food and fuel-wood from the fields. In turn, these households provided other support to the household offering help, such as taking in children, providing food or sharecropping. Further, three households out of the 16 with ill members reported that their ill member moved to close relatives who were able to care for them when they were ill. In the other four instances, the households managed to fend for themselves without outside assistance. In some instances, households reported providing care at one point in time and receiving care or exchanging support at another, and relocating to another household for care. Therefore, strategies varied over time with opportunity.

The importance of ownership of assets, such as land, as a medium for exchanging reciprocal relations was clear. Implying that households with little land, most of which were headed by women, would face difficulties accessing reciprocal support when ill. This could also explain why it was mostly women involved in exchanging support, so as to address their needs. This also highlighted important deficiencies that threaten the effectiveness and efficiency of the social protection provided by informal mechanisms, requiring other strategies of providing social protection to vulnerable groups of individuals.

6.4 Paper III: The influence of social and economic transitions on access to care and support for the elderly

Paper III focuses on exploring the trends in care and support for the elderly in a changing socioeconomic environment. The analysis shows that the following factors affected care for the elderly: young individuals obtaining greater access to schooling, a decline in land ownership per household, and the high mobility of young individuals out of the rural areas, as well as occurrence of death in the household. This is important as the elderly are dependent on having assets and a strong “safety network” to meet their daily demands.

In a context of socio-economic changes, the interplay of various factors influenced the trends of care and support for the elderly in rural Uganda. At the same time, although the position of the elderly as advisers and economic

contributors has declined, they still play an important role as care providers for children whose parents are working in the city or have died. A positive trend, such as increasing universality of education for young people, can be seen as being detrimental to the care and support of the elderly in rural Uganda. As one household expressed in the introduction section, "they were taken away by their parents to live and study in the city, who can give you their child these days". Furthermore, changes driven by the out-migration of youth, the death of adults of prime age, and the erosion of assets, such as land, affects the household composition and structure, and thereby the mechanisms for organising care and support for the elderly. Also, due to weather changes, the productivity of the land is affected by increasing droughts and crop diseases, forcing young people to migrate and find non-farm based livelihoods. However, availing services in the area, such as pensions to the elderly and ART services to HIV infected individuals can contribute to positive experiences for elderly households, as individuals join the households to access these services and support. While education is intended to have positive social and economic outcomes for the whole community, the households studied indicated that educating children and young people also had less positive social outcomes, such as the elderly being abandoned with no one to care for them.

The non-existence of formal social security systems for the rural elderly and limited implementation of community health programmes have left the elderly completely dependent on a functioning extended family system, one that is currently facing increasing constraints. The study also highlighted that women and girls often gave up formal work, were separated from their husbands and children or remained unmarried, or cut down on their education in order to stay with elderly parents in the rural areas to care for them. This imposes hardships on women and creates economic problems, as it limits opportunities to develop and progress. Within such contexts, elderly people become fragile and vulnerable, health-wise, financially and socially, as their existence and wellbeing very much depend on their continued ability to stay productive in the community and home, e.g. continuing to be able to carry firewood, fetch water and hoe in their gardens, as well as on the possibility to turn to family members for support in times of situational difficulties and ill-health.

Policy recommendations in Paper III are that policymakers need to adapt cohesive social policy strategies that strengthen the complementary relationships between the formal healthcare system and other stakeholders, mainly the households and the wider community that provide care for the elderly. All too often, older people represent a population that is vulnerable and invisible, overlooked by interventions to eliminate poverty or improve health and wellbeing.

7 Discussion and Conclusions

This thesis uses a case study from rural Uganda. It set out to explore and describe the social and economic aspects that are important for how individuals and households respond to their needs during chronic illnesses in this context. The population studied is a unique case compared to the rest of the country, as the community has access to free, good quality healthcare provided by the MRC. This offers an opportunity for this study to explore beyond the typical medical needs that individuals and households encounter during prolonged illness. From the material collected, some important factors relating to responses to chronic illness are highlighted. These are; household characteristics, such as life cycle stage, influencing coping outcomes; social relations as an important informal means of social protection preventing expenditure on care from being catastrophic for the household; and how the changes in the wider environment, such as increased opportunities for schooling of children, undermines elderly individuals' ability to cope with chronic illness.

From a health system point of view, it is the tying together of these three aspects that provides the main contribution of the thesis on how to improve well-being in chronic health conditions for households in a rural, low-income setting, such as the one studied. The thesis highlights the contextual factors that are important for responding to needs in households where there is chronic illness in low-income settings, and where health systems are weak. This is valuable information for researchers, policymakers and policy implementers for developing strategies to improve health outcomes in such settings. They will be able to use the knowledge presented here about what constitutes coping and resilience in similar households, as well as the mechanisms such households apply to withstand shocks and stresses.

The insights from this thesis contribute to filling the knowledge gaps in on-going work on addressing chronic illness among individuals and households in low-income settings. Studies from Asia indicate that compared to urban counterparts, households in rural areas are able to maintain access to food and

protect consumption, labour supply and other basic needs during shocks, such as illness, death and droughts (Wagstaff, 2007; Townsend, 1994). This thesis contributes with a focus on a rural area and the mechanisms in operation. Most rural areas of Uganda are inadequately covered by basic services, such as road transport, health and educational facilities, and have limited access to clean water and markets. They are also exposed to risks from inclement weather that affects livelihoods such as farming. These factors exacerbate the impact of chronic disease as they affect an individual's capacity to respond and address needs during illness. The lack of basic infrastructure also presents challenges for the delivery of services to these rural areas due to problems of access and the high cost of providing healthcare services, thus further placing these households in marginalised and vulnerable positions. The remote location and vulnerable position of these households, however, provided this researcher with a wealth of experiential knowledge about living with scarce resources, not having access to basic services, and variable weather. Some of the results supported the finding from a study in Vietnam, which showed that rural households are more able to avoid health expenses from being catastrophic (Wagstaff, 2007). Households build up their own protection infrastructures through strong social networks and a high level of flexibility and adaptability, for example, with the mobility of individual household members. This enables households to respond to various types of challenge and crisis. Policymakers and implementers can learn from this experience to develop innovative tools and frameworks that are better suited for such rural contexts.

In an effort to minimise the vulnerability of households during ill health, health policies such as UHC have been adopted, with the ambitious goal for everyone to be able to access public health services when needed without incurring unnecessary financial hardship. Aiming to improve healthcare access and to provide financial protection is essential to improving health outcomes and wellbeing, also stated in the SDG goal three (Sustainable Development Goals, 2016). In the Ugandan context, one approach has been to remove user fees, and to provide services such as free medicines. In the population studied, free medication and reimbursements for hospitalisations was provided. However, the context-relevant factors that prevented access to health services and eventually resulted in economic loss during ill health, included poor infrastructure and transport, lack of food, and droughts. It is clear from this finding that increased spending on social services needs to be combined with measures to ensure that these services reach the very poorest. The community studied demonstrated the need for broader social protection. In this study, households were often able to make do with services provided through local social relations, where support services for a particular household or individual were obtained and exchanged

through reciprocity. However, some households were unable to engage in such reciprocal systems, especially some households led by elderly individuals. This group was clearly shown to require better social security and protection of their rights and interests (Oloka-Onyango, 2008).

Panel data in the Kagera region of Tanzania (Adhvaryu and Beegle, 2012), a context similar to the one for this study, finds that households headed by the elderly, especially women, experienced the need to work more hours in the long run following a death of an adult member in their prime. This thesis highlights the possible pathways that lead to that experience, which include asset depletion, especially land, and the resulting challenges to attract members to join and contribute to labour. The costs of addressing poor health means affected households may at times sell their land, and deplete their asset base, exposing themselves to poverty and vulnerability or weakening their capability to respond and adapt to future livelihood and health needs. However, another important aspect that the thesis highlights is the timing of events, which can be crucial in determining whether a household copes or struggles to meet its needs. The factors that contribute to strengths or to the development of vulnerabilities vary as the household goes through different stages of its lifecycle. These patterns need to be understood and targeted as the global health community seeks to improve the health of populations in effective ways. A crucial intervention can be to shield households from having to withstand too many adverse events at any given time, for example selling assets to address needs for healthcare and food.

Health systems are reliant on multiple actors. The decisions these actors make have effects across sectors including private individuals and families, local and international NGOs, and the government. Collaboration among these actors is needed to safeguard the effectiveness of the available social services, such as free care and education. For example, the education sector is a direct and indirect actor in the health system. Education for all children directly and positively affects health outcomes through increased literacy. For low-income settings, caregiving is provided solely by the extended family and friends. Hence, the education of children, especially in rural areas, has forced a number of changes that not only impacts rural livelihoods, but also impacts the structure and composition of households and the relationships therein. This study found that young individuals attended school most of the time and then moved away to urban settings for further education or work, which took these young individuals far away from the rural areas where the majority of the elderly live. Although some studies found no negative health effects on the elderly when young adults migrated, partly due to the remittances that compensate for their absence and provide for the wellbeing of elderly members of the household (Abas et al.,

2009). Other health service providers have considered the availability of kin or friends to support individuals when providing treatment, such as ART, that require close monitoring (Foster et al., 2010). However, this type of change calls for an arena for collaborative efforts that includes private actors, such as families and NGOs, as well as other sectors such as the Ministry of Education, and the Ministry of Roads and Transport. Engaging policymaking starting from the household level helps to identify and address the problems experienced and to address nuanced needs during chronic illness. A possible policy could be increasing rural employability of youth to ensure closeness and care to those in need of it. However, policies should avoid transferring too much of the burden of care to communities, households, and individuals, especially women.

To understand chronic conditions, especially in adults, and the challenges they pose to household activities for extended periods of time requires appropriate investigation methods. Applying a longitudinal study perspective such as the trajectories approach and exploring the life cycle of the household allows researchers and health policy implementers to pay attention to household nuances and their changing characteristics. Illness and death are not new experiences for households in Uganda. However, the chronicity of ill health is becoming more widespread, like in most low-income settings, partly due to HIV as well as a rise in non-communicable diseases, aging populations, and general poverty exacerbating chronicity of health conditions (Hirschhorn et al., 2012). On the other hand, as better technologies are discovered, for example: effective ARVs for individuals infected with HIV, and better monitoring for individuals with hypertension, affected individuals will experience episodes of remission from illness. This gives respite to the individuals and households affected and allow them time to plan and adapt so that their needs can be met in the long term. Health and welfare policies need to take all these constantly changing factors into consideration when planning effective interventions.

7.1 Conclusions

In conclusion, addressing the needs of the individuals and households with chronic conditions requires health systems to focus on both medical factors and the broader health determinants that are specific to the contexts in question. Adopting policy interventions across contexts may be inefficient since the contexts in which populations experience health are constantly evolving, while the individuals and households themselves are also continually adapting to their changing situations. This thesis builds on a unique case. It focused on a rural population, which would not normally have access to free good quality healthcare, but was receiving healthcare through the MRC. It was thus possible to observe the factors that were

still hindering their access to the available care or other issues, aside from purely medical concerns that were needed for them to cope with illness. The highlights from the thesis help to fill in gaps in knowledge on how health systems could improve and maintain health outcomes during chronic illness in a low-income setting, such as the one studied in rural Uganda.

At the same time, it must be acknowledged that households are all different and there is no one solution to these challenges. Learning from the cases of households that successfully adapt can provide insights into response strategies that can be built on and strengthened. This is one step towards identifying strategies that can be developed for each context. This could also contribute to developing bottom-up policy strategies, which, among other things, incorporate local and temporary solutions that can be accepted by household members. Also, solutions that have previously proved successful for accessing care during certain critical periods, such as young individuals leaving work, school or marriages to care for their aging relatives, might prove old-fashioned and constrain economic progress in a changing context. Therefore, the solution might not be that the elderly should continue to receive care from people who would rather work or study. Rather, publicly provided social protection in terms of old age and sick pensions as well as right to bedside care during hospital admission could be effective ways of targeting the problem of unequal access to care and protect the rights of the sick and the elderly.

I believe that many underlying mechanisms found in this study may work in similar ways in similar contexts around the world and could be further explored. For example, the conclusion that provision of free medicines alone does not necessarily prevent catastrophic health expenditures is probably true across a wider context. In areas with insufficient or a complete lack of social protection schemes, families sell assets and borrow money to meet needs, such as food and transportation to health facilities. Another factor that is likely to be common to similar settings is that households that own assets and have an income cope better and have better adaptive abilities during chronic illness. The relevance of resources such as support from social networks could also be investigated in other similar contexts. The social aspects of illness and care in rural, low-income contexts and how households in such settings respond to chronic illness is an important field of study at the intersection of public health and rural development research that needs to be further explored.

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Popular science summary

Households with individuals experiencing chronic illness – a health condition that persists over time and becomes a part of a person's everyday life – have exceptional care needs that extend beyond the usual medical care provided. These needs include bedside care, food and transport to access medical care. In resource limited settings, households bear most of the burden of addressing needs during chronic illness. To reduce the burden of chronic illness on such households requires understanding the context, including the social and economic burden of illness on individuals and households as well as how policy measures may influence this burden.

Using a case from the Ugandan context, this thesis explores the individual and household-level factors that determine household's responses to and ability to cope with chronic illness of adults, as well as the stresses from the wider environment. These issues were explored through collecting qualitative data for a life trajectory analysis from households that were part of a much larger study, the General Population Mixed Cohort of the Medical Research Council of Uganda (MRC). The thesis thus builds on a unique case – a rural population which would not normally have access to free good quality healthcare, but was receiving healthcare through the MRC. The qualitative data was analysed and three main aims were identified to drive the inquiry further: how household characteristics influence the ability to respond to chronic illness; the factors that still hamper access to healthcare in a rural setting with free healthcare and the strategies and responses that enable households to overcome these barriers; and, the role of social relations in facilitating access to health care and ensuring that wider needs of social protection are met.

The findings are presented in three papers. The first paper shows that the stage a household is in within a household lifecycle influences response strategies and outcomes during chronic illness, and that the group of households with elderly household heads are an especially vulnerable group. In the analysis, the households were demarcated into three broad stages that reflect the empirical

material collected: 'young' (those headed by individuals under the age of 45 years), 'middle-aged' (those headed by individuals between 45 and 60 years old) and 'old' (those with household heads over the age of 60). The dependency rate, asset ownership and social networks are in general different for these groups. The most important finding was that the timing of stress events (such as illness, death, droughts etc.) in the household life cycle was important for a household's ability to cope. The household stories suggested that middle-aged households coped best, since they had accumulated assets and older children who could help support the household. Due to the high dependency ratio and limited asset base, young and old households had difficulties coping with the illness of adults. The old-age households often foster grandchildren whose parents have left the village or died, and have often given away assets such as land to their children, which increases their vulnerability.

The second paper underlines the importance of broader social protection for minimising financial hardships in households with chronically ill individuals. Policies such as Universal Health Coverage (UHC) – that have the ambitious goal for everyone to be able to access public health services without incurring financial hardship – may not be successful in achieving that goal in certain contexts such as the one studied through only focusing on making medical care and medicines free and accessible. Whereas the households studied had access to quality healthcare services including free medications, locally prevailing factors including expensive transportation to seek care, and lack of energy during illness to keep up food production, nevertheless resulted in economic loss during ill health. The households relied heavily on informal social protection from social networks of kin and friends to obtain the resources necessary to meet their care needs and avoid falling into financial hardship. These social relations were mainly characterised by generalised reciprocity and obligation. Resources obtained through these social relations included information, food, bedside care and transportation to access basic services, including the free healthcare. Households were also able to build resilience and adaptive capacities using these social relations, which was crucial in times of crises and adversity. The free healthcare available was however very important for releasing economic resources, which were used in addressing other needs. The importance of assets such as land as a medium for engaging in reciprocal relations was also clear. Households with little land, most of which were headed by women, could therefore face difficulties accessing reciprocal support when ill.

In the third paper, the interplay of various factors influencing the trends of care and support for the elderly in rural Uganda is discussed. A positive socio-economic trend – the increasing universality of education for young people – proved to be detrimental for the care and support of the elderly, as young people

who had otherwise been instrumental in caring for them tended to move away from rural areas where the elderly lived in order to access education. Other factors included the increasing out-migration of youth to look for work in towns, the death of adults of prime age, and the erosion of assets, such as land. Also, due to climate change, the productivity of the land is affected by increasing incidences of droughts and crop diseases, a factor in forcing young people to migrate and find non-farm based livelihoods. Women and girls however often gave up formal work, cut down on their education and were separated from their parents/husbands/children (or remained unmarried) in order to stay with elderly parents or grandparents in the rural areas to care for them. This imposes hardships on women and creates economic problems in their futures, as it limits their opportunities to develop and progress. An important recommendation in this paper was that policymakers need to adapt cohesive social policy strategies that strengthen the complementary relationships between the formal healthcare system, the households, and the wider community that provide care for the elderly.

I conclude that addressing the needs of individuals and households with chronic conditions requires health systems to focus on both medical factors and the broader context-specific social determinants of health. The unique case of a population accessing free healthcare made it possible to observe the factors that could still hinder access to the available care, and the needs, aside from purely medical concerns, that had to be met in order to cope with illness. The highlights from the thesis help to fill gaps in knowledge on how health systems could improve and maintain health outcomes during chronic illness in similar low-income settings. Learning from the cases of households that successfully adapted can provide insights into response strategies that can be built on and strengthened. At the same time, it must be acknowledged that households are all different, and that solutions that are successful at one point might prove less suitable in a changing context.

The findings in this study could be explored further in similar contexts around the world. The conclusion that provision of free medicines alone is not enough to meet all needs in chronic illness is probably true across a wider context. Another finding is that households that own assets and have an income cope better and have better adaptive abilities during chronic illness. Finally, the relevance of resources such as support from social networks could also be investigated in other similar contexts.

Appendix 1. Interview guide

Table 1. Interview guide

Household member events	
House movement/ relocation	1. Explore any household movements from baseline (first year of participation in the annual survey) to present. Ask:
	- When did the household move?
	- Where did the household go? Look out for lake shores, urban/rural areas for complete change of sources of livelihoods.
	- Why did the household move?
Household membership and relocation	2. Explore household membership at baseline. Look out for who was there at baseline and who joined after baseline. Probe for:
	- a follow-up of each member's life from baseline to now and probe for what they have been doing, *e.g.* schooling, household labour availability/work.
	- Identify and follow up those who left the household for good, and those who left and returned.
	- When did they leave?
	- Where did they go? Look out for lake shores, rural/urban and places prone to prostitution/agriculture.
	- Have those who left been in touch with their original households? Do they send remittances?
	- Why did those who left leave?
	- For those who left and came back, why did they leave and why did they come back?
	- For those that joined the household after baseline, why did they join? What relationships do they have with the household head?
	- Follow them up from the joining time to now; look out for when they joined, where they came from, why they came (fostering following the death of the parents, or otherwise)
Member contributions	Contribution to household productivity: schooling, work/labour availability, ill health episodes and their implications on household labour, cropping patterns - those who left and came back.
	NB Explore household's perceptions of its members attending boarding schools as leavers and joiners.
Illness of household members	3. Explore ill health episodes in the household. Explore:
	- What was done to restore good health?
	- Who paid for the healthcare costs?
	- How did ill health episodes affect school attendance, household labour availability, cropping patterns and household land productivity/harvests/land under use?
Land ownership	4. Explore how much land the household owned at baseline and how land size has changed over time? Probe for:
	- When it increased/decreased
	- Reasons why land size increased/decreased
	- Inheritance in and out, land conflicts, sales and purchases, how purchases were financed.

Land ownership	5. Explore how much land the household was utilising at baseline and how has this changed over time till the present day. Probe for:
	- How much of this belongs to the household/was rented to others/borrowed from others, land under fallow/idle.
	- For rented land, explore the relationship between the renting household and the landlord households.
	- Why does the household rent/borrow land?
	- How does the tenant household pay the landlord for the rented land?
	- What were the terms for renting the land?
	Probe for: - Land conflicts, if any.
Land use patterns	NB. Under this theme consider crops, animal fodder, herbs, trees, fruits and vegetables
	6. Explore what the household grew at baseline and how have these changed in the interim. Ask: What were the major household crops? How have these changed over time to the present day? What were the major household crops at baseline and how have these changed up to the present day? Probe for:
	- When and why have major household crops changed?
	- What has the household been growing for food security and income generation for the last five years?
	- What has the household stopped/started growing of recent (five years ago),when did they start/stop and why?
	- For crops the household was growing at baseline and that have not changed, why is that?
Animal rearing	- Have there been any land conflicts arising out of rearing/keeping poultry/animals?
Labour	Explore household used hired labour at baseline and how this has changed over time to the present time. Probe for:
	- What does the hired labour do?
	- When was the labour hired?
	- What relationship do the hired labourers have with the head of the hiring household?
	- How is hired labour paid for and who finances it?
	- Why does the household hire labour?
Support	Explore household sources of support at baseline and how this has changed over time to the present time. Probe for:
	- Where does the household get support?
	- When does it get support?
	- What relationship do the people who give support have with the head of the household?
	- Probe for remittances and their source.

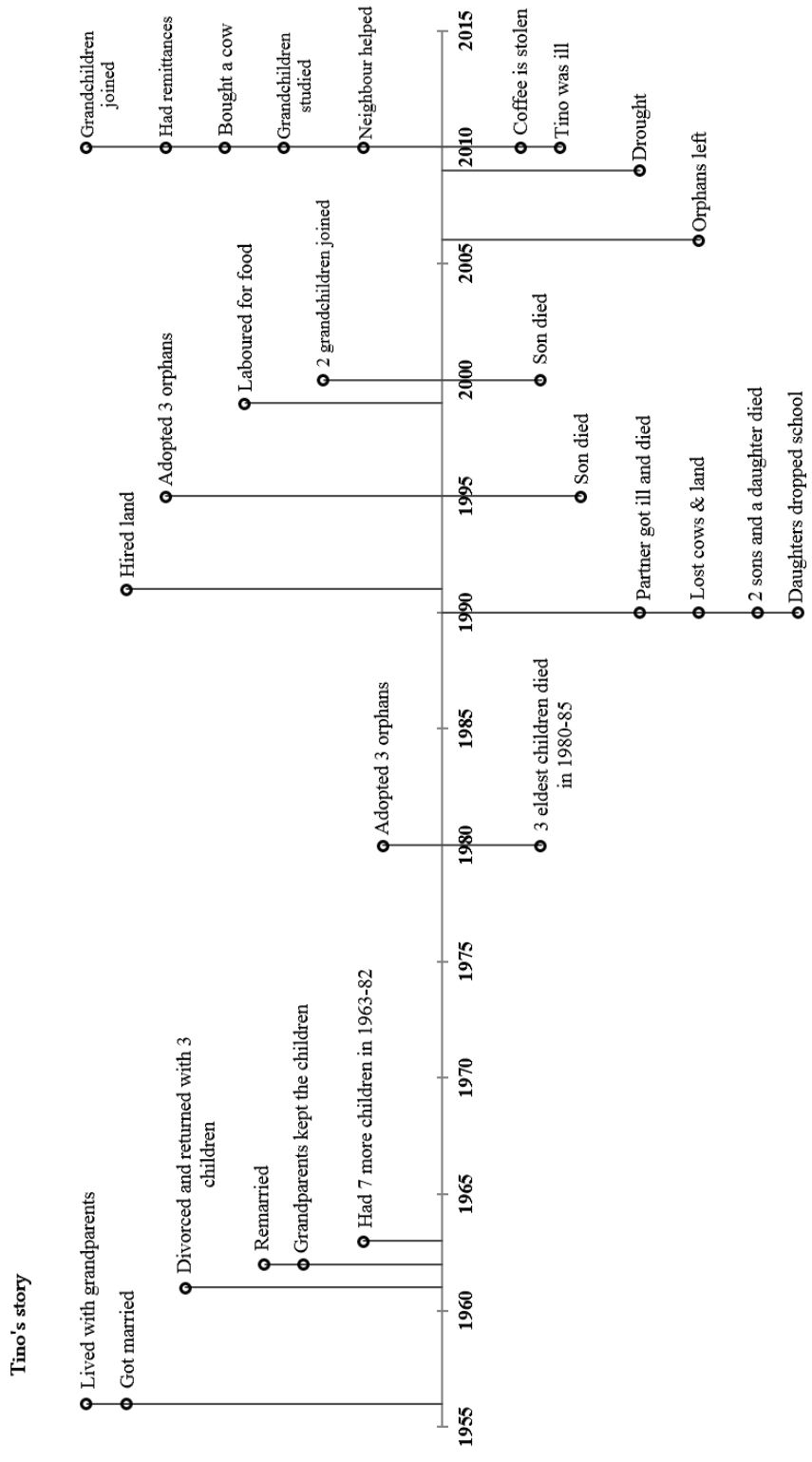
Appendix 2. Summary table of households participating in the qualitative study

Description	*Male headed*	*Male headed*	*Male headed*	*Male headed*	*Male headed*	*Male headed*	*Male headed*	*Male headed*
Age of household head	71	82	74	59	87	71	35	53
Marital status	Married	Single-widower	Married	Married	Married	Married	Married	Married
Land-size (acres)	10	0.5	5 (+ 6 borrowed land)	4	7	3	2	10 acres
Change in assets	- Sold cows, motorcycle, coffee for medical bills - Lost 3 acres in dispute	- Sold 1 acre of land for medical & funeral expenses - Gave sons 4 acres - Rented out 0.5 acres	- Gave 1 acre of land to a son - Borrows 6 acres of land	None	Gave 4 acres to sons and grandsons	- Sold 1 acre of land to pay medical bills for son - Rented out 1 acre - Sold pigs and goats for medical bills, food	- Inherited 1 acre of land - Bought 0.5 acres - Rented 0.5 acres	Purchased
Socio-economic status	Better-off	Poor-declining	Medium-constant	Better-off	Average-declining	Average	Average	Better-off
Household composition	7-8 members: Ages: 71,14,15,15,17, 5, 3	2 members: Ages: 82, 15	6 members: Ages: 74, 74, 7, 8, 14	1 member: Age: 59	6 members: Ages: 87, 81, 50, 31, 6, 4	6 members: Ages: 71, 56, 14, 13, 4, 3	4 members: Ages: 35, 21, 2, 1	10 members: Ages: 53, 48
Change in household composition	- Sons left to find work when household head was ill, daughters went to work and marry.	A son and daughter left to find work	- 3 Daughters left to find work - 1 son moved to own house	All children left to study and live in the city - Wife lives and runs his business in the city	- 4 adult children left for work, all died - Ill daughter returned for care	7 adult children left for work	None	2 adult children left to find work
Movement	4 sons and daughters left to find work in town	Daughter left to find work	Daughters live and work in other towns		2 adult children live in the household	All the adult children left to the city to find work	None	
Off-farm income, incl. remittances	- Remittances from sons and daughters in the city	- Rope weaving - Grandson does Leja-Leja for food, food-aid from church	Beekeeping, selling snuff, coffee and milk	- Pension - Remittances from sons and daughters - Income from restaurant	Income and food from own farm	Remittances from adult sons and daughters in the city	Builder, coffee trader	Coffee trading, charcoal trading
Source of farm labour	- Household labour - Labour hiring in	Own labour	- Household labour - Labour hiring	Hired labour	Household labour	- Household labour - Hired labour	- Household labour - Hired labour	- Household labour - Hired labour
Source of income and food	- On-farm-diversified (crop cultivation, livestock-pigs, cows) - Remittances- from sons and daughters	- On-farm- cultivation - Purchase - Hiring out labour	On-farm-diversified; crop cultivation, livestock-cow -sale of coffee, milk, honey	Cultivation of bananas, coffee, beans, maize, tomatoes, peas, melon, for commercial and home consumption	- On-farm-crop cultivation, livestock -pigs, cows, chicken - Sales coffee, livestock	- On-farm-crop cultivation, livestock -pigs, goats, cows, chicken - Sales coffee, livestock	- On-farm-crop cultivation, livestock - pigs, goats, cows, chicken - Sales coffee, livestock	- On-farm-crop cultivation, livestock -pigs, goats, cows, chicken - Sales coffee, livestock - Bank loans
Food availability	Food is available all the time	Struggling to find food each day	Food is available most of the time	Food is available all the time	Food is available most of the time	Food is available all the time	Food is available all the time	Food is available all the time
Sensitivity to long dry season	Did not result in food shortage	Had food shortage	Had food shortage	Did not result in food shortage	Had food shortage	Did not result in food shortage	Did not result in food shortage	Did not result in food shortage
Challenges to farming	- No rainfall - Soil infertility	- No rainfall - Soil infertility	- No rainfall - Soil infertility	No rainfall	- No rainfall - Crop pests and disease - Poor health	- No rainfall - Crop pests and disease - Poor health	- No rainfall - Crop pests and disease	- No rainfall - Infertile soils
Illness and death (1990 to 2010)	-1 son died in a motor accident - Household head is ill and bedridden	- Wife, 2 sons and daughter died - Household head is ill much of the time	- 4 adult children died - Household head is ill much of the time	Partner died due to cancer	- Household head died in the last month of the interview - 4 sons and daughters died	- Lost 4 adult children - Household head has chronic backache	None	None
Diet	Cassava, matoke,, beans, milk, fish	Cassava and potatoes	- Cassava, maize meal, potatoes	Meat, fish, rice	Posho, beans, potatoes	Posho, beans, potatoes, silver fish	Posho, beans, potatoes, silver fish	Matoke, posho,beans, g/nuts,fish

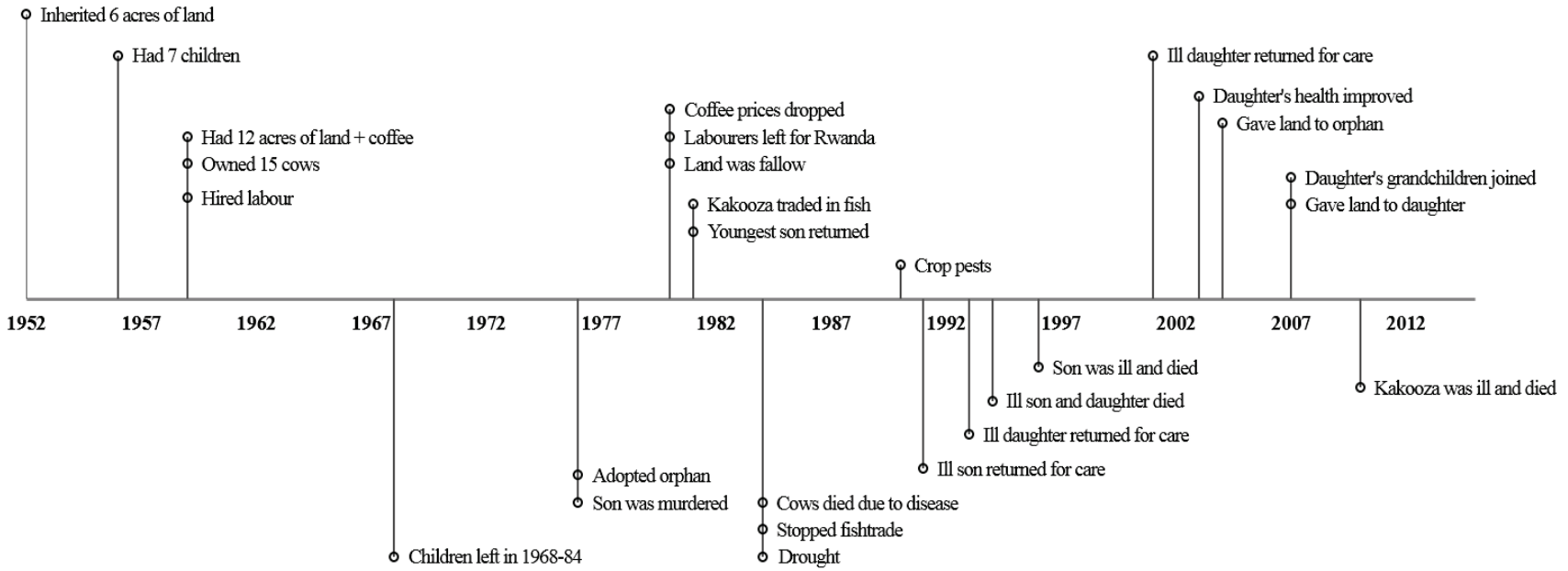
Description	*Male headed*	*Male headed*	*Female headed*	*Female headed*	*Female headed*	*Female headed*	*Female headed*
Age of household head	55	46	35	50	72	68	80
Marital status	Married	Married	Married (not living with spouse)	Single (not living with spouse)	Single-widow	Single-widow	Single-widow
Land holding (acres)	??	2 acres	1	0.5	2	0.25	2.5
Change in assets	??	Rents 2 acres	- Purchased a plot of land in trading centre for business	- Sold ½ of her land to construct a house	- Sold cows for medical and funeral expenses -lost land & cows to relatives	Gave ¾ of land with coffee-field to son	- Inherited 1 acre of land - Purchased 1.5 acres
Socio-economic status	Average	Average	Average	Poor-declining	Poor-recovering	Poor-constant	Constant-average
Household composition (Current)	4 members: Ages: 55, 50,10, 6	7 members: Ages: 46, 30, 10, 7, 5, 3, 1	6 members: Ages: 35, 18, 16,13,11, 2	1 member: Age: 50	4 members: Ages: 72, 15, 16, 16	2 members: Ages: 68, 7	4 members: Ages: 80, 9,13,14
Movement	None	2 teenage children moved to live with the grandmother	None	All adult children (2 sons) left for the city to find work	2 daughters and 2 grandsons moved to find work in towns	No household member moved to town	Daughters left to find work
Off-farm income, incl. remittances	Alcohol sales Coffee trading	Worked at the district offices. Made drug packaging material for sale	Owns a retail shop Partner sends money and food	- Mat-weaving - Brothers come to cultivate for her - Food from neighbour	Remittances from sons and daughters in the city	- Goes for Leja-Leja (hiring out labour) for food - Food from friends, sister	- Remittances from daughters in the city
Source of farm labour	- Household labour - Hired labour	Hired labour Household labour		Brothers cultivate for her	- Household labour - Labour hiring in	Own labour	- Household labour - Labour hiring in
Source of income and food	- On-farm crop cultivation, livestock - pigs, goats, cows, chicken - Sales coffee, alcohol	On-farm and non-farm income. He was employed and had a business	- On-farm crop cultivation, livestock - cows, chicken - Sales coffee - Income from shop	- Own production - Sale of mats - Neighbour sends food everyday	- On-farm-cultivation - Remittances - Coffee sales	- On-farm -cultivation - Leja-Leja for food - Relatives and friends	- On-farm-cultivation - Remittances
Food availability	Food is available all the time	Food is available all the time	Food is available all the time	Has no food in dry seasons	Food is available all the time	Struggling to find food each day	Food is available all the time
Sensitivity to long dry season	Did not result in food shortage	Had income to buy food during drought	Did not result in food shortage	Crops dry and results in food shortage	Did not result in food shortage	Had food shortage	Has not experienced food shortage in recent years
Challenges to farming	- No rainfall	- Infertile soils - No rain	- No rainfall - Infertile soils	- Infertile soils - No rain - Theft of crops	- No rainfall - Soil infertility	- No rainfall - Soil infertility	- No rainfall - Soil infertility
Illness and death (1990 to 2010)	All household members are ill much of the time	None	Youngest child is ill much of the time	Household head is disabled due to wasted lower limbs	3 adults died including husband	- Husband died - Household head is ill much of the time	- Partner died - Son died
Diet	Matoke, maize meal, fish, meat, beans	Matoke, maize meal, fish, meat, beans	Matoke, cassava, potato,rice, milk, fish, meat	Beans, cassava	Cassava, matoke(cooking bananas), beans, milk, groundnuts, fish, meat	Cassava and potatoes and beans	Cassava, matoke , beans, groundnuts, fish

Description	*Female headed*	*Female headed*	*Female headed*	*Female headed*	*Female headed*	*Female headed*	*Female headed*
Age of household head	42	50	42	68	81	46	80
Marital status	Single (not living with spouse)	Single (not living with spouse)	Single (not living with spouse)	Single (separated)	Single (divorced)	Single (not living with spouse)	Single-widow
Land holding (acres)	2.5	10	2	0.4	7.5	1	4
Change in assets	Purchased additional land		Borrows 1 acre for farming			Borrows ½ acres for farming	- Gave 1 acre to son - Sold land for medical bills
Socio-economic status	Average-improving	Average	Poor	Poor	Average	Poor	Poor-declining
Household composition (Current)	4 members: Ages: 42, 11, 11, 7	7 members: Ages: 50, 18, 16, 15, 13, 6, 3	3 members: Ages: 42, 9,5	1 member: Age: 68	8 members: Ages: 81, 65, 33, 7, 7, 4, 4, 3	6 members: Ages: 46, 12, 8, 6, 3, 1	3 members: Ages: 80, 11, 48
Movement	3 adult children left to find work in the city	- 9 adult children left for work in the city - Grandchildren joined the household	- Fostered out 1 child - Daughter left for work	All children live with their father	Lives in her late parents' home	Elder daughter (14-year old) left to find work in the city	-1 son moved to own house - Daughter moved to another town - Adopted a great grandson
Off-farm income, incl. remittances	- Traditional healer - Support from spouse - Remittances from daughter	Remittances from children working in the city	- Mat-weaving - Leja-leja by household head and daughters	- Alcohol sales - Buys and sales matokes	- Support from a brother who lives in the city	- Does leja-leja for income and food	- Son does Leja-Leja for food - Food support from daughter
Source of farm labour	- Household labour - Hired labour	- Household labour - Hired labour	- Household labour	Own labour	- Household labour - Hired labour	- Household labour	Household labour
Source of income and food	- On-farm crop cultivation, livestock- pigs, goats, cows, chicken - Sales crops, livestock, herbs - Support from spouse	- Crop cultivation, livestock- goats, cows, chicken - Sales coffee, maize, - Support from children	- Own farm production - Leja-leja - Brewing - Food from neighbour	- Alcohol and matoke sales - Own farm production	- Own farm production - Purchase - Sale of juice-bananas	- Own farm production - Food and income paid from labouring	- On-farm -cultivation - Leja-Leja for food - Relatives and friends - Rented out land for food
Food availability	Food is available all the time	Food is available all the time	Has no food in dry seasons	Has food	Has food	Has no food in dry seasons	Struggling to find food each day
Sensitivity to long dry season	Does not result in food shortage	Does not result in food shortage	Crops dry and results in food shortage	Not affected	Not affected	Crops dry and results in food shortage	Had food shortage
Challenges to farming	- No rainfall	- No rainfall - Pests and diseases	- No rainfall - Small land size - Infertile soils	- Theft of crops - No rain - Pests and diseases	- No rain - Pests and diseases	- No rain - Pests and diseases - Infertile soil	Ill-health
Illness and death (1990 to 2010)	Has 1 child with disability caused by cerebral malaria	Lost 2 adult children (1 was due to an accident)	None	Sick much of the time	- Nursed father who died - Takes care of a sister who is old and sickly - Herself she is sickly		- Partner died - 3 adult children died - Household head is ill most of the time
Diet	Matoke, potato, cassava, maize meal, yams, meat, fish,	Maize meal, potato, matoke, fish, g/nuts, milk	Cassava, potato, yam, eggplant, silver fish	Cassava, matoke, fish, pork, beans	Cassava, matoke, fish, g/nuts, beans	Cassava, silverfish, maize meal	Beans and maize meal

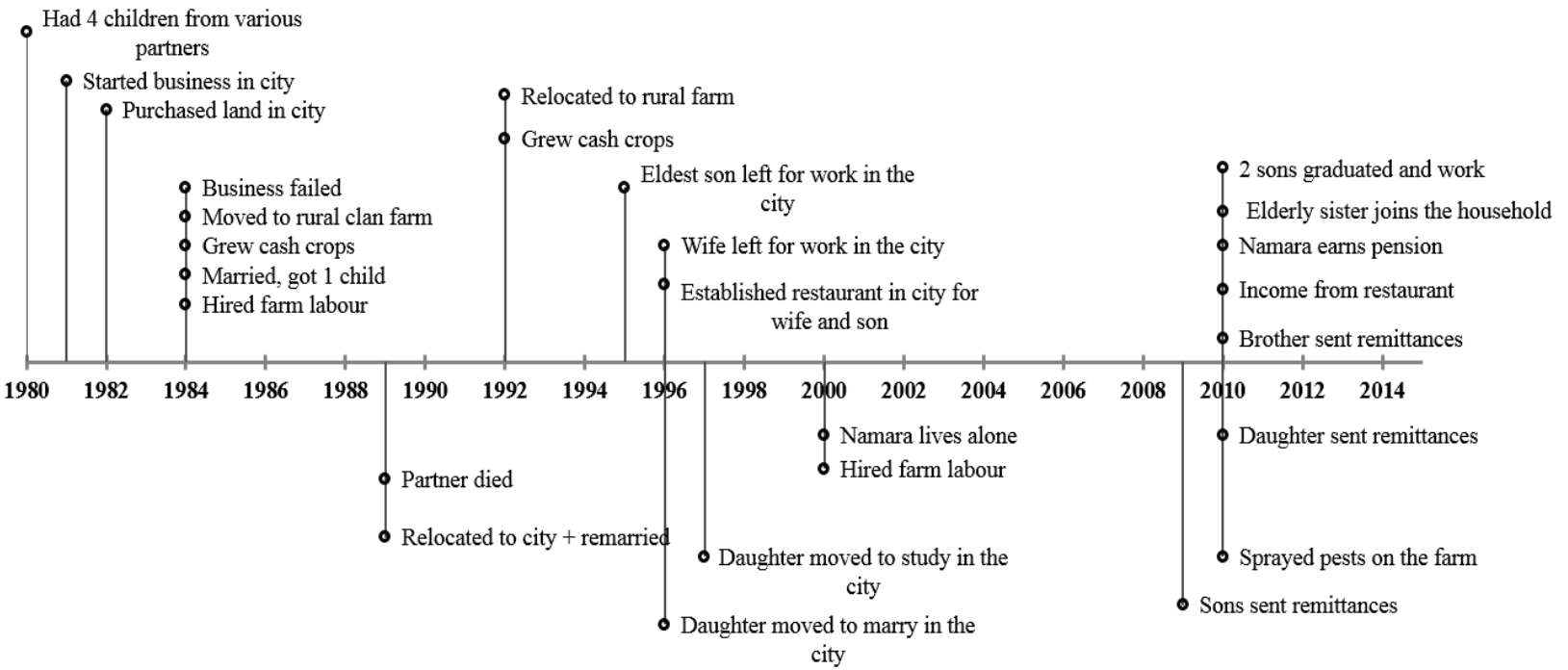
Appendix 3. Selected timelines of household life histories



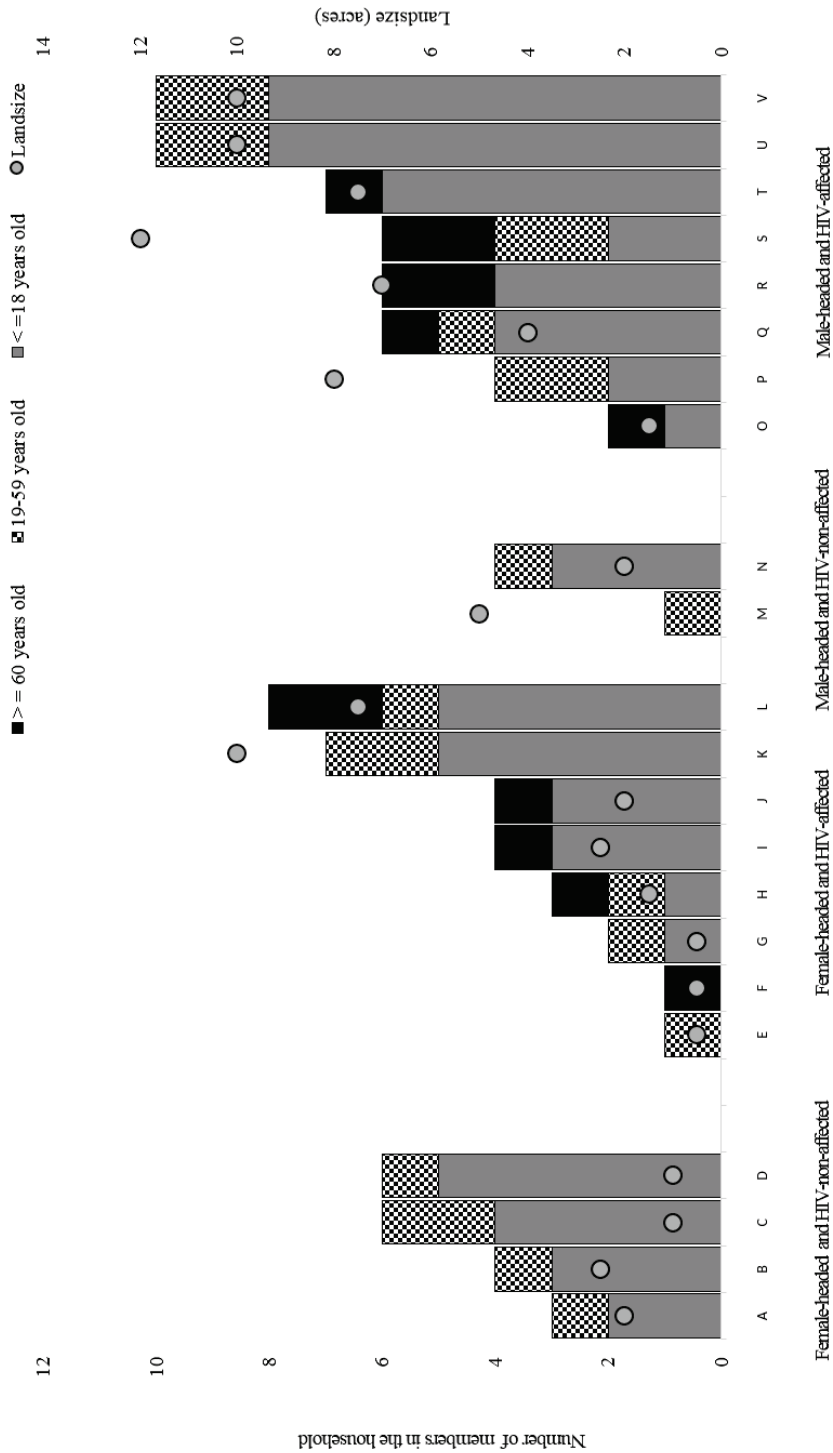
Kakooza's story



Namara's story



Appendix 4. Household composition, land size, gender and HIV-status



Papers